



## Open Research Online

### Citation

Musgrave, Jackie and Levy, Rachael (2020). Including Children with Chronic Health Conditions in Early Childhood Education and Care Settings. *Journal of Early Childhood Research*, 18(2) pp. 159–173.

### URL

<https://oro.open.ac.uk/61012/>

### License

(CC-BY-NC-ND 4.0) Creative Commons: Attribution-Noncommercial-No Derivative Works 4.0

<https://creativecommons.org/licenses/by-nc-nd/4.0/>

### Policy

This document has been downloaded from Open Research Online, The Open University's repository of research publications. This version is being made available in accordance with Open Research Online policies available from [Open Research Online \(ORO\) Policies](#)

### Versions

If this document is identified as the Author Accepted Manuscript it is the version after peer review but before type setting, copy editing or publisher branding

# Including Children with Chronic Health Conditions in Early Childhood Education and Care Settings

## Abstract

This paper sheds light on how chronic health conditions impact upon concepts of inclusion in children's Early Childhood Education and Care (ECEC) in England; it draws upon findings from a small-scale research project which highlights the need to consider health, in particular, the impact of chronic health conditions (CHCs) on ECEC. The study was conducted in two stages, part one involved a postal questionnaire to 60 Early Childhood settings and stage two included interviews with 6 practitioners in 4 settings, interviews with parents and observations of a child (called 'DJ') in his setting over the course of a year. The findings from this study indicate that in an attempt to be inclusive, practitioners may be unintentionally exclusive in their practice. The data suggests that this may be as a consequence of practitioners having different understandings and definitions of what is meant by the term inclusion, leading to confusion about the aims of inclusion. The findings indicate that there is a need to identify what effective pedagogy is for children with CHCs, as well as a need to re-define inclusion in relation to their needs.

## Introduction

The focus of this paper is to explore the influence of children's chronic health conditions on their inclusion in Early Childhood Education and Care (ECEC). Although this paper draws on research conducted in settings in England, the concept of inclusion and the findings from the research is relevant to international ECEC practice. The paper explores how some children may be excluded from some aspects of their care and education as a consequence of having an on-going health condition. One of the guiding principles of ECEC is to ensure practice is inclusive (Powell 2005, Booth, Ainscow and Kingston 2006), and there is substantial literature to suggest that practitioners aim to be inclusive in their practice (Nurse 2001). Yet, research also indicates that inclusive practice is a contested concept (Lingard 2000). This is partly because inclusion is defined in many different ways and there is not a single, shared understanding of what is meant by

inclusion, nor how it translates or is implemented in practice. The impact of a Chronic Health Condition (CHC) such as allergy, asthma, eczema and diabetes and its symptoms, are not recognised in the literature as arenas that may give rise to exclusive practice. This may explain why there is limited research about effective pedagogies for children with CHCs and why the concept of inclusion for them can be problematic. The purpose of this paper is to explore practitioners' views of how they include children with on-going health conditions in early childhood settings.

This paper presents findings from a mixed methods research study designed to understand the challenges and considerations for inclusive practice that are brought about when working with very young children with CHCs. The methodology of this study is described later in this paper, but it is first important to examine literature in relation to inclusion, to chronic health conditions and then, the inclusion of children with CHCs.

### **Current understandings of inclusion**

The concept of 'Inclusion' has a range of different meanings in contemporary education. According to Clough and Corbett (2000), there has not been a linear development from one perspective of inclusion to another. Instead there 'is always a dynamic relationship between the various perspectives' (p 9.) The passage of time and changing ideologies and policies have influenced our understanding of what is meant by the concept of inclusion; consequently definitions of what inclusion means are evolving and contested, as well as being many and varied (Nutbrown 2011a). This in turn may impact on practitioners' views of inclusive practice, especially in areas that are not well researched. The drive to promote 'inclusive education' can be traced back to a time when concerns were raised that children were routinely segregated from mainstream education (Borsay 2005) because they were regarded as ineducable and removing children meant that other children could be educated without being interrupted. The Warnock Report (1978) initiated the move away from integration to inclusion of children with disabilities in education. This has resulted in changes about how the concept of inclusion within the European education system is regarded because there has been a shift from viewing the concept of inclusion as relating to 'special educational need' to a recognition that children may struggle to be included in their educational environment due to many other factors. For example, in the 1980s, Barton (1988) suggested that there was a need to

move away from the traditional pedagogic psychological and medical perspectives. This focused attention on the sociological perspective as a lens through which to view how a physical or mental disability result in socially generated barriers has helped us to understand how individuals can become excluded from society in general. A precise definition of social inclusion is a much-debated topic, however, according to (Duffy 1995 cited in Klasen 1998), social exclusion is defined as ‘the inability to participate effectively in economic, social and cultural life’. Klasen (1998) defines social exclusion “as socially generated barriers that reduce the ability of the excluded individuals to interact with society” (p.1). Similarly, Hills, Le Grand, and Pichaud (2002) offer that social exclusion is the lack of effective participation in significant social activities or societal benefits, such as education. Consequently, participation in education, as pointed out by Klasen (1995) plays a significant role in the process of social inclusion and exclusion.

### **Inclusion in Early Childhood Education and Care**

The role of education as a way of promoting social inclusion has received global interest and this has extended to focusing attention on early education and care for very young children, given that the perceived economic benefits of early education have received attention from the Organisation for Economic Cooperation and Development (OECD) countries. Klasen, writing for the OECD (1998) notes that education is not only an important right, but also an important participatory process that remains to be one of the most important factors affecting the development of children. In response to the recognition that early education reaps positive benefits for individuals and for society, many countries have developed a curriculum for babies and very young children, for example, in England, the first version of the Early Years Foundation Stage (EYFS) was introduced in 2007 (DfES). The purpose of the statutory guidance was to achieve the five outcomes of the Every Child Matters outcomes (DfES 2003) in order ‘to provide the foundation for children to make the most of their abilities and talents as they grow up’ (p7). This implies that one aim of investing in early education is to prepare children to be ‘good’ citizens (Baker 2013) and ensure that they are socially included as adults. This has serious implications for children who may therefore be excluded from aspects of their early childhood education.

A main principle of the EYFS is to ensure that ‘every child is included and supported’ (DfE 2017 p5). In order to include all children, Booth, Ainscow and Kingston (2006) in their Index for Inclusion stated that inclusion should be viewed “as a principled approach to action in education and policy” (p.3). Practitioners were encouraged to examine the culture of a setting and adapt the environment in order to promote inclusion and to widen their consideration of the factors that can contribute to exclusion. This point is critical in relation to inclusion for children with CHCs, the symptoms of which can create barriers that make it difficult, or even dangerous, for children to be included in early education activities. However, the effect of CHCs as factors which may impact upon children, were not highlighted in the same way as factors such as having English as an additional language, gender or the impact of religion and culture. While it is heartening to see that factors such as culture are now recognised as a barrier to inclusion (Klaus and Marsh 2014), it is becoming increasingly apparent that children’s health and in particular the effects of chronic health conditions, remain underexplored with regard to inclusive practice for young children.

Nutbrown and Clough (2006 p.3), offer that “inclusion may be seen as the drive towards maximal participation in and minimal exclusion from early years settings, from school and from society”. This definition is especially useful when considering the purpose of ECEC for young children. This definition highlights the need for practitioners to plan activities in ways that maximise children’s participation, however it also implies that there will be elements of ECEC that some children may not be accessible to all children, and this is particularly pertinent to children with CHCs. Research conducted in Israel with children aged 8-18 years (Oppenheimer, Krispin, Levy, Ozeri and Apter, 2018) addressed the difficulties that chronically ill children reported in relation to feeling ‘different from their peers or even rejected socially’ (p 936). Such feelings of being different may well start in early childhood, thus highlighting the importance of exploring the issue of inclusive practice in relation to children with chronic health conditions.

### **Chronic health conditions in young children**

A ‘chronic’ health conditions is defined as one that last for longer than three months and is incurable (Brown, Krieg and Belluck 1995) and is deemed ‘sufficiently severe to interfere with a child’s ordinary activities’ (Miall, Rudolf and Smith, 2008, p 183). The

term 'chronic condition' includes a number of different conditions, such as asthma, epilepsy, congenital (present at birth) heart disease and diabetes mellitus. Asthma, anaphylaxis/allergy and eczema are the most common, chronic conditions that affect children in the UK (Department for Education and Skills/Department of Health 2005). Moreover, the prevalence of these conditions in children is rising and it is estimated that in Europe, these conditions affect between 5-20% of children (WHO 2007). A review of literature in New Zealand and Australia (Hopkins 2015) reports that as many as 30% of school-aged children in developed countries may have a chronic health condition. Furthermore, it is not uncommon for children to be diagnosed with a combination of these conditions which can 'significantly burden children's health and wellbeing' (Waters et al, 2010, p 428). For instance, a not so obvious consideration to be taken into account for children with chronic health conditions is that besides the physical impact on the child, 'emotional, behavioural and educational difficulties are two to three times more likely than in healthy children' (Miall et al, 2018, p163). A chronic health condition can impact on children's quality of life, causing stress because of intrusive medical interventions, as well as physical and dietary restrictions. Oppenheimer et al's previously mentioned research, highlighted the negative impact on the quality of children's lives as a consequence of making adjustments to everyday life in order to avoid triggering symptoms of their condition. There appears to be a lack of research about the impact on quality of life in younger children who live with a chronic health condition.

It should be noted that the chronic health conditions discussed in this paper are distinct from conditions considered to be complex medical conditions, although a child with complex medical conditions may have one or more of these conditions. Neither do these conditions on their own necessarily mean that the child will be regarded as having 'special educational needs'. However, management of these conditions is likely to mean that children will have additional medical requirements, such as the administration of regular medication, which can impact on their inclusion, or participation, in their ECEC setting. In order to illustrate how a chronic health condition can affect a child's life, it is useful to consider the impact of diabetes (though it should be pointed out that the term 'diabetes' is one name for several conditions). Type 1 diabetes is a condition in which

the pancreas does not produce sufficient amounts of the hormone, insulin, which is a hormone required by the body to metabolise carbohydrate, therefore, insulin needs to be injected or administered via a pump, through a needle inserted into the skin. The balance of carbohydrate and insulin intake, requires careful and continuous management to keep blood sugar levels within safe levels. Blood sugar levels are monitored regularly throughout the day by piercing the child's fingertip to collect a pinprick of blood. Increasingly, there are less invasive ways of monitoring blood sugar levels, but it is still necessary for a sensor to be applied to the child's skin. Most importantly, it is vital that an adult can interpret the meaning of the blood sugar levels and adapt the injection of insulin dose accordingly. Blood sugar levels are affected by the amount of carbohydrate that is ingested and the level of physical activity. In summary, in order to keep a child with diabetes safe and healthy, they will need regular injections through the skin to administer insulin and monitoring of blood sugar levels, which can involve piercing the skin of fingertips to obtain a sample of blood. In addition, diet will be restricted and careful planning of carbohydrate intake is essential to maintain safe blood sugar levels. As physical activity reduces blood sugar levels in the body, it is vital that adults are able to predict the impact of physical activity on the blood sugar level and ensure that either insulin dosage is reduced or carbohydrate intake is increased to maintain safe blood sugar levels.

As mentioned previously, chronic health conditions do not necessarily mean that a child will have special education or complex medical needs. However, CHCs may mean that there are potential barriers to children which may mean that they are unable to carry out normal day-to-day activities. This is not to say that children with CHCs should be regarded as having a disability, however the effects of CHCs may result in experiences which can be described as disabling, meaning that there may be 'those times when the environment, body and psych serves to exclude certain people from becoming full participants in interpersonal, social, cultural, economic and political affairs' (Marks 1999, p611, cited in Goodley, 2011). In England, legislation such as the Special Educational Needs and Disability Code of Practice (Department for Education/Department of Health, 2015) outlines the legal requirements that schools must provide for school-aged children with disability and medical conditions. Especially welcome, is the addition of further

guidance *supporting pupils at school with medical conditions* which aims to ensure that schools aged children with CHCs ‘enjoy the same opportunities at school as any other child’ (DfE, 2015, p7). This quote highlights the awareness that medical conditions can impact upon children’s enjoyment and participation in their education, however, this guidance is aimed at school-aged children and there is a lack of similar guidance for children aged 0-5 years of age. The Early Years Foundation Stage statutory framework for children who attend early years settings in England ‘seeks to provide...equality of opportunity...ensuring that every child is included and supported’ (2017, p 5), but there is not specific guidance for practitioners about supporting children with medical conditions in early years settings. This suggests that there is a lack of awareness that young children also attend education settings. Consequently, lack of specific, statutory guidance may mean that young children in early childhood settings are discriminated against because there is no legal requirement to support their medical needs (Musgrave 2014). Hopkins (2015) reflects a similar situation reporting in the Australian and New Zealand context stating that there is a ‘lack of policy direction, fragmented services and disconnection between education systems and health care systems’ (p4) to support children with chronic health conditions.

### **Inclusion and chronic health conditions**

The impact on children of CHCs is well-reported in medical research; an important study is Pitchforth et al’s (2011) which reported the experiences of 26 families who had a child diagnosed with nut allergy (anaphylaxis). The data from parents highlighted the difficulties they faced when eating out trying to ensure there was a safe place for their children to eat without the risk of coming into contact with nuts, which would be harmful to their health and could be potentially life-threatening. The parental role was described in the study as becoming ‘alert assistants’ (ibid, p 10) because of the need to prevent their child from experiencing the harm that exposure to nuts could cause. Because of the difficulties encountered and the ensuing anxiety, many parents chose not to eat away from home, describing the restrictions as akin to ‘a form of social exclusion or discrimination’ (p 10). Similar findings were reported in Cummings, Knibb, King and Lucas’s (2010) study of school-aged children with anaphylaxis to certain foods, where

the children reported their anxiety about coming into contact with food that was dangerous for them when on school trips and at parties. These findings are interesting in the context of this study because they highlight that there is a vital role for practitioners to include children in activities that involve eating to ensure the safety of children.

The impact that CHCs can have on inclusion for children is scantily addressed in educational research. One exception is a study by Mukherjee, Lightfoot and Sloper (2000) who focussed on the impact upon inclusion of CHCs, namely diabetes, asthma and eczema on primary and secondary aged children. Their findings highlighted that the children's experience and the level of support they received depended on the teachers' level of knowledge and understanding. However, it appears that the impact on inclusion of very young children is poorly-researched. As already discussed, there are compelling reasons why the inclusion of young children with CHCs in education must be explored, not least due to the fact that an over-arching principle of the EYFS is to provide an 'enabling environment' (2017, p 6). But what does that really mean in practice? What does this mean for practitioners who are responsible for the safety and well-being of young children who have conditions such as eczema, asthma and diabetes? Following a discussion of the methods used to collect data, this paper now reports findings from a study that investigated the challenges to inclusion faces by young children with CHCs in early childhood settings.

### **Methods and methodology**

Qualitative and quantitative data were collected in order to explore the challenges and consideration for inclusive education when young children have a chronic health condition. The research was informed by the question 'How do practitioners create inclusive environments for young children with CHCs in early childhood settings?' The study was designed in two stages: Stage 1 invited managers of all of the 60 early childhood settings in one metropolitan borough in England, to respond to a postal questionnaire. The questions were broad-ranging designed to find out the numbers and types of CHCs affecting children in their settings; to explore practitioners' perspectives of the impact on children of having a CHC, as well as understanding the practitioners' level of experience, knowledge and training about managing CHCs. The questionnaire invited respondents to participate in stage 2 of the study, and they were asked to include

their contact details on the questionnaire. Out of the 60 questionnaires sent, 19 were returned, meaning that there was a 33% return rate. At the time the data was collected, the settings in the borough where the research was conducted was going through a period of change and uncertainty, which led to management changes. These changes impacted upon the ability of settings to participate; therefore just 4 of the respondents from Stage 1 of the study proceeded to Stage 2.

Stage 2 of the study involved 4 early childhood settings. Details of the four settings and the participants who were interviewed are summarised in Table 1. The details of the parent participation are summarized in Table 2. Serendipitously, a practitioner in Setting 18 was the mother of ‘DJ’ (aged 20 months) and on hearing me talk about the research during a visit to the setting, she volunteered to be a participant. When she became aware that I was keen to explore a child’s perspective by carrying out observations to learn how, or if, the presence of a CHC impacted upon a young child’s ECEC, she offered me the opportunity to observe her son, which I did during a series of visits over the period of a year. ‘DJ’ had been diagnosed with asthma, eczema and was allergic to several foods, including kiwi, tomato and fish.

**Table 1: summary of data collection from Stage 2 – practitioners**

| Date of data collection, Name (all are fictional) and role in setting | How practitioners were recruited to contribute to study | Description of setting                             |
|---|---|--|
| May: Joan: Manager in Setting 1                                       | Offered to be interviewed                               | 90 children. Part of a chain in an affluent area   |
| June: Maria: Deputy Manager in Setting 8 and key person to Freddie    | The Manager of the setting volunteered Maria’s time     | 70 children. Privately owned. Most parents working |

| <b>Date of data collection, Name (all are fictional) and role in setting</b>              | <b>How practitioners were recruited to contribute to study</b> | <b>Description of setting</b>                                       |
|---|--|---|
| June: Mary: Manager in Setting 14   | Offered to be interviewed                                      | 84 children. Privately owned setting on a school site               |
| March: Joint interview with Sharon (Manager) and Charlotte (Deputy Manager) in Setting 18 | Offered to be interviewed after being contacted                | 85 children in an area of social deprivation. Local Authority owned |
| April: Becky: Key person to DJ (child observed as part of the study) in Setting 18        | Manager suggested that I interview her and she agreed          | As above  |

**Table 2: summary of data from Stage 2 - parent participants**

| <b>Research method</b>   | <b>Relationship to setting and children in the case</b>   |
|--|---|
| June: Questionnaires completed by parents (instead of being interviewed) | 2 parents of children with eczema from Setting 1  |
| June: 30 minute semi-structured interview plus emails from Freddie's mum | Mum to Freddie (who has eczema and asthma) in Setting 8<br>She came and met me at the setting during her lunch break to be interviewed  |
| 4 x 30 minute interviews, plus emails over 12 months                     | Kate (pseudonym). Mum to DJ (who has asthma, eczema and dietary restrictions) in Setting 18.<br>DJ's mum is also a practitioner working in the setting in a different room. DJ's mum was interviewed during breaks from her work in the setting |

### **Ethical considerations**

Ethical considerations were embedded in every stage of this research and were not confined to the regulatory procedure of gaining approval for the research. In particular, I was aware of my privileged position as an outsider in Stage 2 of the study, having been given access to the settings and, in particular, allowed to conduct interviews with parents of children within the settings. With this privilege, came responsibilities to ensure that I

had the consent of all participants. The observations of ‘DJ’ (the pseudonym chosen by his mum) took place in the toddler room, because of the age of the children it was especially important that I remained alert to any indications that ‘DJ’ was being affected by my presence. It was equally important that I minimised the impact of my presence on the other children and practitioners. Such access brought responsibilities in relation to maintaining confidentiality of the data and protecting the anonymity of the participants.

### Data analysis

The data from the postal survey were collated in to Table 3. The settings that proceeded to stage 2 of the study are indicated in bold.

**Table 3: data from postal survey**

| Setting ID no | No of children in setting | Allergy                | Asthma                 | Diabetes                 | Eczema                 | Epilepsy                 | No. of children with a chronic condition | Volunteered participation to the next stage               |
|---------------|---------------------------|------------------------|------------------------|--------------------------|------------------------|--------------------------|--|---|
| <b>1</b>      | <b>90</b>                 | <b>2<sup>1</sup></b>   | <b>6<sup>2</sup></b>   | <b>0</b>                 | <b>3<sup>3</sup></b>   | <b>0</b>                 | <b>11/90 12%</b>                         | <b>Manager interview and possibly parent</b>              |
| 2             | 65                        | 2 <sup>4</sup>         | 4                      | 0                        | 4 <sup>5</sup>         | 0                        | 10/65 15%                                | No  |
| 3             | 40                        | 3                      | 2                      | 0                        | 1                      | 0                        | 6/40 (15%)                               | N/A   |
| <b>4</b>      | <b>84</b>                 | <b>0</b>               | <b>5</b>               | <b>0</b>                 | <b>4</b>               | <b>0</b>                 | <b>9/84 (11%)</b>                        | <b>Practitioner not parent</b>                            |
| 5             | 21                        | 1                      | 1                      | 0                        | 3                      | 0                        | 5/21 (24%)                               | Contact details inc, not indicated level of participation |
| 6             | 44                        | 0                      | 5                      | 0                        | 2                      | 0                        | 7/44 (16%)                               | No  |
| 7             | 46                        | 1                      | 3                      | 0                        | 3                      | 0                        | 7/46 (16%)                               | No  |
| <b>8</b>      | <b>55</b>                 | <b>1</b>               | <b>NG<sup>6</sup></b>  | <b>NG</b>                | <b>NG</b>              | <b>NG</b>                | <b>1/55 (5.5%)</b>                       | <b>Practitioner/parent/child</b>                          |
| 9             | 64                        | 0                      | 4                      | 0                        | 1                      | 0                        | 5/64 (8%)                                | Practitioner/parent/child                                 |
| 10            | 72                        | 1                      | 1                      | 0                        | 3                      | 0                        | 5/72 (7%)                                | No  |
| 11            | 40                        | 1                      | 1                      | 0                        | 1                      | 0                        | 3/40 (7.5%)                              | Parent/practitioner/child                                 |
| 12            | 16                        | 0                      | 1                      | 2                        | 0                      | 0                        | 3/16 (19%)                               | Parent/practitioner/child                                 |
| 13            | 54                        | 10                     | 0                      | 0                        | 5                      | 0                        | 15/54 (28%)                              | Practitioner  |
| 14            | 58                        | 1                      | 3                      | 0                        | 0                      | 0                        | 4/58 (7%)                                | No  |
| 15            | 54                        | 1                      | 0                      | 0                        | 2                      | 0                        | 3/54 (5.5)                               | No  |
| 16            | 65                        | 2                      | 2                      | 0                        | 1                      | 1                        | 6/65 (9%)                                | Practitioner  |
| 17            | 100                       | 1                      | 6                      | 0                        | 2                      | 2                        | 11/100 (11%)                             | Parent/practitioner/child                                 |
| <b>18</b>     | <b>85</b>                 | <b>3</b>               | <b>5</b>               | <b>0</b>                 | <b>6</b>               | <b>0</b>                 | <b>14/85 (16.5%)</b>                     | <b>Parent/practitioner/child</b>                          |
| 19            | Not completed             |                        |                        |                          |                        |                          |  | Parent/practitioner/child                                 |
| <b>Totals</b> | <b>1053</b>               | <b>30</b><br><b>3%</b> | <b>43</b><br><b>4%</b> | <b>2</b><br><b>0.18%</b> | <b>41</b><br><b>4%</b> | <b>3</b><br><b>0.28%</b> | <b>114</b><br><b>11%</b>                 |   |

## Notes

- 1 Eggs and dairy products
- 2 2 of this number also have eczema
- 3 2 of this number also have asthma
- 4 1 also has eczema
- 5 1 also has allergy
- 6 Not given

The qualitative data were analysed using an approach borrowed from Glesne and Peshkin (1992), meaning that the raw data was read and frequently occurring words were colour coded. The words that were similar and recurred frequently in the data meant that connections emerged from the data and this meant that I was able to put ‘like-minded pieces together into data clumps’ (p 133). These data clumps of frequently occurring similar words and phrases were plotted on a master sheet. Following on from this, tree diagrams were created which helped to organise the main points of the data and from this themes were identified which gave an ‘organisational framework’ (p 133).

## **Findings**

### *Overview*

One important finding from the completed postal questionnaire revealed that 114 of the 1053 children attending the settings in the study (11%) of the children attending the settings had been diagnosed with one or more CHC. This figure reflects the World Health Organisation (2007) data that suggest 5-20% of children have a CHC. This is a significant number and suggests that there is a high number of children with CHCs attending early years settings in the UK. The most common CHCs affecting the children were asthma, allergy and eczema, some children had a combination of two or in some cases, all three of these conditions. Thus, it is likely that the challenges and considerations for practitioners in relation to inclusive practice for children with CHCs accounts for a significant amount of their work. The findings from the data revealed that children having a CHC, or more than one CHC, raised challenges and considerations for inclusive practice within the early years settings that participated in this study. The areas of care and education that were especially problematic related to play and the provision of food.

### **Play: considerations and challenges**

It is well-documented that play is a vital factor in children’s learning and development (Piaget and Inhelder 1969, Moyles 2012, Wood 2013), however the data revealed that

play, and in particular sensory, outdoor and physical play, were problematic for a number of children with CHCs. This section demonstrates how these kinds of play resulted in considerations and challenges for practitioners working with children with various CHCs.

### *Sensory play*

Sensory play proved to be especially problematic for children with eczema; this point was illustrated in the interview with Freddie's Key Person, 'Maria' in Setting 8. Maria described how she had planned a sensory activity for the children which included the use of shaving foam. She realised from the outset that Freddie would be unable to handle the foam because contact with the foam on his skin would trigger an eczematous reaction.

She reported:

We had shaving foam the other week and we had it on trays and we let the children, particularly the 2-3 year olds, explore it and my colleague was doing it with me and said "oh, what about Freddie's skin?" So I said "put some Clingfilm over it and do it quite loosely so that he's not messing with the foam but he can poke it and press it and feel that it's soft and do what the other children are doing, not the wetness, but he can still explore it in that way.

This shows that while Maria had adapted the activity skilfully by using the clingfilm to protect Freddie's skin so that he could participate, he was still unable to experience the full sensory engagement in the way the activity had been planned. Consequently, Freddie's participation was maximised as safely as possible, but despite Maria's best intentions, full inclusion in the activity was not possible. Similarly, Maria spoke of Freddie's interaction with paint, she reported that:

Things like painting, sometimes his hands are very, very sore and it's important to make sure that he doesn't get too much paint on them.

Again, this shows that Maria was ensuring that Freddie did experience handling paint but it raises the question of whether interventions to minimise contact with 'too much paint' interrupt the child's learning and "disrupt the finely balanced process of children's thought" (Nutbrown, 2011, p.28).

Further data from the questionnaires revealed that other practitioners were equally innovative in attempting to balance children's well-being with their educative experiences when the child had a CHC. For example, one respondent reported how she thought ahead about the suitability of other activities that involve skin contact for children with eczema and allergies. She said, "We have got to remember if we have the dough out we have to be careful with the colouring. Or, if we are doing a cooking

activity.” Other data revealed that practitioners substituted sand, which is an irritant for most children with eczema, and replaced it with lentils.

The data revealed that these practitioners had developed creative and strategies to ensure that the children for whom they were responsible were enabled to participate in the activities. However, despite this care and attention, these children were not able to be fully included, but rather as Nutbrown and Clough (2006) state, their participation was maximised. The examples presented above relate to aspects of indoor play, however similar issues were raised in relation to outdoor play.

### ***Outdoor play***

The findings highlighted that planning outdoor play for children with CHCs presented particular challenges relating to inclusive practice for practitioners. As previously stated, asthma symptoms can be triggered by cold air or exercise (Levy, Weller and Hilton 2006). This was raised as an issue by Joan in Setting 1, who reported concerns about children with asthma playing outdoors. She explained how she ensured that a child with asthma could have his participation in outdoor play maximised by remembering “if we have got football practice, he needs to have an inhaler beforehand”. The consequence of not administering the inhaler could have resulted in the child becoming breathless and needing to stop playing football, thus he would not be included in the activity. The practitioner’s action of administering the inhaler, also helped to reduce the risk of the child having an asthma attack, an event which is potentially fatal.

Messy outdoor play also raised considerations for children with eczema because sore and cracked skin is vulnerable to infection. In particular, practitioners demonstrated their concern about children playing with soil and with worms, which they felt could be a risk of infection. The consequences of a child getting infected eczema is described by one respondent to the survey as her most memorable experience of caring for children with CHCs. She wrote: “One child had severe eczema and needed to be hospitalised as the eczema was infected”. This highlights the need for practitioners to be acutely aware of the consequence of failing to consider the possible outcome of not adapting activities in ways that are appropriate for children with eczema. However, the example also highlights that planning outdoor, messy play activities for children with eczema is

problematic because fully including them in such an activity may be a danger to their health.

***Food: considerations and challenges***

Eating meals and snacks together is another important part of the nursery routines.

Research has shown that children benefit from the social act of eating, and according to Albon and Mukherji (2008) ‘nursery settings and parents share responsibility for socializing children into culturally accepted food norms’ (p109). Yet the data revealed that practitioners felt very anxious about the provision of food when working with children with food allergies.

For example, Joan in Setting 1, explained that children with food allergies, who were aged under three, were expected to remain seated until all food debris was removed to reduce the risk of a child with a food allergy having contact with food that could provoke a potentially fatal allergic reaction. Similarly, Maria in Setting 8, illustrated that the need to prevent a child from having contact with an allergy causing food during mealtimes was an issue for another participant. When discussing the seating arrangements for children with food allergies, she demonstrated her awareness of the tension between including children with food allergies at mealtimes and keeping them safe. Speaking of a child with food allergies, she reported:

... Making sure he wasn't sitting right next to other children (when eating). You didn't want to ostracise him, but you didn't want him too close in case he touched something that could make him go into shock

While it is not possible to know the impact of these actions on the children, both examples demonstrate an element of exclusion. These young children were not able to enjoy aspects of socialisation associated with meals, as practitioners had to prioritise safety above this. This data concurs with Pitchforth *et al's* (2011) findings where parents described how they became ‘alert assistants’ to help their children avoid dangerous food and create safe spaces for food. The data suggested that a similar role is taken by practitioners and appears to cause them anxiety as illustrated by Charlotte in Setting 18 who commented that, “it was more emotionally draining for staff because it was more of a life-threatening condition. We were always double-checking things...”

These findings reveal that food was an area of anxiety for practitioners, and that the steps they took to mitigate risk could have resulted in exclusive practice for the children.

However, data gathered from one of the children indicated that protective measures to ensure the safety of children with food allergies, actually caused some distress for the child. Over the year, a number of observations were made of DJ during mealtimes. DJ was allergic to several foods; including fish, tomatoes and kiwi fruit and this resulted in an inability for him to be fully included in mealtime activity. The following extracts are taken from direct observations of DJ; in each case the observation is followed by reflections in italics from the main researcher which were documented in a research journal after the observation.

**30<sup>th</sup> March, 1205 hrs: lunch time.** There are 12 children sitting around two tables, waiting for their bowl containing lunch. Chilli con carne is served in a variety of different coloured bowls. As the bowls are put in front of each child, DJ gazes at the contents of each bowl. A bowl covered in cling film with his name on it is unwrapped and put in front of him. “Here you go DJ, here’s your dinner” (practitioner). The food is brown rather than the red coloured food in the other children’s bowls. He gazes at his bowl and then looks again at the other bowls of food and his gaze follows the children’s hands as they put spoons of the food into their mouths. A practitioner says “Come on DJ, eat your dinner”. DJ shakes his head. The practitioner picked up his spoon and pretends to eat the food: “yum, yum, now your turn DJ”. DJ starts to feed himself.

*I have reflected on the use of the word ‘gaze’ in this observation and realise I selected it because DJ was not simply looking, but he was looking “steadily or intently, especially in thought” (Oxford English Dictionary). As well as gazing, DJ sat quietly, with his back erect and he fixed his gaze for a sustained period of time, watching intently and unsmilingly. The use of the word ‘look’, as opposed to gaze, demonstrates a less intensive scrutiny by DJ. DJ is an observer and his responses suggest he is beginning to understand that meal times are different for him (Research Journal entry 2<sup>nd</sup> April)*

**1450 hrs: The ‘orange incident’ snack time** – children are called to the table. A brightly coloured bowl containing orange quarters still in their skins is put in the middle of the table. The room smells of oranges and the spring sun is shining on the oranges and they are glistening. DJ is gazing at the oranges, as the children are invited to help themselves. DJ looks with interest at the children sucking on the oranges. DJ and another boy are given a bread stick by a practitioner “Oranges aren’t for you DJ and Josh”. DJ gazes at the bread stick and then turns his gaze to a child eating a piece of orange. He repeats this action but looks at a different child each time.

**1505 hrs:** the children are still sitting at the table. DJ is given another breadstick. DJ points at the bowl, then his hand slowly goes towards the bowl, he puts his fingers on the edge of the bowl and a practitioner says “No DJ”. He removes his hand but then repeats the action and sits for about 30 seconds with his hand on the bowl, his gaze alternates between looking at the breadstick and the orange segments. He takes small nibbles at the breadstick. He then slowly tries to move

the bowl closer to him... a child is having his hands wiped and is told he can leave the table. DJ looks at the child who is toddling to the outdoor area. DJ makes a small sound, puts his half eaten breadstick on the table, and leaves the table. He runs to the door and returns to the outdoor play area.

*The 'orange incident' haunts me. He is 20 months old and he is clearly noticing difference between the food that he is given and other children's food. What is he thinking? His level of 'stillness' is striking for such a young child. His attention from the events of 'the orange incident' was only taken away when he realised he could leave the table and go outdoors. He sits and gazes and is still and silent, clearly thinking deeply. The routines for meal times are lengthy and I am wondering if this makes mealtimes difficult for DJ? Perhaps a snack station would be better in order to avoid prolonged periods of time sitting at a table?*

The next observation was made a month later when DJ was 21 months old.

**27<sup>th</sup> April, 1625: tea time** – children are seated at tables. Plates of toast, bowls of grated cheese and bowls of apple slices are placed in the middle of the table. Children are helped by practitioners to serve their choices. There is no discussion about restrictions for any of the children. DJ looks at the food but does not gaze with intensity, he gives a quick look at the other children's food and settles down to eat. He eats two servings of grated cheese and a quarter of a slice of buttered toast and drinks two cups of juice. He gives small, almost imperceptible nods of his head occasionally (DJ 21 months)

*I am acutely aware that I have had an all-consuming interest in DJ and his responses to mealtimes. I was relieved that when he had tea the other day he ate with enthusiasm after he had checked that the other children were eating the same. Using observations has helped me, in a way that no other research method could have done, to see DJ's responses to food. Pascal (2012) describes how observations help the observer to try and feel what it is like for a child in a setting, how the data can capture the moment, how the observer can use gut feelings and trust what is being observed. I feel as if I am a conduit that can pass on the information of DJ's responses to food in order to illustrate how he observes difference. I don't know what he is thinking, but my gut feeling is that he is either: perturbed, unhappy, or just wondering why his food is different. Or, is his response even more profound?, is he relieved that the food provided that he is offered is the same as the other children's food? Therefore, has he learned that the food is not going to cause him to have a reaction and is therefore safe for him so he can relax and enjoy eating? I would love to know what he is thinking. I would also like to make all his mealtimes the same as the one the other day, to make mealtimes more inclusive for him. (Research Journal entry 30th April)*

The description of the observations and the reflections highlight that despite his very young age, DJ notices when he is served food that is different to the other children, which may reflect Nutbrown's (2011b) assertion that anything that is different is of interest to children. However, DJ's ability to notice this difference appears to go unnoticed by the practitioners. It is possible that DJ is especially attuned to noticing when he is given food

that is different to the other children as this is a common occurrence for him. However, DJ clearly demonstrated that his demeanour was happier and he felt included when he is given the same food as the other children.

The data presented in this section demonstrates that the provision of food causes great tensions for practitioners who want to include children in all aspects of daily nursery activity, but who have to ensure the safety of children with food allergies. However, DJ's data suggests that precautionary measures to ensure this safety can cause distress for young children who are being excluded from aspects of provision. This is not to suggest in any way that children's safety should be compromised, however it does raise questions about the extent to which practitioners consider issues of inclusion and exclusion when working with children with CHCs.

### **Discussion**

The findings revealed that 11% of children in the overall study had been diagnosed with one, or more, ongoing medical conditions which provoked considerations and challenges to their inclusion within their early education. This figure was in the range given by the World Health Organisation's (WHO 2007) data, who report that 5 – 20% of children have one or more CHCs. What is more, the number of children being diagnosed with a CHC is increasing. Consequently, there is a need to develop effective pedagogies which enable these children to take part in activities and routines that enhance their early education. Whilst it is clear that the practitioners in this study worked tirelessly to address and meet the needs of children with CHCs in their setting, they were unable to draw on existing examples of effective pedagogy for children with CHCs. Instead, they drew on what Greenwood and Levin (2005 p 51) describe as the Aristotolean concept of their 'phronesis' (wisdom derived from experience) to address the considerations and challenges that CHCs presented to them when planning to include children in their early education.

The findings revealed that practitioners adapted activities in innovative ways, but it was not always an inclusive approach and it would appear that achieving a fully inclusive environment for children with CHCs is especially challenging. This may well be because practitioners identified themselves as an 'alert assistant', in a similar way to the findings in Pitchforth et al's (2011 p 10) study, in order to keep children safe. However, this

paper has demonstrated that the need to keep children safe causes a tension with the aim of being inclusive. This study has shown that children with CHCs are likely to be excluded from important aspects of their early childhood education, and it is important that educationalists recognise this. In doing so, practitioners may need to be advised on how they can promote inclusion for children with CHCs by modifying activities and so on without compromising safety. This study has shown that some practitioners are skilfully doing this, but there is a need for clear guidance for children under 5 in a similar way to the guidance available for children with chronic health conditions in schools. It is also important that we understand how to maximise inclusion for these children. For example, it may be possible to make adjustments during mealtimes so that children with food allergies are not isolated or unhappy, in order to minimise the possibility of emotional and behavioural difficulties as highlighted by Miall et al (2016). Finally, and very importantly, we need to understand the impact of unavoidable exclusion on young children; this calls for more research of a neglected area.

### **Conclusion**

The findings from this study illustrate the need to identify effective pedagogies for children with CHCs help them to maximise participation in their early education. However, the findings also demonstrate that whilst inclusion is a sought after aim of education, achieving inclusion is, as Allen (2000) points out, an on-going process and one that is never complete. It may be the case that achieving full inclusion for some children in their early education is not a feasible ideology and this may have attendant consequences for children and young people across their life span; it may even have consequences for society. Therefore, it may be time to reconsider the concept of inclusion and the consequent exclusion that can evolve. As this paper reaches its conclusion it is helpful to draw on the New Zealand philosophy of te wāhutu pōkeka (Ministry of Education 2009, p2):

A wāhutu pōkeka is a baby blanket made of muka (fibre) from the harakeke (flax) plant. Carefully woven into the inside of the blanket are albatross feathers to provide warmth, comfort, security, and refuge from the elements. The pōkeka takes the shape of the child as it learns and grows. It is a metaphor for this project, the development of a curriculum that is determined and shaped by the child.

This reminds us that just as we need to consider the individual learning, social and emotional needs of children in early childhood settings, we must also consider their individual needs regarding inclusive activity. This paper argues that inclusion, in its full

sense, may not be possible for some children with CHCs. The wellbeing and safety of children must always remain a priority, however it is important that we consider the implications of compromised inclusion. On a practical level this may mean adaptation of daily activities to ensure maximal participation, but this will not always be the case. However, this might also mean that we become more alert and aware of the implications of CHCs on children's individual experiences in settings and find ways to work with children to ensure that any issues created by this are addressed.

## References

Albon, D. and Mukherji, P. (2008) *Food and Health in Early Childhood*. London: Sage.

Allen, J. (2000) Reflection: Inconclusive education? Towards unsettled uncertainty.in Clough, P. and Corbett, J. *Theories of Inclusive Education*. London: Paul Chapman Publishing

Baker, F. S. (2013). Responding to the Challenges of Active Citizenship through the Revised UK Early Years Foundation Stage Curriculum. *Early Development and Care*. DOI:10.1080/03004430.2013.792254. Retrieved 6 June 2013 from: <http://dx.doi.org/10.1080/03004430.2013.792254>

Barton, L. (1988) Ed. *The Politics of Special Educational Needs*. Lewes: Falmer Press

Booth, T. Ainscow, M. and Kingston, D. (2004). *Index for Inclusion: Developing Play, Learning and Participation in Early Years and Childcare*. Bristol: Centre for Studies on Inclusive Education.

Borsay, A. (2005). *Disability and Social Policy in Britain since 1750*. Basingstoke: Palgrave Macmillan.

Brown, D.G., Krieg, K. and Belluck, F. (1995). A Model for Group Intervention with the Chronically Ill: Cystic Fibrosis and the Family. *Social Work in Pediatrics*. Vol. 21, No.1, p. 81-94.

Clough, P. and Corbett, J. (2000) *Theories of Inclusive Education*. London: Sage  
Cummings, A. J., Knibb, R. C., King, R. M. and Lucas, J. S. (2010). The Psychosocial Impact of Food Allergy and Food Hypersensitivity in Children, Adolescents and their Families: a Review. *Allergy*. Vol 65, p. 933-945.

Department for Education and Skills and Department of Health (2005). *Managing Medicines in Schools and Early Years Settings*. London: DfES.

Department for Education and Skills (2003) *Every Child Matters*. London: The Stationery Office

Department for Education and Skills (2007) *The Statutory Framework for the Early Years Foundation Stage: Setting the standards for Learning, Development and Care for Children from Birth to Five*. Annesley: DfES Publications

Department for Education/Department of Health (2015) *Special Educational Needs Code of Practice 0-25 years*. Available from [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/398815/SEND\\_Code\\_of\\_Practice\\_January\\_2015.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf) accessed 14 September 2018

Department for Education (2015). *Supporting pupils at school with medical conditions*. Available from [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/638267/supporting-pupils-at-school-with-medical-conditions.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/638267/supporting-pupils-at-school-with-medical-conditions.pdf) accessed 15 September 2019

Department for Education (2017) *The Statutory Framework for the Early Years Foundation Stage: Setting the standards for Learning, Development and Care for Children from Birth to Five*. Available from [https://www.foundationyears.org.uk/files/2017/03/EYFS\\_STATUTORY\\_FRAMEWORK\\_2017.pdf](https://www.foundationyears.org.uk/files/2017/03/EYFS_STATUTORY_FRAMEWORK_2017.pdf) accessed 2 September 2018

Duffy, K. (1995) *Social Exclusion and Human Dignity in Europe*. Council of Europe  
Glesne, C. and Peshkin, A. (1992) *Becoming Qualitative Researchers*. White Plains:  
Longman

Greenwood, D. J. and Levin, M. (2005). Reform of the Social Sciences and of universities through Action Research in Denzin, N. K. and Lincoln, Y. S. *The Sage Handbook of Qualitative Research* (3<sup>rd</sup> Ed). London: Sage.

Klasen, S. (1998) *Social Exclusion and Children in OECD Countries: Some Conceptual Issues*. Paris. OECD.

Klasen, S. (1995). *Social Exclusion, Children, and Education: Conceptual and Measurement Issues*. Background paper for OECD. Accessed 18 June 2018: <http://www.oecd.org/education/school/1855901.pdf>

Diabetes UK (2013) UK has 5<sup>th</sup> highest incidence of Type 1 diabetes in the world. Available from [https://www.diabetes.org.uk/about\\_us/news\\_landing\\_page/uk-has-worlds-5th-highest-rate-of-type-1-diabetes-in-children](https://www.diabetes.org.uk/about_us/news_landing_page/uk-has-worlds-5th-highest-rate-of-type-1-diabetes-in-children) accessed 16 August 2018

Greenwood, D. J. and Levin, M. (2005). Reform of the Social Sciences and of universities through Action Research in Denzin, N. K. and Lincoln, Y. S. *The Sage Handbook of Qualitative Research* (3<sup>rd</sup> Ed). London: Sage.

- Hills, L., Le Grand, J., and Piachaud, D. (2002) *Understanding Social Exclusion*. Oxford: Oxford University Press
- Hopkins, L. (2015) *An Australian and New Zealand Review of Educational Support for Children with Chronic Health Conditions*. Melbourne: The Royal Children's Hospital Education Institute. Available from <https://www.rch.org.au/uploadedFiles/Main/Content/education/National%20Review%20of%20Hospital%20Based%20Education%20Support.pdf> accessed 15 April 2019
- Klaus, S. and Marsh, A. (2014) A Special challenge for Europe: The Inclusion of Roma Children in Early Years Education and Care. *European Early Childhood Education Research Journal*. Vol 22, No 3, p 336-346
- Levy, M., Weller, T. and Hilton, S. (2006). *Asthma at your fingertips* (4<sup>th</sup> Ed). London: Class Publishing.
- Lingard, B. (2000) Profile: Bob Lingard, in Clough, P and Corbett, J. *Theories of Inclusive Education*. London: Paul Chapman Publishers/Sage
- Marks (1999b) in Goodley D (2011) *Disability Studies: an Interdisciplinary Introduction*. London: Sage
- Miall, L., Rudolf, M. and Smith, D. (2016) *Paediatrics at a Glance*. Chichester: Wiley Blackwell
- Moyles, J. (2012) *The A to Z of Play in Early Childhood*. Maidenhead: Open University Press.
- Mukherjee, S., Lightfoot, S. and Sloper, P (2000). The Inclusion of Pupils with a Chronic Health Condition in Mainstream School: What does it mean for Teachers? *Educational Research*, Vol. 42, No. 1, Spring 2000, p. 59-72.
- Musgrave, J. (2014) Reflections paper (2014) *Supporting children with chronic medical conditions in the Early Years Foundation Stage: a case for discrimination?* Available at <https://tactyc.org.uk/reflections/> accessed 15 April 2019
- New Zealand Ministry of Education (2009) Te Phatu Pokeka. Available from <https://education.govt.nz/early-childhood/teaching-and-learning/assessment-for-learning/te-whatu-pokeka-english/introduction/> Accessed 15 April 2019
- Nurse, A. (2001) A question of inclusion. In Abbott, A. and Nutbrown, C. (Eds) *Experiencing Reggio Emilia: implications for pre-school education*. Buckingham: Open Press
- Nutbrown, C. (2011a). *Threads of Thinking: Schemas and Young Children's Learning*. London: Sage Publications.

Nutbrown, C. (2011b). *Key Concepts in Early Childhood Care and Education 2nd Edition*. London: Sage.

Nutbrown, C. and Clough, P. (2006). *Inclusion in the Early Years*. London: Sage.

Oppenheimer, S., Krispin, O., Levy, S., Ozeri, M. and Apter, A. (2018) The impact of coping patterns and chronic health conditions on health-related quality of life among children and adolescents. *European Journal of Pediatrics*, June 2018, Vol 177, Issue 6, pp 935-943. Available from <https://link.springer.com/article/10.1007%2Fs00431-018-3146-6> accessed 15 April 2019

Pellegrini, A. D. and Smith, P. K. (1998). Physical activity play: the nature and function of a neglected aspect of play. *Child Development*. 68, p 577-598.

Pellegrini, A. D., Dupuis, D. and Smith, P. K. (2006). Play in evolution and development. *Developmental Review*. Vol 27, p 261-276.

Piaget, J and Inhelder, B. (1969) *The Psychology of the Child*. New York: Basic Books.

Pitchforth, E., Weaver, S., Willars, J., Wawrzakowicz, E., Luyt, D., and Dixon-Woods, M. (2011). A qualitative study of families of a child with nut allergy. *Chronic Illness* Vol. 0 No.0, p. 1-12.

Powell, J. (2005) Anti-discriminatory practice matters in Abbot, L. and Langston, A. (eds) *Birth to Three Matters: Supporting the Framework of Effective Practice*. Maidenhead: Open University Press.

Warnock Report (1978) *Special Educational Needs: Report of the Committee of Enquiry into the Education of Handicapped Children and Young People*. London: Her Majesty's Stationery Office

Waters, E., Davis, E., Nicolas, C., Wakes, M. and Lo, S. K. (2008). The Impact of Childhood Conditions and Concurrent Morbidities on Child Health and Wellbeing. *Child: care, health and development*, p. 418-429. Doi:10.1111/j.1365-2214.2008.00825.x

Wood, E. (2013). *Play, learning and the early childhood curriculum* 3<sup>rd</sup> ed. London: Sage.

World Health Organisation (2007) *Prevalence of Asthma and Allergies in Children*. Factsheet No. 1. May 2007. Available from [http://www.euro.who.int/\\_data/assets/pdf\\_file/0012/96996/3.1.pdf](http://www.euro.who.int/_data/assets/pdf_file/0012/96996/3.1.pdf) Accessed 14 September 2018