A broken start? An examination of the impact of chronic illness and hospitalisation on the early childhood care and education careers of children attending hospital schools in Ireland.

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Declaration

I hereby declare that this dissertation is a presentation of my original research work. Wherever contributions of others are involved, every effort is made to indicate this clearly. This work has not been submitted previously at this or any other educational institution. The work was done under the guidance of Dr. Rory Mc Daid at the Marino Institute of Education, Dublin. I agree that the Library may lend or copy this dissertation upon request.

Signed: Jennifer Hogan

Date: 1st June 2020
Abstract

The title of this study is “A broken start? An examination of the impact of chronic illness and hospitalisation on the early childhood care and education careers of children attending hospital schools in Ireland.” This dissertation examines the challenges and impact infrequent attendance of early childhood care and education (ECCE) can have on a chronically ill child’s life.

One of the most important developmental tasks of a young child’s life is to move beyond the family sphere into the school community, where academic achievement, social skills, emotional regulation and regular attendance are major goals. Among children at increased risk for school dysfunction and absenteeism are those with a chronic illness. They are vulnerable not only because of the medical aspects of their illness but also because of the secondary effects of the illness on the child’s social, emotional and developmental functioning.

Some children, by virtue of acute or chronic medical needs, are unable to attend their own pre-school, primary school or secondary school on a regular basis due to recurrent or continuous hospitalisation. Continuing education while in hospital is an integral part of maintaining a child’s wellbeing, giving them hope for a future without illness or indeed a future despite illness. At present in Ireland, if a child over the age of four years should be admitted into a paediatric hospital they would usually attend a hospital school to continue with their educational needs, yet prior to four years of age there is no educational service available to them. Hospital schools serve to address the gaps in concepts frequently observed in chronically ill students as a result of multiple school absences due to illness. However, little research has been conducted in this area.
This research employs a qualitative design. The data collection for this study included compiling information from Ireland’s two tertiary paediatric hospitals. It includes semi-structured audio-recorded interviews with the teachers and SNAs employed in these settings. Their views and perceptions towards the benefits of ECCE within a hospital setting were explored in depth. By engaging in semi-structured interviews, the effects ECCE can have on a chronically ill young child’s life were identified and documented.

This study examines the main contributors to both academic challenges and challenges affecting the social and emotional development of children with chronic medical needs, who have access to education and also for those who do not have access to ECCE. The research study concludes with participants’ views towards equal access to ECCE within a hospital school setting.
Acknowledgements

I would like to express my sincere gratitude to my supervisor, Dr. Rory McDaid, for his guidance and encouragement over the past year. Without his valuable support, this research would not have been possible.

I would also like to extend my appreciation to the Boards of Management of the two hospital schools who generously agreed to allow their schools to be included in this research study. Each staff member who participated in this study shared valuable insights and made significant contributions to my research for which I am incredibly grateful.

Finally, a very special word of thanks to my husband Adrian and to my loving family and friends for their unending love, support and encouragement over the past year.
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<td>Child and Adolescent Mental Health Service</td>
</tr>
<tr>
<td>CF</td>
<td>Cystic Fibrosis</td>
</tr>
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<td>Department of Children and Youth Affairs</td>
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<td>DES</td>
<td>Department of Education and Skills</td>
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<td>ECCE</td>
<td>Early Childhood Care and Education</td>
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Chapter One: Introduction

Introduction

The purpose of this research is to identify the challenges and impact infrequent attendance of early childhood care and education (ECCE) can have on a chronically ill child's life. This research aims to identify the impact complete or partial disruption of ECCE due to recurrent or continuous hospital admissions can have on children when they attend hospital schools. The expertise of those working with children in hospital schools was sought as their opinions, observations and knowledge are invaluable to this study.

This study is guided by my own desire and inherent interest to closely examine the needs of children with chronic illnesses who do not have frequent access to ECCE. From my observations as a hospital school teacher, these children are often at a disadvantage to their healthy peers due to long absences from their base schools, unplanned hospital stays and daily medical demands. At present, ECCE for children aged three to four years is the only aspect of the continuum of education which is not met in our nation's hospital schools. As noted in an Irish hospital school’s Whole School Evaluation (WSE) report, (DES, 2017) this service is currently unavailable, yet in my experience, this is highly sought after by medical staff, patients and parents alike.

It was easy for me, the researcher, to notice an inconsistency in the educational service provided by hospital schools in Ireland, yet I was interested in hearing from other hospital school staff members. Their views, opinions and aspirations were important to me and I was interested in researching how they value ECCE in a chronically ill child’s life, whether they are eager to see a pre-school service being established within the hospital setting or if various factors such as
compulsory age, lack of available money and planning for ECCE are permitting such a service being implemented.

**Rationale for the Education of Children with Medical Needs**

The majority of illnesses experienced by children are self-limiting, running their course in a matter of days or weeks. Furthermore, childhood illnesses, acute or serious, when treated accordingly, generally require a month or so for complete recovery (Perrin, Ireys, Shayne & Moynihan, 1984). In contrast, Perrin et al. (1984) define chronic illness as a medical condition which lasts for more than three months, requires medical attention and interferes with a person’s daily living. For the purpose of this research, the terms *chronic illness* and *medical needs* will be used when best suited to the occasion. Chronic illness and medical needs refer to the a long term health problem, its associated treatments and/or ailments.

One of the most important developmental tasks of a young child’s life is to move beyond the family sphere into the school community, where academic achievement, social skills, emotional regulation and regular attendance are major goals. This is not always possible for children with chronic illness. These children are very often at risk of school dysfunction and absenteeism. They are vulnerable not only because of the medical aspects of their illness but also because of the secondary effects of the illness on the child’s social, emotional and developmental functioning.

Children with chronic illnesses make up to 13-27% of the population (Wijlaars, Gilbert & Hardelid, 2016). For many of these children, their illness impacts on many aspects of their lives, with consequences that endure into adulthood. For those with illnesses requiring extended and/or recurring hospitalisation, there is a significant risk
of low achievement and poor academic accomplishment, much of which stems from a lack of suitable educational services (Burns, 2013).

According to Cashin and Witt (2010) children who are hospitalised require as many normalising encounters as possible. Some children, by virtue of acute or chronic medical needs, are unable to attend their own pre-school, primary school or secondary school on a regular basis due to recurrent or continuous hospitalisation. Yet, for many of these children, school is exactly what they need. According to Ferguson & Walker (2014) school is extensively recognised as a “stabilising and normalising influence for young people with chronic illness” (p.236). It is this desire for normality that necessitates hospital schooling for such children during their hospitalisation. Continuing education while in hospital is an integral part of maintaining a child’s wellbeing, giving them hope for a future without illness or indeed a future despite illness.

Currently in Ireland there are nine hospital schools, yet hospital based pre-school education is currently not an option for young children who are suffering with a short or long term illness. At present in Ireland, if a child over the age of four years should be admitted into a paediatric hospital they would usually attend a hospital school to continue with their educational needs. Before the age of four, there is no educational service available to them. Hospital schools serve to address the gaps in concepts frequently observed in chronically ill students as a result of multiple school absences due to illness. However, little research has been conducted in this area.

The present study
In order to explore the educational needs of chronically ill children who do not have access to ECCE within a hospital setting, this study was guided by the following research question:
What are the views of a selection of hospital school staff with regard to early childhood care and education for children with chronic medical conditions?

Two sub-questions further helped to guide the work:

a) What impact does absence or limited access to early childhood care and education have for children when they attend hospital schools?

b) What are hospital school staff’s feelings with regard to early childhood care and education within a hospital setting.

Following this introduction to the research, the literature review will outline relevant research pertaining to children with chronic medical needs, ECCE and hospital schools. The literature review revealed five main themes into which the literature was divided: *Early Childhood Care and Education; Access to Education; The Impact of Infrequent School Attendance on Young Children; Students and Chronic Illness; and The Role of Education for the Chronically Ill Student*. Chapter Three outlines the research design employed to answer the research question. Findings and analysis of data collected will be outlined in Chapter Four, in line with the objectives of the research. These findings will be analysed throughout this chapter in the context of current literature, policies and practices. This dissertation will conclude with a discussion of the implications of this study for the provision of ECCE.
Chapter Two: Literature Review

Introduction

The purpose of this chapter is to review the literature on the challenges and impact the absence of ECCE can have on a chronically ill child’s education.

Children with acute or chronic medical needs are often unable to attend school on a regular basis due to recurrent or continuous hospitalisation. These children may require hospitalisation for various reasons throughout their childhood such as receiving ongoing treatment, undergoing operations, spontaneously spiking temperatures or contracting infections. Whilst an inpatient in a paediatric hospital in Dublin, Ireland, children over the age of four years may receive schooling on site from a Department of Education and Skills (DES) recognised hospital school teacher. Hospital schools serve to fill the gaps in concepts, academic attainment and socialisation frequently observed in chronically ill students as a result of multiple school absences due to illness (Our Lady’s Hospital School, 2019). Currently in Ireland, formal education within a hospital setting is solely accessible to children who are four years of age and older (Our Lady’s Hospital School, 2019; HSE, 2019; Children’s Health Ireland at Temple Street, 2019). This is an area of education about which little is formally known.

The broad area of hospital education is under-researched in the Irish and international literature. Lemke (2004) analysed that “little information describing hospital schools is available from the literature...Information describing hospital schools and how they deliver education to children does not seem to be available” (p.2). While several important contributions to the field do exist, notably Lemke (2004), generally the literature is insufficient. This observation is even more
applicable to the field of ECCE in a hospital setting. Nevertheless, following a systematic review of the literature, key areas of concern emerged. In the first instance, this literature review examines the relevant literature pertaining to the importance of ECCE more generally. Following this, several subsequent themes will be explored and presented; Access to Education; The Impact of Infrequent School Attendance on Young Children; Students and Chronic Illness; and The Role of Education for the Chronically Ill Student.

Early Childhood Care and Education

Early years education in Ireland.

Early childhood is perhaps the most critical period in a child’s development (INTO, 2016). It is a time of remarkable growth with brain development at its peak. During this stage, children are highly influenced by the environment and the people that surround them. ECCE settings provide children with their first formal experience of early learning prior to commencing primary school. It focuses on the holistic development of a child’s social, emotional, cognitive and physical needs in order to build a solid and broad foundation for lifelong learning and wellbeing (UNESCO, 2019).

ECCE is underpinned by a strong tradition which regards play as essential to learning and development. This is based extensively on the work of pioneer educators, yet more recently, this tradition has been linked to current contexts, receiving further recognition and critical examination from researchers, policy-makers and practitioners (Wood & Attfield, 2005). The term 'early childhood' is universally recognised as a distinct duration in a child’s life and, within the Irish policy context, it refers to the period from birth to the age of six years (Department of Education and Skills, 1999; CECDE, 2006; NCCA, 2009). ECCE developments
incorporate pre-schools, naíonraíthe and the infant category of primary schools in Ireland, in addition to providers of services such as creches and childminders (INTO, 2016).

In many countries around the world (including the United Kingdom, New Zealand, Denmark, Spain and Sweden) an integrated system of ECCE operates under a single Government Ministry, however a split system of governance operates in Ireland (Ring et al., 2016). In this system, primary school children from four to twelve years are under the auspices of the DES (Ring et al., 2016), while ECCE services are regulated by Irish Government funded schemes. Despite the fact that the statutory school starting age in Ireland is six years, (Government of Ireland, 1998), see Table 1 (p.10), approximately all five year olds and half of four year olds are enrolled in infant classrooms in primary schools (Ring et al., 2016).

**Developments in ECCE since the turn of the 20th century.**

Ireland joined the United Nations Convention on the Rights of the Child (UNCRC) in 1992, placing children’s rights at the centre of social and political agendas (Gray & Ryan, 2016). The UNCRC defines children as competent citizens with rights and responsibilities (Gray & Ryan, 2016). Ireland, along with many other countries, found it challenging to implement the obligations of the UNCRC. Gray and Ryan (2016) note that Ireland was compelled to rethink their existing policies to facilitate the enactment of the Convention.

Ireland has seen great advances in ECCE since the turn of the 20th century. Up until the mid-1990s, the Irish State had little involvement in childcare. An amalgam of historical, social, economic and political factors contributed to this (INTO, 2005; Ring et al., 2016). Following the publication of the UNCRC, significant investments were made in the development of ECCE facilities and practices. A
change to taxation structures within the state forced two-income families into existence. As a result of the economic boom between 1998 and 2007, almost 30,000 women joined the workforce making way “for out-of-home childcare arrangements” (Ring et al., 2016, p.17; NESF, 2005). The female participation rate increased from 34.1 per cent in 1992 to 48.6 per cent in 2001 (Hayes, 2002). This was seen as a key factor impacting on the early years, as the increased participation of women in the workforce forced the Irish government to develop higher standards of quality and provide safer, more efficient and more effective services for children and families (INTO, 2005).

Ring et al. (2016) clarify that since 2000, the Irish government has introduced various educational programmes to develop our nation’s ECCE infrastructure. More recently, several policies and initiatives have been developed under the auspices of the DES. These developments included: a revised Primary School Curriculum (1999), the development of Síolta: The National Quality Framework for Early Childhood Education (2006) and the introduction of Aistear: The Early Childhood Curriculum Framework (NCCA, 2009).

Echoing global movements, in 2009 Aistear: the Early Childhood Curriculum Framework was introduced to early years settings across Ireland. Modelled on the New Zealand Curriculum of Te Whāriki (Churchill Dower et al., 2013) and developed by the National Council for Curriculum and Assessment (NCCA), Aistear is the curriculum framework for children from birth to six years in Ireland (NCCA, 2009).

These policies and initiatives have “underpinned the inextricable link between care and education for children aged from birth to six years, leading to some changes in the Childcare Regulations and allowing for more attention to be given to child development and well-being” (Ring et al., 2016, p.19).
Free pre-school year.

In recent years, the Department of Children and Youth Affairs (DCYA) introduced the universal Free Pre-School Year (FPSY) scheme (Ring et al., 2016; Citizens information, 2019). Citizens Information (2019) note that the ECCE scheme caters for pre-school aged children in Ireland. Since September 2018, children can start ECCE when they are two years and eight months of age and continue until they transfer to primary school, provided that they are not older than five years and six months at the end of the pre-school year (Citizens information, 2019). The FPSY is delivered three hours a day, five days a week and its main objective is to benefit the children in the key developmental period prior to starting school. Ring et al. (2016) explain that it is mandatory to implement the principles of both Síolta and Aistear in ECCE settings participating in the FPSY scheme. In many ways, the importance of Aistear and Síolta lies in their potential to maintain the continuity of learning between the pre-primary setting and the primary school.

School starting age.

Drawing from data from the DES and the Growing Up in Ireland study (Watson, Maitre, Whelan & Williams, 2014), a recent review of school starting age in Ireland found that, from 1994 to 2012, there was a steady decline in the number of four-year-olds starting school (Wolfe, 2014 as cited from Ring et al., 2016). It is well established that high quality ECCE can make a significant difference in the lives of young children, especially for children from disadvantaged backgrounds (Oke, 2019). High quality ECCE programmes are shown to have positive effects on children’s readiness to start school (Health Affairs, 2019) yet, with the introduction of the FPSY, parents are holding off on sending their children to Junior Infants, and alternatively choosing an extra year of pre-school education. Ring et al. (2016) note that the data
demonstrates that Ireland is similar to the majority of European countries in that it is not compulsory for children to start school until the age of six years or older. (See Table 1).

<table>
<thead>
<tr>
<th>Age</th>
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<tr>
<td>4 years</td>
<td>Northern Ireland</td>
</tr>
<tr>
<td>5 years</td>
<td>England, Malta, Netherlands, Scotland, Wales</td>
</tr>
<tr>
<td>6 years</td>
<td>Austria, Belgium, Croatia, Cyprus, Czech Republic, Denmark, France, Germany, Greece, Hungary, Iceland, Republic of Ireland, Italy, Liechtenstein, Lithuania, Luxembourg, Norway, Portugal, Romania, Slovakia, Slovenia, Spain, Switzerland, Turkey</td>
</tr>
<tr>
<td>7 years</td>
<td>Bulgaria, Estonia, Finland, Latvia, Poland, Sweden</td>
</tr>
</tbody>
</table>

Table 1: Compulsory school starting age in European countries.

Source: Eurydice, 2014 (as cited in Ring et al., 2016, p.19)

Access to Education

Chronic absenteeism in the yearly early years.

Certain groups, for social and cultural reasons, do not attend ECCE. The impact of poor attendance can be damaging to a child’s development. There are many explanations why a child may be absent from their ECCE setting, and certain groups of children are much more likely to be more frequently absent than others. With the absence of specific literature on hospitalised children and chronically ill children, I have examined relevant material from various groups of children to establish the impact of school absence.

Absenteeism amongst minority ethnic children.

Ehrich et al. (2014) state that in North America racial differences are particularly stark: African American students are almost twice as likely as white, Latino, and Asian students to be chronically absent. In Australia, First Nations children are
intermittently attending their ECCE settings and similarly, in Ireland, Traveller and Roma children are less likely to continuously attend a formal early years education due to their cultural heritage. Concern surrounding absenteeism in early childhood education, particularly of First Nations children, is a key issue in Australian education. Taylor (2010) examined the impact of intermittent attendance on the academic, social and personal wellbeing of young Aboriginal children.

As well as early school exit, intermittent attendance is linked to individual and society related issues - unemployment, poverty, homelessness and criminal behaviour (ACER, 2004, as cited in Taylor, 2010). Taylor (2010) states that although patterns of chronic absenteeism vary with location, age, stage and gender, debate tends to focus on the upper grades rather than absenteeism in ECCE or its effects at this level.

Taylor argues that occasional attendance impacts on children’s ability to enjoy, as well as profit from schooling and importantly reinforces a pattern of ‘laissez faire’ involvement. In Taylor’s (2010) article, it was noted that Indigenous parents did not deliver children with adequate consistency or punctuality, as they were otherwise preoccupied, circumstances made it too difficult and/or they did not have the will to deal with yet another system. However, when Taylor looked into the findings, the underpinning explanations were complex and varied as to why caregivers and parents decided not to deliver their young children regularly to early childhood centres. They involved a complex and differing interaction of factors associated with: socio-economic circumstances, the widespread absence of personal histories and indigeneity, in particular, culturally specific ways of raising children and the empowerment of children’s independence.
Sustained behavioural change takes time and inter-generational change particularly so. Taylor (2010) reports that measures are required to address the outcomes of current chronic and intermittent attendance, especially before unexcused absences become a way of life and children slip so far behind academically and socially that schools have little to offer them.

**Irish traveller and Roma children.**

In the absence of data for the cohort of the study, I am looking at other areas of chronic absence in the early years sector in Ireland. School attendance can be problematic for children who are mildly or chronically ill, as well as young children from the Irish Travellers and Roma communities and children from lower-socioeconomic backgrounds.

Irish Travellers and Roma represent two of the main ethnic minorities in Ireland (DCYA, 2018). Both Roma and Traveller communities in Ireland comprise of a very young population with 42% of Travellers and 35.7% of Roma communities being under 15 years of age. Murray (2014) states that 'high' quality ECCE constitutes a necessary start for children from all backgrounds, including young children from the Traveller or Roma communities in Ireland.

The extended family is the embodiment of community for Irish Travellers, and not a particular geographical location. Moving from town to town or alternatively being forced by Irish legislation - Housing Miscellaneous Act (2002), into shared housing has led to isolation and loneliness for many Travellers, which, in turn, has had an effect on their wellbeing. Sheltering themselves from society and thus educational opportunities for their children, can lead to major long term consequences. Roma do not share a particular homeland, but akin to Travellers, they are a minority ethnic group and share a common ancestry of origin, culture and
language. Poor accommodation is a strong factor in determining ability to attend school regularly (Murray, 2014).

Murray (2014) states that Roma and Traveller children are a minority within a minority and suffer all the ill effects of marginalisation and exclusion in line with their community. This leads to restricted opportunities in society and has a detrimental effect on educational attainment. According to the 2016 Census, 25% of Traveller children were attending an early years service. Similarly, the DCYA (2018) noted that just under half of Traveller children in early years services availed of ECCE (47%). 276 services reported having at least one Roma child attending their facility (7% of all survey respondents). In total, 688 Roma children were enrolled in early years services, of whom just under two thirds (65% or 444 children) availed of ECCE.

In Ireland, practitioners have tended not to celebrate the ‘cultural’ aspects of the Traveller community nor address possible discrimination, causing young children to feel as though they are not welcomed, included or valued members of their early childhood groups. Unsurprisingly, this leads to sporadic engagement with their ECCE setting or complete withdrawal (Murray, 2014). Attendance of Traveller children at school and at childcare facilities can vary. Attendance can be affected by a number of factors, including seasonal migration, travel occasioned by family and social events, and even the day of the week, with attendance being poorer on Friday. Smart (2009) states that when Traveller children are enrolled in primary school, many are inadequately placed in the special educational needs category as teachers have failed to recognise that they are not dealing with a child with learning difficulties, but one who has had little opportunity for formal learning. Duffy (2007) explains that early intervention is key to school readiness and poor school readiness
can lead to poor peer relationships, lower academic achievement, unemployment, teenage pregnancy, criminal activity, and poor psychological well-being.

**Lower socioeconomic status and attendance.**

Another cohort of children experiencing chronic absence in the early years sector are those from lower socioeconomic backgrounds. Research shows (O'Rourke, O’Farrelly, Booth and Doyle, 2017) that children facing socioeconomic risk often have “poorer skills at school entry, greater difficulty adjusting to school, more negative school experiences, and lower scholastic achievement, relative to their peers” (p.206). Additionally, Romero and Lee (2007) state that across all class levels, the lower family income, the higher the absenteeism rates. Living in a poor family (one whose income is below the governmental poverty level), or a low-income family (one whose income is up to 200% of the governmental poverty level) greatly increased the chances of being an at-risk or chronic absentee. Furthermore, Romeo and Lee (2007) note that while attendance improved for all income groups through the class levels, chronic absenteeism was evident amongst a greater proportion of poor children than other income groups. This proportion diminished between the early years and third class, but increased again in fifth class.

According to O'Rourke et al. (2017), in early childhood, socioeconomic risk operates solely through its weakening effects on parents’ ability to provide ideal parenting practices and stimulating learning interactions. Often parents who are living in disadvantaged communities are younger with lower educational engagement which places their children at risk for lower ability at school entry (Janus and Duku 2007). Furthermore, relationships between families and schools are often weaker in disadvantaged communities (Moles 1993, as cited in O'Rourke et al., 2017), yet
these connections are crucial for any possible positive school experiences throughout children’s education (Ramey and Ramey 1994).

Granting that growing up in areas of socioeconomic disadvantage places children at increased risk of negative school experiences and having high absenteeism rates, an acute or chronic illness is the most commonly reported reason for sporadic school attendance.

**Mild and chronically ill children.**

As mentioned, school attendance can be problematic for children from a variety of different social backgrounds. The effects of this have been explained above. For the purposes of this study, it is important to consider the phenomena in the context of children who suffer from an acute or chronic illness. Lynch, Lewis, and Murphy (1992) (as cited in Gordon, 2016) state that in the United States 60% of children with a long term illness regularly miss a day of school, and over 45% report struggling with academic progress. There are many reasons for children to underperform at school, including both long term and short term medical problems, school absenteeism, repeated hospitalisation, specific learning disability and poor socio-cultural home environment (Karande & Kulkarni, 2005).

Over time, children with cancer exhibit frequent school absences due to both standard treatments and medical complications. In addition, these children miss an average of over 40 days of school during their initial treatments (Lanksy, Cairns, & Zwartjes, 1983). Even three years into treatment, or past diagnosis, when 50% of children are considered cured or in remission, average yearly absenteeism is over twenty days (Lanksy et al., 1983). Children who are frequently absent from school tend to perform poorly academically and drop out prematurely. Lanksy et al., (1983) state that this effect may be even greater for children with cancer or other chronic
illnesses. School provides the arena for meeting the child’s needs in areas of socialisation and achieving academic success.

Shaw and McCabe (2008) note that the reduced class time associated with recurrent hospital visits results in decreased time spent learning core academic concepts and bonding with peers. Shiu (2001) draws attention to evidence which suggests that children with long term illnesses miss more school and underachieve academically in contrast with their home school friends. Sexson and Madan-Swain (1995) suggest that more than half of students with chronic illness will return to their home schools in need of extra help from their teachers in order to “catch up” with their peers. The potentially damaging effect of such absences is further reiterated by Thies (1999) who notes that self-confidence, motivation and achievement are undermined as the child falls behind academically, and proposes that when this occurs, efforts are directed towards catching up which in turn takes time away from keeping up (p. 395).

Complementing Shiu, Eiser’s (1980) study on how leukaemia affects a child’s schooling found that a child with leukaemia suffered from a high school absence rate during the first six months of treatment. Eiser (1980) states that all school absences could be accounted for by necessary hospital appointments, their own ill-health or to avoid contact with childhood illnesses. (p. 367). In contrast, Emerson et al. (2015) note that although most children with a chronic illness are associated with increased school absenteeism due to “symptom flare-up, medical follow-ups, and medical procedures, not all children with chronic illness who miss school suffer academically” (p.2). Emerson et al. (2015) note that along with a return to optimal physical health, the child’s social well-being can either promote or hinder their return to school. Results show that children with chronic health issues are less likely to miss school
when their parents report a higher level of physical functioning. “Conversely, these youths are more likely to stay home from school when parents report a higher level of social functioning. Parental impression of child health drives school attendance, above and beyond child impression and past school absenteeism” (Emerson et. al., 2015, p. 7). Ehrlich, Gwynne, Stitzel Pareja, et al. (2014) indicate that absenteeism is not only a problem among older children in primary school, but it also is a significant problem among very young students.

Lemke (2004) believes that an expectation for higher performance in school has the potential to increase pressure on children who have a long term illness. Due to hospitalisation and treatment, children may experience an immense amount of pressure to remain caught up in school during absences (Lemke, 2004). Ferguson and Walker’s (2014) study indicates that while many of their participants described an ongoing disconnection with school, education still played an important role in their life goals. Opportunities, therefore, must be afforded to these students to allow them to embark on or continue with their educational journey, normal growth and developmental tasks and routines.

**Illness related absenteeism in the early years.**

Studies indicate that children attending ECCE settings are more prone to infections (Moen et al., 2007). Certain parents are anxious about sending their children to ECCE settings. Parents can be seen to be more cautious and limit their sick child’s ECCE attendance due to the fear of spiking high temperatures or developing infections (Moen et al., 2007; Enhrilch et al., 2014). In saying this, parents with stronger beliefs about the importance of regular ECCE attendance had children with greater attendance (Enhrilch et al., 2014).
In Europe, and especially in the Scandinavian countries, the proportion of children who attend day care centres is increasing. It is unclear to what extent the time these young children spend outdoors impacts on their health and sickness absenteeism in ECCE centres, yet certain studies have indicated that children attending day care centres are more prone to infections. The literature indicates that the main reasons for day care absenteeism are respiratory tract infections (76% of cases) and other infections (18%), whereas disabilities, injuries and chronic illnesses play minor roles (Moen et al., 2007). Moen et al.’s findings from their 2007 study indicate that it does not matter whether a child attends a regular or an outdoor day centre when it comes to sickness absenteeism. Additionally, there are no records of health benefits in outdoor day centres for children with chronic diseases and disabilities.

Chang et al. (2016) recognise that chronic absence is typically higher in three – six years, essential ages for gaining the fundamental academic and social skills students need to thrive in their school careers. Enhrilch et al.’s (2014) study suggests that ensuring ECCE students attend regularly is an essential factor in preparing children for primary school and beyond.

**The Impact of Infrequent School Attendance on Young Children**

Although the data shows that chronic absence is more prevalent among older students (Chang, Russell-Tucker and Sullivan, 2016), a growing body of research calls attention to chronic early absence. This concern undermines educational opportunity for far too many young students, especially those from the most vulnerable populations. Research shows that recurring absence in the early years can result in weaker reading skills, higher retention rates, and lower attendance rate
in later years (Connolly & Olson, 2012; Chang et al., 2016). This is especially true for children who are mildly or chronically unwell.

Early childhood is a critical period for the nurturing of each individual child’s curiosity, resilience, creativity, confidence and potential. There has long been a debate on whether pre-school education holds long term academic benefits. On the one hand, Piper (2018) suggests that children who go through intensive education at the ages of three and four years do not flourish in terms of academic abilities, yet they may show growth in social and emotional development. By the first two years in primary school much of their advantage has receded, and by the fourth year researchers typically cannot detect a difference in academic achievement at all (U.S. Department of Health and Human Services, Administration for Children and Families, 2010). On the other hand, there’s a substantive body of research suggesting that well designed pre-school education programmes have proven to produce long-term improvements in future school success (Barnett, 2008; Barnett & Frede, 2010; Melhuish, 2011; Melhuish et al., 2013; Thomas & Currie, 2002).

Academic attainment.

Evidence shows (Melhuish, 2011) that starting pre-school at three or four years of age can produce multiple benefits decades later. Gayden-Hence (2016) note that inconsistencies in academic achievement between children of varying abilities exist when children enter primary school. Thomas and Currie (2002) found that as students with learning difficulties advanced through school, many of them continued to experience issues, causing the gaps to widen even further, resulting in many of them eventually dropping out of school (Thomas & Currie, 2002). In order to close or minimise this gap, early intervention in a child’s life is necessary (Gayden-Hence, 2016).
The Effective Pre-school Provision in Northern Ireland (EPPNI) project was established in 1999. For an extended period of eleven years, a longitudinal study of child development was undertaken. In the EPPNI project, children were followed from three to eleven years of age in order to investigate the effects of pre-school experiences on children’s development (Melhuish et al., 2013). The results were compelling as the EPPNI project provided clear evidence of the benefits of pre-school education. The results indicate that high-quality pre-school experiences influenced later academic attainment at the end of primary school (Melhuish et al., 2013). Greater progress was notably apparent in mathematics and literacy scores. Melhuish et al. (2013) report that further pre-school experience and better pre-school quality are vital in boosting longer term educational, social and emotional outcomes.

Developmental milestones.

Children who spontaneously or continuously refrain from attending their early years settings for various reasons are at risk of regressing and falling behind in later years. Preschool activities are known to support children in many ways including socially, emotionally and developmentally.

Physical development should be regarded as being just as critical in young children’s development as is intellectual development. Research shows that physical activity in young children can enhance concentration, motivation, learning and well-being (Callcott, Hammond & Hill, 2014). Fine and gross motor skills development along with pre-literacy skills and language acquisition are proven to have a positive developmental impact on preschool children (Callcott et al., 2014). Yoshikawa, Welland & Brooks-Gunn (2016) report strong evidence that early years education boosts children’s language, literacy, and math skills in the short term; it may also reduce problem behaviours such as aggression.
According to French (2007) active learning, positive relationships between the adult and the child, social interactions with others and experiencing a challenging and interesting environment are crucial factors in the child’s early stages of learning and development. Additionally, French (2007) highlights the importance of play as an essential feature in guiding young children to developmentally achieve their full potential. “Through relationships in play, children develop and demonstrate improved verbal communication, high levels of social and interaction skills, creative use of play materials, imaginative and divergent thinking and problem-solving capacities” (French, 2007, p.8). Play is a key feature of all pre-school settings and it is an essential and critical part of all children’s development. Similarly to French (2007); Walsh, McMillan and McGuinness (2017) believe that play has been extremely meaningful and of deep significance for children since the beginning of the eighteenth century. Walsh et al. (2017) note that play can be promoted as the medium through which young children learn best and through which the ‘whole’ child is fully developed. Play cannot be easily defined due to varying contexts and environments, yet Wood and Attfield (2005) note that there are various forms of play: “role play, imaginative play, socio-dramatic play, constructive play, fantasy play, free flow play, structured play, rough and tumble play, all of which involve a wide range of activities and behaviours and result in varied learning and developmental outcomes” (p.5).

Play starts in the child's infancy and ideally and continues throughout his or her life. Research shows that 75 percent of brain development occurs after birth (Anderson-McNamee & Bailey, 2010). Play helps with that development by stimulating the brain through the formation of connections between nerve cells. Its
process helps with the development of fine and gross motor skills as well as language development and socialisation skills.

**Social and emotional difficulties.**

Maul-Mellott & Adams (1987) (as cited in Lemke, 2004, p.19) note that the emotional and social impact of school is a significant force in a child’s development. The social skills children obtain from schooling will be with them their entire lives. Bakken et al. (2017) report that according to teachers, from the early years on, children are significantly able to behave more appropriately in situations than the other children in their classrooms.

Bakken et al. (2017) note that from the early years and throughout primary school, children are able to interact significantly more competently with their peers and adults than other children their age. Competent social interactions allow children the chance to develop relationships with other children. By early adolescence, pupils need relationships with their peers to continue to develop their sense of self, their self-esteem, and their sense of belonging (Bakken et al., 2017). A child’s emotional response to an illness may impact school functioning. Prolonged absences with little peer communication and contact creates social discomfort for the child with a chronic illness (Sexton and Madan-Swain, 1995).

Sexton and Madan-Swain (1995) note that anxiety over returning to school results when a child has encountered a major physical change such as hair loss due to chemotherapy, disfigurement associated with burns or amputations as a result of trauma, a cancerous tumor or disease. Physical limitations can not only hinder children of all ages from socialising with their peers but it can also delay their return to school.
Transitions.

Transitioning from one educational service to another can be a daunting experience for many, especially for pre-school aged children (Skouteris, Watson & Lum, 2012). Young children in Ireland experience an extensive range of educational transitions including moving from their home to an ECCE setting, moving within or between a range of ECCE settings, sporadically attending a formal pre-school setting due to repeated hospitalisation, and the transition from pre-school to primary school.

Developing a sense of belonging within a new setting is a vital aspect of transition for young children. Ackesjö (2013) argues that “at times of transition children must interpret and negotiate both the old and the new arena as they construct their identity in the new setting” (p.24).

Both challenges and opportunities arise from the demands placed on young children during these transitions (O’Kane, 2016). For many children, challenges arise not only in the changing environment but also in their academic, social and emotional experiences (Margetts, 2002). While certain children entering formal schooling are able to work independently, form new friendships and adapt to the new routines, others may not be able to adjust so effortlessly (Skouteris et al., 2012). Continued support for the young child is essential for a positive experience during educational transitions. A wider support system of parents, early childhood educators, primary school teachers, hospital school teachers and SNAs can all provide attention and encouragement throughout the process (O’Kane, 2016). It has been noted by Skouteris et al. (2012) that the greatest capacity for achievement lies in the cooperation of primary school and early childhood teachers, “with the aligning of teaching practices and philosophies across the two institutions ensuring continuity and support for children as they progress through their education” (p.78).
The NCCA has recently published reporting templates called *Mo Scéal* along with a range of materials to support children’s transitions from pre-school to primary school (Fallon, 2019). Fallon (2019) highlights the benefits of the *Mo Scéal* reports stating that they will highlight the child’s interests, strengths and challenges in order to give the teacher insights into the child’s learning and development. This vital information can help the teacher to plan for continuity in learning approaches, differentiated learning opportunities and topics and projects links to the child’s individual interests and needs.

**Students and Chronic Illness**

**Understanding chronic illness.**

According to the DCYA (2016), almost half of the total hospital discharges of children in 2015 were children under five years of age. Children will rarely go through infancy and childhood without suffering from mild health problems, yet they generally do not interfere with their daily life and development. For others, however, chronic health conditions affect everyday life throughout childhood. (Boyse, Boujaoude & Laundy, 2012). Research findings by McPherson et al. (1998) concluded that one quarter of all school-age children will face at least one injury or illness that requires prolonged medical intervention, substantial bed-rest, and/or extensive school attendance disruption.

Chronic illness can be defined as a condition which lasts for a reasonable amount of time, typically interferes with daily functioning for greater than three months per year and may necessitate a period of continuous hospitalisations for more than a month (Thompson & Gustafson, 1996; Lemke, 2004; Compas, Jaser, Dunn & Rodriguez, 2012). Shaw, Glaser, Stern, Sferdenschi, and McCabe (2010) suggest that chronic illnesses are long standing and recurring medical conditions
that have a continuous effect on an individual’s life. Specifically, Van Cleave, Gortmaker and Perrin (2010) define childhood chronic health conditions as “any physical, emotional, or mental condition that prevented him or her from attending school regularly, doing regular school work, or doing usual childhood activities…” (p.624).

A multitude of lifelong illnesses and disabilities originate in early childhood (Irish Medical Organisation, 2012). Boyse et al. (2012) explain that chronic illness can be used as an “umbrella term”. Children with chronic illnesses may be in poor health or well at any given time, but they are always living with their condition. As identified by Brown, Daly, and Rickel (2007) (cited in Burns, 2013), chronic diseases vary in stability and predictability. Some chronic diseases included in the research include cancer, sickle cell anemia, congenital heart disease, cystic fibrosis and chronic renal failure. Due to early detection and diagnosis and powerful methods for the treatment and management of many life-threatening conditions, diseases that were once fatal are now successfully treated, and children survive at much higher rates today than 20 to 30 years ago (Compas et al., 2012).

As a principal of a Ronald McDonald Children’s House School associated with a prominent Toronto children’s hospital, Doering (2008) provided an insight into the impact serious illness can have on children’s education:

Access to education is severely compromised when children get sick and cannot attend schools in their areas. Depending on their illnesses and stages of treatment, a variety of reasons prevent seriously ill children from receiving the educational opportunities promised…” (p. 13). Doering (2008) continued to explain those reasons in depth, which included the fact that many children are immune-suppressed and must be hospitalised even with a
slight common cold. Public places, including regular classrooms, bring about potentially dangerous exposure. Furthermore, a child’s return to school may be postponed due to ongoing out-patient appointments for follow-up care, physical limitations and potential for infection.

**Prevalence of chronic illness in children.**

The prevalence of specific diseases and conditions ranges widely. For instance, in Ireland alone, approximately 130 children under the age of 15 years are diagnosed with cancer each year (Irish Cancer Society, 2020) and around 500 - 600 babies are born with congenital heart defects annually. Furthermore, “Cystic Fibrosis Ireland” (2020) note that Ireland has among some of the most severe strains of Cystic Fibrosis (CF) and also the highest incidence (per head of population) of CF in the world, with three times the rate of the United States and the rest of the European Union. CF is a multi-organ disease that primarily affects the lungs and digestive system. Children with CF have a variety of symptoms including persistent coughing, recurrent chest infections, frequent lung infections, poor growth and related health problems all of which lead to recurrent hospitalisation and frequent school absences.

Congenital heart disease is common illness among children of all ages. This disease occurs when the heart, or blood vessels near the heart do not develop properly before birth. According to Irish Health (2018) children with congenital heart disease usually undergo open-heart surgery in early childhood, after which, long-term follow ups and hospitalisation may be necessary. They are at risk of emotional and behavioural problems and impaired school functioning.

Children with sickle cell anemia show high rates of poor educational attainment due to silent cerebral infarcts (Karande and Kulkarni, 2005). Chronic
kidney disease is a long-term condition where the kidneys do not work as well as normal. Renal diseases are rare in children, with incidence and prevalence varying depending on the condition. Health Service Exclusive (HSE) (2011) note that chronic renal failure impacts significantly on children’s ability to learn both physically and socially. Physical impacts on children’s education include: low energy related to anaemia, low attention span and nausea, short stature and physical restrictions related to lines/transplant. Social impacts on children’s learning include: the effect on school attendance due to regular hospital visits, the need for medications to be taken at school, physical differences from other children in terms of lines or scars and continence problems. Children with end-stage renal failure face the additional burden of fitting dialysis into their lives.

**Effects of ongoing treatment.**

Cancer treatment affects a child’s physical, psychological, and academic development (Brown, Bolen, Brinkman, Carreiri, & Cole, 2011). Many paediatric cancer survivors desire to return to school and ability to be successful in school can be affected as they develop cognitive impairments and learning difficulties, endure extensive school absences, and experience diminished academic performance. (Brown et al., 2011).

Researchers at the National Institutes of Health (NIH) state that young patients who have been treated for cancer tend to reach certain developmental milestones later than their healthy peers do. When compared with children who had not had cancer, children under four years who had been treated for cancer “progressed more slowly in vocabulary, cognitive functions such as attention and memory, and motor skills” (NIH, 2012, online report). Importantly, having cancer did not appear to affect children’s social and emotional development or their ability to
engage in make-believe play, which typically develops between twelve and eighteen months of age. The researchers observed 61 children between six months and three and a half years old who were all being treated for tumors or cancers of the blood when they were listed in the study (NIH, 2012). In comparison to the children who did not have cancer, the children with cancer did not score as well on tests of language, cognition and motor milestones. According to researchers, children who had cancer were seven points below average on tests of mental development, and fourteen points below average on motor tests. Similarly, Taverna, Tremolada, Bonichini, Tosetto, Basso et al. (2017) note that therapies for the treatment of leukemia can negatively affect the acquisition of new skills, such as reading, writing and mathematics. Following their study on the development of motor skills in pre-school children with leukemia they found that “two years after the end of treatments, children show gross and fine motor skill delays that may persist even when patients are considered healed” (Taverna et al., 2017, p.1).

Taverna et al. (2017) note that basic motor competencies are acquired early in a child’s life, reflecting abilities in interaction with formal or incidental learning. Chemotherapy could encourage delayed skeletal muscle impairments in cancer survivors. In addition, pain and fatigue limit physical functioning, with gross and fine motor problems evident in cancer survivors even two years after the end of treatment.

Parents and guardians of children with cancer often wait until the cancer is in remission before addressing other concerns such as language, education and fine and gross motor skills development. The NIH’s (2012) study recommended that future investigations are needed to determine if early intervention, even as soon as the first round of treatment is completed, might be helpful. Parents may be reluctant
to send their chronically ill child to school due to fears of infection or a medical emergency, teasing by peers, or even the misperceived sense that there’s no point in sending a child with cancer to school (Prevatt, Heffer, & Lowe, 2000). Parents may feel guilty about their child’s disease and react with overprotectiveness and unrealistic fears, or they may unwittingly promote absenteeism if they believe that their child’s illness is terminal (Lansky et al., 1983).

In a survey of over 100 children with chronic illness, conducted by Larcombe, Walker, Meller, Jones and Mott (1990), it was found that parents identified many more problems than do teachers, including physical limitations, academic concerns, psychological and behavioural difficulties, and extended absences. In addition, many parents feel that their child’s teacher does not have the time to devote to their chronically ill child (Chesler & Barbarin, 1986).

**Stress and fear during hospitalisation.**

Generally, hospitalisation is a stressful experience for children, no matter their age or health concerns, yet during early childhood, young children are particularly vulnerable to the effects of stress and fear during hospitalisation (Coyne, 2006; Salmela, Salantera & Aronen, 2010). Early experiences in a child’s life interact with their genes to shape their brains. Yoshikawa, Weiland & Brooks-Gunn (2016) explain how environmentally influenced brain development encourages a range of early cognitive and social skills, as well as self-regulation and executive function (Yoshikawa, Weiland & Brooks-Gunn, 2016). Salmela et al. (2010) state that although children of pre-school age can verbally express their emotions and experiences quite well, they desire information and guidance to adapt themselves in unknown everyday experiences. Yoshikawa, Weiland & Brooks-Gunn, (2016) echo Salmela et al. (2010) and state that “during early childhood, the brain is especially
sensitive to environmental enrichment” (p.22). Salmela et al.’s (2010) findings highlight that pre-school aged children require opportunities to play and experience pleasure in order to support their individual coping strategies.

Studies have shown (Coyne, 2006) that despite age or illness, children have fears and anxiety concerning illness and hospitalisation. Coyne’s (2006) study on children’s experiences of hospitalisation identifies a range of worries and concerns from primary school aged children from seven to fourteen years. Several fears which children found to be potentially stressful are: concerns about pain, loss of control and disruption to everyday life, routines and activities. The children voiced concerns about missing ‘normal’ events in everyday life such as social contact at school, attending school and playing sport. A number of children expressed “anxieties about missing school in relation to ‘falling behind’ with schoolwork” (Coyne, 2006, p. 330). Coyne (2006) found that interventions devised to reduce children’s stress during a stay in hospital are not only likely to reduce their stress levels at the time, but also likely to influence how future experiences are evaluated and controlled. Children of all ages are more likely to be less distressed if their views are heard and their lives within the hospital environment were as normal as possible (Coyne, 2006).

**The Role of Education for the Chronically Ill Student**

School as a stabilising influence for the chronically ill student.

Research has established significant risk of low achievement, poor academic accomplishment, and lack of educational services for students who face extended and/or recurrent hospitalisation (Burns, 2013). Many chronic childhood illnesses of varying diagnoses have major impacts on schooling and, therefore, learning (Eiser, 1993; Gordan, 2016). Larcombe and Charlton (1996) believe that the inclusion of school as a component of treatment for cancer and other chronic illnesses in children
is felt by some to promote a positive adjustment to cancer treatment. School services are identified as a contributing factor in the recovery process for school-age children (Lemke, 2004).

**The role of the hospital school for the chronically ill student.**

Ferguson & Walker (2014) state that school is extensively recognised as a “stabilising and normalising influence for young people with chronic illness” (p.236). It is this desire for normality that necessitates hospital schooling for such children during their hospitalisation. Hospital schools focus on assisting school-age patients to continue with their education or regain academic levels or performance whenever possible (Breitweiser & Lubker, 1991, as cited in Lemke, 2004). Continuing education while in hospital is an integral part of maintaining a child’s wellbeing, giving them hope for a future without illness or indeed a future despite illness. Literature suggests that continued participation in education while experiencing a chronic illness offers children continued hope (Lemke, 2004). Similarly, St. Leger (2014) identified the need for future goals with regard to students’ physical and mental health by enabling them to focus on the future, which in turn has the psychological effect of allowing them to commit to difficult ongoing medical treatments.

Hospital schools are a growing phenomenon in both the health and education structures. Doering (2008) identifies a hospital school as the only place a seriously ill child can go and be something other than a patient. Similarly, in as early as 1951, Walton noted that children can be spared emotional trauma if they are given opportunities to develop as social beings when they are given learning experiences in as normal an environment as possible.
Hospital schools cater for children with chronic health conditions who would otherwise, due to hospitalisation, be missing out on the education. By their nature, these schools attend to quite a transient population and while across the span of a school year, many hundreds of children will be taught, yet enrolment numbers are low compared to traditional schools (Uggeri et al., 2016). Children who attend a hospital school can be: In-patients; Patients or siblings of patients who reside in hospital owned accommodation; Repeat day-patients; Patients from the hospital attending other hospitals for treatment; Siblings of patients when there is no alternative available; and Post Primary students who are under 18 years of age and are the parents of children who are in-patients of the hospital (HSE, 2019; Children’s Health Ireland at Temple Street, 2019). Hospital schools not only provide education to bridge the gaps caused by not being in a position to attend their own school, but they also give students the opportunity to complete their education satisfactorily in order to reap the full rewards of having overcome or lived with an illness or life threatening disease (Shiu, 2001).

If a child is cleared for school by the clinical nurse manager of their allocated ward, they may be eligible for a bedside or classroom school session. While a multigrade class or small group sessions are desirable, due to postoperative, medical or infection control purposes, the delivery of education is often on a one-to-one basis between the learner and the teacher by the bedside, consequently making it more intensive than the relationship between the teacher and learner in a mainstream class (Uggeri et al., 2016).

Planning and developing a flexible curriculum that may include both hospital school-designed assignments and originating school lesson plans adjusted according to the child’s needs is imperative (Searle et al., 2003). Walton (1951)
advocated that, as school attendance and even student energy levels vary from day to day, teachers must be flexible in adjusting their plans rapidly in order to ensure that every child may feel they have learned and accomplished something in spite of interruptions for treatments or operations (Walton, 1951).

While we know this about schools internationally, in the context of Ireland hospital school provision is unique given that the two disciplines are integrated into two of the largest service systems in our society, health care and education. In Ireland, the *Key Statistics National School Annual Census for 2017/2018* issued by the DES (2018) identifies nine schools catering specifically for children with medical needs. Among these schools are schools catering for children who attend the country’s acute tertiary national paediatric hospitals, children who attend as outpatients at Child and Adolescent Mental Health Service (CAMHS) centres, children who attend rehabilitation services, among others. These DES regulated and funded schools are committed to the continuity of education for children who have been hospitalised at both primary and post-primary level (Beaumont Hospital School, 2019; Our Lady’s Hospital School, 2019). Presently in Ireland, if a child over the age of four years should be admitted to a paediatric hospital they would have the opportunity to attend a hospital school to continue with their educational needs. Due to the absence of a pre-school service within our national paediatric hospitals, if a child of three or four years of age is hospitalised they are instantly at a disadvantage to their peers. Additionally, at the present time, children who are inpatients in a non-specialised paediatric ward located within a general hospital may be absent from school for a substantial amount of time due to the lack of a hospital school service.
The hospital school teacher.

Hospital school education draws on the experience of a variety of professionals within its structure. These individuals may include therapists, social workers, and counsellors (Doering, 2008). The role of the classroom teacher in the education of an ill child cannot be underestimated (Brown et al., 2011; Shiu, 2001; Hay et al., 2015). It is a role and responsibility of the hospital school teacher to deliver and implement successful programmes to maintain academic continuity and meet the needs of the child (Steinke et al., 2016). Hospital school teachers facilitate normality by enabling a hospitalised student to participate in a routine activity in an environment that is far from normal (Lemke, 2004). Äärelä et al. (2018) maintain that hospital school teachers who facilitate education form a marginal group of special teachers. Hospital schools cannot run successfully without the dedication of this cohort of primary and post-primary teachers who play instrumental roles in providing hope, normality and routine for children during hospitalisation. Observing the difficulty in maintaining children’s motivation, the short attention span of students and the fact that they are easily fatigued, Barckley (1954) noted that hospital school teachers must encompass originality in using unusual teaching methodologies and resources to reach students who are mildly or chronically ill.

In order to implement a successful hospital school programme, Steinke et al. (2016) suggest that hospital schools must be staffed with competent teachers who can overcome obstacles with the ability to effectively deliver individualised education to the wide range of needs and ages they encounter daily. Hospital school teaching for a transitory population is a hyper complex occupation. Various layers exist teaching children of all ages and abilities, including the possibility of teaching children who have not obtained the foundation of learning sought from pre-school.
education. Children with long term illnesses often face recurrent or continuous hospitalisation from a young age, thus causing them to potentially lack the foundation of basic motor skills which are learned early in a child’s life (Taverna et al., 2017).

Another essential member of the hospital school team is the devoted Special Needs Assistant (SNA). From the data collected, it was noted that hospital schools generally have access to one full time SNA per school. As well as providing special assistance for pupils with particular difficulties and assisting with feeding, toileting and general hygiene (AslAm, 2019), SNAs within a hospital school setting also bring children to and from the wards each morning/afternoon, take parents details on arrival to school and provide assistance to classroom and ward teachers throughout the day.

**Conclusion**

Although learning can occur at any age, starting a child off with a solid foundation rooted in knowledge and skills necessary for future educational success is beneficial (Melhuish et al., 2013). Laying a strong foundation in the early years makes learning in the future possible. A chronically ill child may lack a solid educational foundation by experiencing repeated hospitalisation, thus beginning his/her educational career at a disadvantage.

With advances in medical treatments, more children with chronic health conditions are surviving into adulthood. Children who spontaneously or continuously refrain from attending their early years settings for various reasons are at risk of regressing and falling behind in later years. Regular school attendance and access to early childhood education is essential for the nurturing and development of each child’s curiosity, confidence and potential. Their developmental, intellectual,
emotional and social skills may be jeopardised and not be at par with their peers upon entering Junior Infants. ECCE boasts a multitude of benefits and it is every child's right to this education.
Chapter Three: Methodology

Introduction
This chapter provides an overview of the methods undertaken to gather and present the data compiled for this study. The aim of this study, along with the research questions that guided the research project are presented. The delivery of the research approach is subsequently detailed to include the methods employed to collect data. The rationale for choosing a qualitative research design to inform the research questions is explained. The methodological tools utilised and methods of data analysis are then presented. Ethical procedures adhered to are outlined to conclude this chapter.

Purpose of the Study
The purpose of this research is to identify the challenges and impact infrequent attendance of ECCE can have on a chronically ill child’s life. Data was generated from the perspectives of nine hospital school staff members from two paediatric hospitals located in Ireland. By engaging in qualitative data collection, the effects ECCE can have on a young child’s life were identified and documented. This research employs a qualitative design to identify attitudes and experiences expressed by teachers and SNAs working in hospital schools.

Children with chronic medical needs are often at a disadvantage to their healthy peers due to long absences from their base schools, unplanned hospital stays and daily medical demands. Participants identified a diverse range of challenges by acknowledging their causes and the impact they can have on a young child’s daily life and educational development. School aged children who have access to a hospital school service were discussed in contrast with pre-school aged children who are missing out on a daily ECCE service within a hospital setting.
Literature Review

The literature review has established a gap in the academic knowledge pertinent to this issue. The initial purpose of the literature review was to establish available knowledge in the area of ECCE within a paediatric children’s hospital. The result of conducting a literature review was the identification of relevant research questions to expand on existing knowledge and acquire new knowledge, previously undocumented within an Irish context. The literature review revealed five main themes into which the literature was divided: Early Childhood Care and Education; Access to Education; The Impact of Infrequent School Attendance on Young Children; Students and Chronic Illness; and The Role of Education for the Chronically Ill Student.

These themes were used to refine the research and sub questions, and to establish a focus for the research outcomes. The research question and sub questions that emerged from conducting the review of the relevant literature were as follows;

- What are the views of a selection of hospital school staff with regard to early childhood care and education for children with chronic medical conditions?
  a) What impact does absence or limited access to early childhood care and education have for children when they attend hospital schools?
  b) What are hospital school staff’s feelings with regard to early childhood care and education within a hospital setting.

Research Design

There were five stages to this research, as outlined in Table 2 below. This staged approach enabled a research schedule to be developed and adhered to within the
given timeframe. Due to the worldwide COVID-19 pandemic, the time frame remained the same yet the data collection methodology altered slightly (see Interviews section below). The staged approach used included desk based research, instrumental development, data collection analysis and analysis of findings.

<table>
<thead>
<tr>
<th>Stage One</th>
<th>Desk based research</th>
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<tbody>
<tr>
<td></td>
<td>A systematic review of relevant literature, both Irish and International, relating to the area of early childhood care and education within a hospital setting.</td>
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<table>
<thead>
<tr>
<th>Stage Two</th>
<th>Development of instruments</th>
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<tr>
<td></td>
<td>Collection and examination of school documents</td>
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<td></td>
<td>Invitation to hospital school staff from two hospital schools - primary teachers, SNAs and principal teachers to participate in case study.</td>
</tr>
<tr>
<td></td>
<td>Written consent obtained via email and verbal consent obtained prior to the beginning of each interview.</td>
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<td></td>
<td>Development and piloting of videoconferencing interviews</td>
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<thead>
<tr>
<th>Stage Three</th>
<th>Data collection</th>
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<tbody>
<tr>
<td></td>
<td>Semi-structured videoconferencing/phone interviews with participants of two hospital schools, audio recorded and transcribed verbatim.</td>
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<tr>
<th>Stage Four</th>
<th>Data analysis</th>
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<td></td>
<td>Analysis of data gathered from semi-structured interviews using a thematic analysis.</td>
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<th>Stage Five</th>
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<tr>
<td></td>
<td>Writing up of findings, discussion and concluding chapters.</td>
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Table 2: Research Design

**Qualitative Research**

A qualitative research design was chosen for this study in order to capture the complexity of hospital school teachers’ and SNAs’ thoughts and experiences in the area of ECCE. These participants were purposefully selected unlike a quantitative approach which typically depends on larger samples selected randomly (Patton, 1990). As qualitative research is exploratory, open ended and organic, it may be used to produce rich and detailed data from which to make claims (Braun & Clarke, 2006). According to Laubschagne (2003) “qualitative data provide depth and detail through direct quotation and careful description of situations, events, interactions and observed behaviours” (p.100).
In the context of this research study, a qualitative research design was determined as an appropriate method to expand the scope of expertise and understanding to accommodate unexpected ideas expressed by participants that may have been lost using quantitative methods (Braun & Clarke, 2006). A qualitative approach was deemed the most suitable for this particular research study due to its ability to give a voice to the small community of hospital school staff involved (Penny & Albon, 2018; Laubschagne, 2003), to explore their thoughts and perceptions on the impact infrequent attendance of ECCE can have on a chronically ill child’s life.

Remaining acutely aware of the potential for bias from the research method adopted, credibility, reflexivity and subjectivity in this qualitative research were valued greatly throughout the data collection and analysing process (Braun & Clarke, 2006; Penny & Albon, 2018).

**Data Collection**

**Interviews.**

Due to the worldwide pandemic of COVID-19 and nationwide school closures in March 2020, the researcher was compelled to amend the initial data collection method of face-to-face semi-structured interviews with hospital school staff. These interviews were to take place in a private classroom or office located on school grounds, before, during or after school hours, yet they would not have interfered with valuable teaching time. Following advice from the researcher’s supervisor, the researcher explored videoconferencing and phone interviews in great depth. In line with ethical requirements of *Marino Institute of Education*, the participants information sheet was subsequently re-drafted and amended, as was the method of gaining consent. Participants were contacted individually via phone calls with detailed information sheets sent to their work email addresses (Appendix A).
Participants willing to participate in the interviews contacted the researcher via phone or email with their suggestion of a suitable interview time, in which the researcher accommodated.

Face-to-face interviews were replaced with the efficient and engaging videoconferencing method of data collection. Data were recorded on a portable Dictaphone. Prior to each interview the researcher ensured that the battery level was adequate and that the device was positioned in a secure and appropriate location on the desk next to the laptop.

Videoconferencing technology has changed how education at university level takes place. Researchers have recognised how software programmes such as Skype, Zoom and Google Hangouts can act as viable tools to host videoconferencing for data collection purposes (Chapman & Rowe, 2002; Glassmeyer & Dibbs, 2012). Researchers found that videoconferencing provided a rich medium where participants could provide nonverbal and verbal cues, use natural language and express personal feelings and emotions (Chapman, Uggerslev & Webster, 2003). Donaghy et al., (2019) echo these views and note that interviews via videoconferencing are considered superior to telephone conversations in providing visual cues and reassurance, building rapport, and improving communication.

Conducting interviews via videoconferencing required more planning than face-to-face or phone interviews for numerous reasons (Sedgwick & Spiers, 2009). The participant seeing only part of the researcher and interview environment proved to be a concern. Whilst conducting the first number of interviews, the researcher usually spent some time looking at the list of questions that were on the desk, thus the participant only saw the interviewer looking away from the computer screen. The
apparent lack of concern suggested by this action, combined with the suggested beneficial effects of virtual eye contact (Chapman & Rowe, 2002), prompted the researcher to open the list of questions on a Pages document during the interview. This vast improvement allowed the researcher to reference the questions without looking away from the screen. Managing two programmes (Zoom/Google Hangouts and Pages) simultaneously was not difficult, but it did require additional setup prior to the interview. To ensure optimal computer performance, all other programmes which were not in use were closed, which also helped eliminate unwanted distractions during the interview.

A minor technological issue which was unable to be resolved was the poor internet connection experienced by one of the participants. This participant lived in a rural area and because of the low-quality internet connection, the video and audio transmission would sometimes slow down during the interview. The Dictaphone was paused for a moment each time a poor connection was detected and the interview would resume when the audio and video would return to normal.

Upon compilation of an interview schedule, a pilot interview (Appendix B), via the videoconferencing application Zoom, was conducted with a primary school teacher currently teaching in a hospital school located within a paediatric hospital in Dublin, Ireland. The pilot interview set out to identify potential ambiguities in the phrasing of questions, redundancy of questions or to determine the appropriateness of the questions to the needs of this study. The questions were revised for clarity and repetition and re-drafted prior to conducting case study interviews (Appendix C).

Semi-structured interviews were subsequently conducted. Each interviewee had the option to choose which method they were most comfortable with, with seven participants opting for videoconferencing conversations and the latter choosing to
conduct their interview via phone calls. Adams (2015) notes that highly efficient semi-structured interviews can be administered many ways including via phone, mail, Internet or in person. Conversational in nature and informal in tone, semi-structured interviews were utilised due to their flexibility in allowing the interviewer to go into more depth with respondents where necessary, to clear up any misunderstandings and make a true assessment of what the respondent believes (Cohen et al., 2018). Effectively conducted semi-structured interviews should be worth the effort in terms of the insights and information gained (Adams, 2015).

Having the ability to control the order of the interview whilst still allowing for spontaneity, semi-structured interviews allowed me, the researcher, to press not only for complete answers but for responses about complex issues (Cohen et al., 2018). Verbal consent was obtained from interviewees at the beginning of each interview and participants emailed their written consent. Interviews were digitally recorded with a recording device placed on the desk next to the laptop and transcribed verbatim.

It is important to note that the sample interviewed for this study have taught a multitude of children over the years, all of whom come from various educational backgrounds, with differing abilities. Children attending a hospital school can be students of a mainstream school or a special school, they may have had a steady ECCE experience to date or a complete lack of ECCE, they may have been engaging in consistent formal schooling or have experienced an absence in schooling over the years. The majority of the participants in this study were, at the time of data collection, physically separated from their students. This was due to nationwide school closures in response to the worldwide COVID-19 pandemic. Via audio recorded, semi-structured interviews conducted through videoconferencing applications, participants were asked to recall how their chronically ill students
engaged with education during and after medical treatments. They were compelled to think back to their long term students who they had been working with over the years, to what certain students were like as a four or five year old, as they may have surpassed their ECCE years, or to reminisce on their students’ attributes from their most recent teaching experiences.

**Ethical Considerations**

**Access and permissions.**

Approval to conduct this research study was granted following an application in November 2019 to the Ethics Committee of *Marino Institute of Education*. Permission was also sought and granted from the Board of Management of the researcher’s school (Appendix D). As part of the initial research design, the researcher planned to interview parents and guardians of chronically ill long term patients under the age of 6 years. Following approval from both committees, the researcher sought permission from the hospital board to interview parents of chronically ill patients within the hospital. Due to the hospital existing as a separate identity to the DES run school located within its building, and the concept of interviewing vulnerable parents during a time of uncertainty in their lives, ethical approval to interview parents could take up to one year to be granted. Following advice and numerous discussions between the researcher and her supervisor, an alternative decision was made to interview hospital school staff from two paediatric hospital schools.

Upon receiving approval, relevant ethical issues were addressed and two paediatric hospital schools were invited to participate in this study. Principal request letters were sent to the respective schools (Appendix E) detailing the purpose of the research, the intended method of data collection and time span of the data
collection. Prior to any attempt at data collection, access to the hospital school was approved via verbal consent from the respective principals.

Following the nationwide school closures in March 2020, face-to-face interviews with hospital school staff were no longer an option. A letter was written to the Ethics Committee of Marino Institute of Education seeking approval to conduct interviews via online videoconferencing or alternatively via telephone calls (Appendix F). All conversations were audio recorded and transcribed verbatim.

Participants.
Participants were invited to partake in the research upon meeting the criteria of being a principal teacher, a primary school teacher or an SNA currently working full time in the hospital schools involved. A participant information sheet (Appendix A) was distributed among the staff of the hospital schools outlining the aims of the study and what participation would involve. Participants were informed that they were not obliged to participate in the study and that they reserved the right to withdraw from the study at any time without reason or prejudice. Upon reading the information sheet, signed consent was obtained from each participant and emailed to the researcher prior to data collection. Verbal consent was also granted at the beginning of each interview. The participants of the study consisted of two principals, five primary school teachers and two special needs assistants. The anonymised participants are provided in Table 3 below.
<table>
<thead>
<tr>
<th>Staff member</th>
<th>School</th>
<th>Preferred method for data collection</th>
</tr>
</thead>
<tbody>
<tr>
<td>Teacher 1</td>
<td>A</td>
<td>Videoconferencing conversation</td>
</tr>
<tr>
<td>Teacher 2</td>
<td>A</td>
<td>Videoconferencing conversation</td>
</tr>
<tr>
<td>Teacher 3</td>
<td>A</td>
<td>Videoconferencing conversation</td>
</tr>
<tr>
<td>Teacher 4</td>
<td>A</td>
<td>Videoconferencing conversation</td>
</tr>
<tr>
<td>Teacher 5</td>
<td>A</td>
<td>Videoconferencing conversation</td>
</tr>
<tr>
<td>SNA 1</td>
<td>A</td>
<td>Telephone conversation</td>
</tr>
<tr>
<td>Teacher 6</td>
<td>B</td>
<td>Videoconferencing conversation</td>
</tr>
<tr>
<td>Teacher 7</td>
<td>B</td>
<td>Videoconferencing conversation</td>
</tr>
<tr>
<td>SNA 2</td>
<td>B</td>
<td>Telephone conversation</td>
</tr>
</tbody>
</table>

Table 3: List of Participants

Confidentiality and anonymity.
Confidentiality was assured for both schools and participants and it was presented both in writing and as a verbal reminder prior to the commencement of interviews. Pseudonyms were used for the school names, addresses and the names of hospital wards. Participants’ identities were anonymised by assigning pseudonyms in the transcripts and removing any identifiable information from each transcript where relevant. Students’ names were also pseudonymised and all identifying information removed. By ensuring neither school, participants nor students were identifiable, responses were not attributed to individuals.

In order to replicate the face-to-face situation as much as possible, the researcher was consciously looking for non-verbal cues from the participants throughout the videoconferencing sessions (Gorin et al., 2008). These non-verbal cues could indicate that participants did not wish to share further information, were losing motivation for the interview or alternatively their body language suggested that they are more relaxed.
Data storage.

All data, including audio recordings and signed consent forms were stored securely on an encrypted USB and retained for a period of 13 months post completion of the dissertation examination process upon which data will be deleted and destroyed in line with the ethical guidelines of Marino Ethic in Research Committee (MERC). Access to personal information such as mobile phone numbers and email addresses in order to phone or video call participants was required on various occasions. All emails used were participants' work email addresses. The collection and storage of personal data is in accordance with current General Data Protection Regulation (GDPR) legislation enacted on 25th May 2018.

Ethical Concerns.

As I, the researcher, have worked with many of the participants involved in the study through my career as a hospital school teacher, it was my duty to remain acutely aware of the potential for bias and prejudice. Assuring confidentiality was maintained at all times, interviews were conducted in confidence and were not discussed with any other staff members. Interview questions were carefully scripted in order to avoid any leading of participants’ responses. The semi-structured qualitative interviews contained mostly open ended questions so participants could answer in as much or as little detail as they wished. The questions were not deviated from and the interview schedule was identically executed for each ensuring all participants were asked the same questions (Appendix C).

One ethical concern for this study was the potential for teachers to be identifiable given the relatively few hospital schools in the country. To prevent this, data collected throughout this research was anonymised for all participants and schools and was accessible only by myself, my supervisor and examiners.
Participants were informed in writing that their participation was entirely voluntary (Appendix A). Participants had the right to refuse to answer any particular question or withdraw from the study at any time without having to give a reason and without prejudice.

**Data Analysis**

Qualitative analysis of data can involve the non-numerical organisation of data in order to discover themes found in interview transcripts (Laubschagne, 2003). Thematic Analysis (TA) was used to identify, analyse and report emergent themes within the qualitative data retrieved (Braun & Clarke, 2006). TA was chosen as it provided an accessible and flexible approach to analysing qualitative data through a systematic method of generating codes, themes and subthemes relevant to the research questions (Appendix G). Braun and Clarke (2017) note the ability of TA to analyse large and small data sets to capture both explicit and hidden meanings.

Each interview was transcribed verbatim. Initial codes were generated from the data collected during interviews before being collated and analysed to produce overarching themes (Braun & Clarke, 2006). The researcher broke these themes, subthemes and codes down further and created first-to-fourth level coding tables as a process of tightening and summarising the data (Appendix G). These identified themes were then reviewed and refined to form specific themes and subthemes capturing the essence of the data and allowing for comparison across individual respondents (Braun & Clarke, 2006). The final themes that emerged from TA were: *Contributors to academic challenges for children with chronic medical needs; Challenges affecting the social and emotional development of children with chronic medical needs;* and *Access to early childhood care and education within a hospital school.*
The emergent themes, subthemes and discussion points are provided in the fourth level coding table below (Table 4). Additional first, second and third levels of coding can be seen in the appendices (Appendix G). These served to provide a framework for organising and reporting qualitative data pertaining to the research questions (Braun & Clarke, 2013).

<table>
<thead>
<tr>
<th>Theme:</th>
<th>Subtheme:</th>
<th>Code:</th>
<th>Discussion points:</th>
</tr>
</thead>
</table>
| Contributors to academic challenges for children with chronic medical needs | Academic challenges (caused by medical conditions and long term treatments) | ACADEM | • Fatigue, Sickness, Low mood, Anxiety  
• School attendance  
• Disengaging from school  
• Lack of concentration  
• Effects of treatments  
• Medical conditions having long term damaging effects on a child’s motor skills, neurological skills and cognitive development  
• Children who have not had access to ECCE:  
• Extra challenges  
• At a further disadvantage to their peers  
• DES rules of 4years + to be enrolled on school rolls  
• Poor language and communication skills  
• Developmental delays - fine and gross motor skills |
| Challenges affecting the social and emotional development of children with chronic medical needs | Social and emotion difficulties | SOCEMO | • Children who have access to education  
• Hindered social and emotional development  
• Peers  
• Isolation status – temper tantrums  
• Children who have not had access to ECCE:  
• Socialisation - mixing with adults/peers  
• Emotional regulation  
• Separation anxiety from parents  
• Behaviour issues  
• Poor language and communication skills |
| Familial and social | | FAMSOC | • Children/families missing out on life events  
• Living in the hospital  
• Building strong relationships between hospital school staff and parents  
• Seeking normality  
• Craving a sense of normality  
• School room is a medical free zone  
• Normal school environment and resources  
• Stress and Fear |
Access to early childhood care and education within a hospital school | Continuity in education | CE | • Continuity in education  
• A right to education for all |

Parents desire for a pre-school service | PARPRESCH | • Parent’s desire for pre-school service |

The implementation of a pre-school service within a hospital setting | PRESCH | • Hospital school teachers’ and SNA’s aspirations and thoughts towards the establishment of a pre-school service within the hospital |

| **Table 4: Fourth level coding table** |

**Conclusion**

This chapter outlined the staged approach undertaken to carry out this research study. A qualitative research design was selected for its suitability to generate rich and detailed data from which to inform the research questions. This chapter provided an overview of the methods employed in this study for data collection by means of semi-structured interviews. The rationale for choosing TA as a method of analysing the data retrieved was explained and ethical considerations discussed. The findings presented in the following chapters are based on the data set compiled from the TA of the data retrieved from this qualitative research design. The development of the data collected, provided me with a unique insight into both early childhood education and hospital school education, while the establishment of the five key themes as outlined above enabled me to make fair connections and observations amongst all participants.
Chapter Four: Analysis and Discussion of Research Findings

Introduction
As outlined in Chapter One, the aim of this study is to identify the challenges and impact infrequent attendance of ECCE can have on a chronically ill child’s life. The purpose of this chapter is to interpret and discuss the findings of this research study within the context of the relevant literature pertaining to the research questions. This chapter will explore the key themes generated through thematic analysis (TA) of the data. The themes that emerged from TA were: *Contributors to academic challenges for children with chronic medical needs; Challenges affecting the social and emotional development of children with chronic medical needs;* and *Access to early childhood care and education within a hospital school.* Collectively, these themes provide a greater understanding of the importance of ECCE for young children with medical needs.

Some children, by virtue of acute or chronic medical needs leading to recurrent or continuous hospitalisation, are unable to attend their own pre-school, primary school or secondary school on a regular basis. If deemed medically fit by medical staff, these children may attend a hospital school for a short or extended period of time. Significant information arising from the data shows that, unlike their peers, they are more prone to academic challenges due to their medical needs. These challenges can be broken down into two components - academic struggles and underdeveloped social and emotional skills.

According to the data, challenges effecting a child’s education usually appear whilst they are undergoing treatment for a medical condition. Many of these issues may leave a long lasting effect for years to come. A certain amount of these issues are not uncommon and affect most children from four years of age, yet there are also
many concerns that are specific to the children who do not have access to ECCE within a hospital setting. Both groups of chronically ill children will be discussed separately in themes one and two below.

A considerable amount of pre-school aged children attend paediatric hospitals around the country on a daily basis. According to the DCYA (2016), almost half of the total hospital discharges of children in 2015 were children under five years of age. These young children are at risk of experiencing complete or partial disruption of ECCE due to recurrent or continuous hospital admissions. Currently in Ireland, formal education within a hospital setting is solely accessible to children who are four years of age and older (Our Lady’s Hospital School, 2019; HSE, 2019; Children’s Health Ireland at Temple Street, 2019). Interestingly, although the data shows that pre-school is not usually catered for within hospital schools, on certain occasions, under exceptional circumstances, this rule was occasionally broken for long term students residing in the hospital. One participant spoke about a young girl who was living in the hospital for two and a half years and was missing out on her vital pre-school years. The hospital school took her in for daily sessions and “that was just such a big thing for the parents, for her to be the same as everybody else” (Participant 2). It was reported that it was not only a “big moment” for the child herself, but also for her parents. The photo they received of her first day of school made her “just like every other child” (Participant 2).

Academic, social and emotional challenges and the substantial impact they can have on a child’s development will be discussed in this chapter. General issues will be addressed at the beginning of each section, with specific non-ECCE related issues following after. This second section refers to children with medical needs who do not have access to an ECCE setting due to their recurrent or continuous
hospitalisation. The chapter will close with a deep analysis and discussion of data to represent participants’ specific aspirations towards establishing an ECCE service within a hospital setting. Verbatim excerpts from the interviewees are included to demonstrate teacher attitudes and practices.

Theme One: Contributors to Academic Challenges for Children with Chronic Medical Needs

One of the key findings to emerge from this study is that practically all children who attend a hospital school experience academic, social and emotional difficulties. While these may vary in their severity they are all directly linked to the child’s medical conditions and associated treatments. One teacher emphasised that “all of the medical conditions that you could think of within our hospital definitely impair a child’s ability to learn” (Participant 8). Another teacher echoed this statement stating that “every condition brings its own challenges, whether it's physical…developmental or emotional wise as well” (Participant 6). Boyse, Boujaoude & Laundy (2012) noted that chronic health conditions affect everyday life throughout childhood. Research has also established that many chronic childhood illnesses of varying diagnoses have major impacts on schooling and, therefore, learning (Eiser, 1993; Gordan, 2016).

There are two key elements to consider when reflecting on the impact that a medical condition may have on a child’s academic development. The first of these, obviously relates to the medical condition itself. However, the participants were also clear that the treatment for conditions also contributes to these difficulties. With regard to the medical conditions and their associated treatments, the data demonstrate the affects they can have on a child’s academic development to varying degrees. The following section is divided into two sub themes and outlines the main
causes of problems children with chronic illnesses encounter on a daily basis, as well as the effect these issues may have on a child’s schooling. The data are informing us as to why these children have a more problematic engagement with education than their healthy peers.

**Academic challenges caused by medical conditions and long term treatments.**

There was overwhelming agreement among the participants that children within hospital settings experience significant academic challenges. While each patient is different, there was general agreement that most children face significant barriers to their learning. The majority of participants reported that as well as feeling sick, having low mood and feeling anxious or fearful of attending an unfamiliar school setting with new teachers and children, school attendance can be quite erratic. Children’s ability to attend school sessions or to concentrate can be severely hampered due to a lack of energy or sleep. More frequently than not, a child residing in a hospital bed experiences spells of disturbed sleep “due to machines beeping, nurses checking observations or having to use their nebulisers” (Participant 4). Being kept awake at night can be a major hindrance for any child, but especially if they are already feeling unwell and hoping to complete school work from their hospital bed the following morning. Sleep is only one of the areas affecting a child’s academic development whilst in hospital. Doering (2008) provided an insight into the impact serious illness can have on children’s education:

> Access to education is severely compromised when children get sick and cannot attend schools in their areas. Depending on their illnesses and stages of treatment, a variety of reasons prevent seriously ill children from receiving the educational opportunities promised... (p. 13).
Doering (2008) continued to explain those reasons in depth, which included the fact that many children are immunosuppressed and must be hospitalised even with a slight common cold. Cancer treatments and vigorous medications for various conditions “can cause children to become immunocompromised and immunosuppressed” (Participant 1).

All hospital school staff reported that medical conditions can have long term damaging effects on a child’s motor skills, neurological skills and cognitive development. Between sickle cell anemia causing strokes leaving children with lasting memory issues, “rheumatoid arthritis causing terrible flare ups in their joints” (Participant 1) and cancer treatments leaving children with “neurological difficulties” (Participant 2) and underdeveloped fine and gross motor skills, all chronic medical treatments can lead to unfavourable diverse life-altering effects. Additionally, children with cardiac conditions often experience physical changes such as developing swollen fingertips which in turn prevent them from establishing efficient fine motor and pre-writing skill development from an early age. The reality of this was captured expertly by one of the participants who described:

Some of the conditions lend themselves to the fact that the tips of their fingers are quite swollen and chubby and the impact on that educationally is that it’s very tricky to hold a pencil or crayon. It can be very tricky to slip their fingers into scissors and to cut so they don’t have the same fine motor skills that the rest of us would have with our fingers (Participant 4).

Brown et al. (2011) state that cancer treatment affects a child’s physical, psychological, and academic development, while research also shows (Taverna et al., 2017) that therapies for the treatment of leukemia can negatively affect the acquisition of new skills, such as reading, writing and mathematics. Following their
study on the development of motor skills in pre-school children with leukemia, Taverna et al., (2017) found that “two years after the end of treatments, children show gross and fine motor skill delays that may persist even when patients are considered healed” (p.1). Taverna et al. (2017) also note that basic motor competencies are acquired early in a child’s life, reflecting abilities in interaction with formal or incidental learning.

Side effects from medical conditions and affiliated treatments are certainly one of the major elements contributing to academic challenges for children in hospital schools, yet throughout this study, extensive emphasis was also placed upon academic concerns of young children with a chronic illness who have experienced infrequent attendance of ECCE.

**Academic concerns for children with a chronic illness due to a lack of ECCE.**

There was consensus among the participants of this study that without ECCE, children who are chronically ill experience similar difficulties to their ill peers, yet with extra challenges. Participants reported that they are at a further disadvantage due to their illness and age. Children under four years of age who are suffering from an acute or chronic illness may unwillingly experience the impact of infrequent school attendance on a daily basis due to the lack of a pre-school service within an Irish paediatric hospital setting. Participants reflected on this at length during the interviews. One participant highlighted how this fits with national legislation: “According to the rules of national schools, once a child turns four years of age they are enrolled on our roll” (Participant 8) and “our remit is to look after children of school going age, between four, once they have had their fourth birthday, to eighteen or a little longer if they have special needs, until they’ve finished their schooling”
(Participant 6). As well as not having access to a pre-school within a paediatric hospital, this leaves copious pre-school aged children with medical needs without access to ECCE. Many of these children would be unable to attend a local pre-school due to feeling unwell, being immunocompromised and spontaneous hospital admissions.

An appropriate level of independence and maturity comes with having attended a formal pre-school service during a child’s early years. It can become quite evident to a Junior Infant teacher when a four or five-year-old child has not received any form of pre-school education. Researchers have found that children attending pre-school programs are better prepared for school than similar children who have not attended pre-school ("The Current State of Scientific Knowledge on Pre-Kindergarten Effects", 2017). Findings from this report (2017) state that a year of formal pre-school education promotes both school readiness and longer-term educational success. One participant echoed this statement and stated that: “When they have been at pre-school there’s a very big difference at the start of Junior Infants, as opposed to the child who has had nothing” (Participant 6). Children who have not had access to ECCE due to receiving ongoing treatment for a medical condition or being subject to long term or recurrent hospitalisation are at risk of experiencing the same difficulties as their ill peers, yet they are at a further disadvantage due to the lack of an educational input. “Our children would already be at a disadvantage because they haven’t been at home, they’ve been in hospital and then they’re at a further disadvantage because they haven’t had the pre-school everybody else has had” (Participant 6). Ehrlich et al., (2014) note that children with high ECCE attendance rates have greater readiness scores during their first year of primary school; this is especially true for students entering with low skills. Similarity,
it was reported in “The Current State of Scientific Knowledge on Pre-Kindergarten Effects” (2017) that while all children benefit from pre-school education, children from lower socioeconomic backgrounds often make the greater gains. Researchers have found that children “who have had early experiences of economic scarcity and insecurity gain more from these programs than their more advantaged peers” (p.22).

Interviewees reported many issues in relation to children with chronic medical needs who have been unable to attend pre-school, being developmentally delayed in comparison to their peers. Early childhood is a critical period for the nurturing of each individual child’s curiosity, resilience, creativity, confidence and potential. During the data collection process, participants noted that children were unable to zip up their own coats, to put their shoes on or to sit in a chair. Underdeveloped fine and gross motor skills were extremely common as well as the inability to make simple jigsaws, to hold their pencil, to recite numbers, to match objects, to engage in a nursery rhyme or song, or to identify common colours, “all of those things that prepare the child for their reading and writing at school” (Participant 7). The literature shows that recurring absence in the early years can result in weaker reading skills and lower attendance rates in later years (Connolly & Olson, 2012; Chang et al., 2016). This is especially true for children who are mildly or chronically unwell.

Poor language acquisition and communication skills were also noted as dominant concerns by many participants. One participant stated that language is a key sign of school readiness for a young child. “If they’re able to communicate...if they have some sort of level of attention to be able to respond to instructions and directions…” (Participant 7) then they’re definite signs that a child is ready to begin Junior Infants.
Chang et al. (2016) recognise that infrequent attendance in the early years can lead to long lasting effects on a child’s education, affecting the fundamental academic and social skills students need to thrive in their future educational careers. Enhrilch et al.’s (2014) study suggests that ensuring ECCE students attend a pre-school setting is an essential factor in preparing children for primary school and beyond.

**Theme Two: Challenges Affecting the Social and Emotional Development of Children with Chronic Medical Needs**

A significant finding that emerged from the analysis of the data gathered, is that challenges arise on a daily basis for children with medical needs. It is important to note that the families of chronically ill children also suffer from ongoing difficulties and challenges, all of which will be detailed below. The structure of the following sub themes will mirror that of the first theme. The subsequent sub themes will detail the findings pertinent to the challenges experienced by children with chronic illnesses who have either attended a hospital school service or who have experienced infrequent attendance of ECCE due recurrent or continuous hospitalisation.

**Social and emotional difficulties for children with a chronic illness.**

There was consensus among the participants of this study that poor social and emotional development is a considerable issue for all children who are acutely or chronically ill. One participant explained, “these children are not having a normal life experience. They are coming in and out of hospital and they are affected by all of that...and of course their social and emotional development is also hugely compromised” (Participant 8). Long term or recurrent periods of hospitalisation can impact on a child’s development, causing children to feel different from their peers. Shaw and McCabe (2008) note that the reduced class time associated with recurrent
hospital visits results in decreased time spent learning core academic concepts and bonding with peers. The potentially damaging effect of such absences is further reiterated by Thies (1999) who notes that a child’s self-confidence can be hugely affected due to falling behind in school (p. 395).

Numerous participants agreed that being too unwell to socialise with school friends or to attend their base school was damaging to the child in more ways than one, with one participant commenting: “They’re missing out on their vital school years and if they weren’t in hospital they would have attended school. It’s an important piece, an extremely important part to miss” (Participant 2). Continuity of education and maintaining a connection to school and peers was acknowledged by all participants as an essential element of maintaining a sense of normality. “Children with chronic illnesses will always be playing catch up with healthy peers” (Participant 8) and upon returning to school they may stand out in class as they require help to catch up. Another participant reiterated this statement: “They’re just having to play catch up on reduced energy, which is awful” (Participant 1).

Shaw and McCabe (2008) note that the reduced class time associated with recurrent hospital visits results in decreased time spent learning core academic concepts and bonding with peers. Shiu (2001) draws attention to evidence which suggests that children with long term illnesses miss more school and underachieve academically in contrast with their home school friends. Sexson and Madan-Swain (1995) suggest that more than half of students with chronic illness will return to their home schools in need of extra help from their teachers in order to “catch up” with their peers. The potentially damaging effect of such absences is further reiterated by Thies (1999) who notes that self-confidence, motivation and achievement are undermined as the child falls behind academically, and proposes that when this
occurs, efforts are directed towards catching up which in turn takes time away from
keeping up (p. 395).

Vulnerable and susceptible to infections and bugs, chronically ill children can
be placed in an isolation room for the duration of their hospital stay, which in turn
brings about challenges of its own. Interaction with others is limited as these children
are unable to socialise with peers and create or retain friendships. Feeling alone and
often angry, children in isolation are known to act out and have temper tantrums.

Social and emotional concerns for children with a chronic illness due to
a lack of ECCE.

All participants reported socialisation and emotional regulation to be major issues for
children who have not previously attended a formal pre-school service. These
children lack the ability to follow instructions and directions with ease, they are
unwilling to share or take turns and they can struggle to socialise and to be around
other children. As a result of residing in a hospital setting for long periods of time,
young children can become accustomed to exclusively socialising with adults on a
daily basis. Participants highlighted this issue on numerous occasions stating that:
“they have absolutely no opportunity to interact with kids their own age so all of their
interactions are with adults” (Participant 4). Another participant echoed this
statement and declared that long term, chronically ill children are “not as well able to
interact with other children because they’re not used to it. You’d notice the way in
which they can speak to adults is just way above their years (Participant 1).

emotional and social impact of school is a significant force in a child’s development.
The social skills children obtain from schooling are essential lifelong skills. Bakken et
al. (2017) report that according to teachers, from the early years on, children are
significantly able to behave more appropriately in situations than the other children in their classrooms (who have not had ECCE). Bakken et al. (2017) note that from the early years and throughout primary school, children are able to interact significantly more competently with their peers and adults than other children their age. Competent social interactions allow children the chance to develop relationships with other children. By early adolescence, pupils need relationships with their peers to continue to develop their sense of self, their self-esteem, and their sense of belonging (Bakken et al., 2017).

One participant noted a child’s inability to regulate their emotions due to their lack of experience of a classroom routine and setting: “Often when we meet children who have not received pre-school, they may have an emotional meltdown and end up crying because they don’t understand the rituals and routines within the school day” (Participant 5). An everyday task can become a great ordeal for a child, causing them to become extremely upset and distressed when in the company of other children their own age. According to Sexton and Madan-Swain (1995), a child’s emotional response to an illness may impact school functioning. Prolonged absences with little peer communication and contact creates social discomfort for the child with a chronic illness.

Another participant recalled a five-year-old child who was living in the hospital and receiving daily school sessions by her bedside. Over time this child progressed to attending classroom sessions with her peers yet she would become very distressed when she was in the company of other children: “There was nothing wrong with her, it was just because there was another child and she wasn’t used to it. She had siblings but it wasn’t the same” (Participant 2). According to Irish Health
(2018) children with a chronic illness such as congenital heart disease are at risk of emotional and behavioural problems and impaired school functioning.

In order to deal with teaching emotional regulation to a long-term patient of five years of age, one teacher found herself teaching the pupil how to express feelings and emotions through play with the use of the teddies during a one-to-one school session in a child’s bedroom:

She hasn’t had opportunities to play with other children and I often find myself having to use her teddies as play companions and giving them names and making a classroom from her teddies in her bedroom, just so she has the experience of sharing with others (Participant 5).

Reports of separation anxiety from parents was also highlighted continually throughout the data. Children who had not previously attended pre-school were noted to have difficulties leaving their parents or guardians at the school-room door or to allow them to leave the bedroom when it was time for school. Two teachers emphasised this issue from recent teaching experiences. According to one teacher, remedying this can take a lot of work on the part of the teaching staff:

It took us a couple of months to establish that with the child. That the parent would have to leave the room even though it might have been only for 30 minutes but was part of the ‘going to school’ experience. And because this child would have had no access to pre-school due to being in hospital, this is something she’d kick up to (Participant 4).

Another teacher mentioned the importance of learning this key life skill: “It’s so huge...emotionally being in school, being away from a caregiver who’s always there, they have to learn that emotional regulation” (Participant 7).
It was noted by participants that young children with chronic medical needs who are long term or recurrent hospital patients can express behaviour issues from time to time. They are prone to becoming “a little indulged” and “doing things on their own terms” due to their age and circumstances. One participant explained that it can be a major battle with four and five year old children who have not attended pre-school:

...to understand the simple thing like it’s not their way all of the time. That can be a massive battle with kids who are being hospitalised, who are nearly institutionalised, haven’t had access to pre-school is that they believe that you’re there to entertain them on their grounds, and when try to change the dynamic and go ‘it’s this way’ you can have quite a battle on your hands so that can be quite a tricky one to break down (Participant 4).

Another participant highlighted the same issue: “they can be difficult to engage as they’re used to doing things on their terms, because they begin to think that the world is about them all of the time” (Participant 9).

**Difficulties experienced by families of children with a chronic illness.**

According to the participants in this study, there is no unanimous opinion among parents regarding hospital school attendance for their children. This is unsurprising, though the rationale for the positions taken are interesting. Participants noted throughout the data that parents can be for or against hospital school education. Several participants mentioned that the majority of parents they meet on a daily basis are “very supportive” and “have a lot of gratitude for the service” (Participant 3). There are numerous issues that may affect a parent or family during a hospital stay, the most common being the stress of living in a hospital for a long period of time, craving a sense of normality for their child and feeling anxious and vulnerable.
in an often emotional environment. Regular hospital school attendance was highlighted as a balancing factor to enable children to feel normal again, while allowing parents to have time out for themselves. “I find that really important, that the parent has time for themselves…to have conversations, whether it be with the doctors or family or friends and the children aren't with them because children pick up an awful lot, way more than we even think” (Participant 2).

The disruption to family life and challenges experienced by parents and guardians can be seen as the result of a chronically ill child’s social and emotional difficulties. More often than not, families find themselves putting their entire lives on hold when their child has a chronic medical condition. Children can find themselves missing out on a childhood similar to that of their peers, and parents are missing out on family occasions, work and “normal life”. “…Their entire lives are on hold. They can’t forward plan, they can’t plan holidays like other families, they can’t plan for the family being together for things like holy communions, confirmations, they can’t be there for christenings…” (Participant 4).

Living in a hospital environment for the unforeseen future can be exhausting and challenging for the entire family. “Sometimes it might be one parent and a child who move into a hospital setting and the remainder of the family live in family homes. On more occasions the entire family will move into the hospital setting” (Participant 4). Hospital services provide great support for parents in this situation and the hospital school can be seen as a comforting aid. “They’ve moved away from home, they’ve moved away from their structures and it’s really tough. The little things mean an awful lot to them…it can be the first day at school” (Participant 4).

Numerous teachers cited a reward of their job as having daily opportunities to build strong relationships with families, especially as they are always alongside their
child. One teacher stated: “That's one huge bonus of a hospital school, you always have access to a parent or a guardian” (Participant 8). Hospital school staff meet parents on a daily basis and it was noted by many that building a strong rapport with parents, communicating daily, discussing a child’s likes and dislikes and learning prior knowledge of a child’s educational background are essential factors in forming trusting relationships. “Parents provide a prior knowledge of a child’s emotional maturity, physical health and independent learning” (Participant 8).

**A sense of normality.** There was consensus among most participants that education was key to providing a sense of normality in the lives of these children and their families. Participants cited that providing normality through education was imperative to giving hope to every family they encounter on a daily basis. All participants reported the uniqueness of the setting in which they work. Many participants acknowledged that every day is different in hospital school and education is delivered in an environment that is far from the norm. Within this unique environment, teachers described the practice they engage in as they strive to facilitate normality by providing the students with school that they are familiar with. “We just make it as warm and as inviting as possible…it’s going to be a similar setting to their normal school” (Participant 2). Hospital school is a medical free zone, with no medical procedures allowed in the school rooms. It is a safe and comforting environment for all children to enjoy. “In the school room there’s nothing medical at all…the nurses or doctors can’t come in and do anything, they have to take the child back to the ward, so…it’s a safe spot for the children…” (Participant 2).

Lemke (2004) state that hospital school teachers facilitate normality by enabling a hospitalised student to participate in a routine activity in an environment that is far from normal. Additionally, Äärelä et al. (2018) maintain that hospital school
teachers who facilitate education form a marginal group of special teachers. Hospital schools cannot run successfully without the dedication of this cohort of staff who play instrumental roles in providing hope, normality and routine for children during hospitalisation.

It was reported that parents of chronically ill children tend to crave a sense of normality whilst living in a hospital environment for a substantial amount of time. They understand that their child is different to their peers “They are not like their peers who have had a healthy childhood” (Participant 8), yet hold on to any ounce of normality given to them. “They want for their child what other kids are getting…they want to try and normalise this hospital experience as much as possible...school is one of the few things that is normal in a very abnormal setting” (Participant 4). A child’s first day of junior infants, a school test or simply completing school work and bringing it back to the ward to show parents can bring a spark to parents eyes:

...they’re so grateful then when they come to collect their happy child and they are running out with their schoolwork or what they’ve painted today, the relief coming over the parents eyes because it’s good to have a bit of normality in a child’s life when they are in hospital (Participant 2).

Ferguson and Walker (2014) state that school is extensively recognised as a “stabilising and normalising influence for young people with chronic illness” (p.236). It is this desire for normality that necessitates hospital schooling for such children during their hospitalisation.

Breitweiser & Lubker (1991) (as cited in Lemke, 2004, p.15) note that hospital schools are a growing phenomenon in both the health and education structures. Doering (2008) identifies a hospital school as the only place a seriously ill child can go and be something other than a patient. Similarly, in as early as 1951, Walton
noted that children can be spared emotional trauma if they are given opportunities to develop as social beings when they are given learning experiences in as normal an environment as possible. Continuing education while in hospital is an integral part of maintaining both the child and parents’ wellbeing, giving them hope for a future without illness or indeed a future despite illness. Literature suggests that continued participation in education while experiencing a chronic illness offers children and their families continued hope (Lemke, 2004).

**Stress and fear.** The majority of participants reflected on the stress and fear that children and their families experience while they reside in a hospital setting. Regardless of the length of time involved, participants explained that many families and children feel anxious, stress and indeed extremely vulnerable during their stay in the hospital. A number of participants highlighted meeting families when they are defenceless and exposed as a major challenge of the job, “you’re meeting families when they’re at their most vulnerable” (Participant 4). This anxiety can be reduced by reassuring parents about the school service, explaining the daily routine and taking their mobile numbers before school sessions. Easing parents’ anxiety around their child attending school can be very beneficial for all, with one participant stating that “I think parents would be most appreciative of it and it would prevent a whole anxiety for the parents because it’s a huge milestone for a child starting primary school.” (Participant 8).

Another teacher reiterated this high level of stress and worry in relation to parents of children who are “constantly waiting for a call from the UK for a heart transplant” (Participant 4). This teacher continued and explained that “the vast majority of these parents are living on their nerves. They’re constantly waiting for that call for a heart transplant. It can come at any hour on any day and you have to be
ready to go.” It was noted that it can be very difficult for those parents watching other children in similar positions get the call and they’re not, “and that’s very upsetting for these parents…it’s an emotional time bomb.” (Participant 4). As a result, parents can be very sensitive and stressed on a daily basis.

Generally, hospitalisation is a stressful experience for children and their families, no matter their age or health concerns, yet during early childhood, young children are particularly vulnerable to the effects of stress and fear during hospitalisation (Coyne, 2006; Salmela et al. 2010). Several fears which children found to be potentially stressful are: concerns about pain, loss of control and disruption to everyday life, routines and activities (Coyne, 2006). During Coyne’s (2006) study, children voiced concerns about missing ‘normal’ events in everyday life such as social contact at school, attending school and playing sport. A number of children expressed “anxieties about missing school in relation to ‘falling behind’ with schoolwork” (p. 330). Children and their parents are more likely to be less distressed if their lives within the hospital environment are as normal as possible (Coyne, 2006).

**Theme Three: Access to Early Childhood Care and Education within a Hospital School**

According to all participants, access to pre-school education within a hospital school setting is a feasible solution to help ease the challenges and barriers children with chronic illnesses and their families face on a daily basis. All participants agreed that they would like to see a pre-school service established within a paediatric hospital setting, yet their views and opinions differed in relation to how they envisage this service to be run.

The following sub themes: *Continuity of education; Parents’ desire for a pre-school service; and The implementation of a pre-school service within a hospital*
setting, detail the findings pertinent to the research question examining hospital school staff’s feelings with regard to ECCE within a hospital setting.

**Continuity of education.**

The necessity of the continuity of education was acknowledged by all participants as a fundamental element in every child’s life. The continuity of education does not strictly apply to the primary and post primary years, but also to the continuity of learning from pre-school to primary school. One participant emphasised this point: “We want to provide a continuity of education from pre-school to infant level” (Participant 6). Hospital school teachers are dedicated to providing an education to children from four years of age. These children are missing out on education from their base school, yet hospital school teachers are helping them to catch up with their peers by providing daily school sessions and remaining in contact with their base school teachers. However, the data shows that one cohort who remain stubbornly behind their peers are children under four years of age. Many participants noted that one of the main goals of a hospital school is to endeavour to try to bridge the educational gap as much as possible, with one participant stating that there is a gap and it is ready to be filled: “It's a gap and I've identified it and we have staff who would be able to fill that gap” (Participant 6).

With permission from parents, junior infant teachers within the hospital school are willing to contact a child’s previous pre-school teacher in order to liaise with him/her for the benefit of a child’s continuity of education. It has been noted by Skouteris et al. (2012) that the greatest capacity for achievement lies in the cooperation of primary school and early childhood teachers, “with the aligning of teaching practices and philosophies across the two institutions ensuring continuity and support for children as they progress through their education” (p.78).
One teacher stated that: “All of the children have a right to all levels of education” (Participant 1). Teaching children to learn new skills they’ve missed out on due to being in hospital is essential for their future development. “It’s important to remember that they are children at the end of the day and there are a lot of skills that they’re missing out on...that they would be able to develop if they were in full time school” (Participant 1).

Parents’ desire for a pre-school service.
Participants highlighted the necessity of a pre-school service as parents and hospital staff have demanded a service for pre-school aged children. “I've had parents come to me, and hospital staff demanding a service for that age group” (Participant 6). Another participant echoed this statement: “…parents or other hospital staff have approached myself and others on the staff about teaching three and four-year-old patients in the school” (Participant 3). Participants noted that parents can be understanding when they hear that there is no pre-school service available to them, yet they are usually disappointed to hear this. “They understand but they are disappointed. I think they would love to have another set of services for their child, not to pass the time but to bridge the gap that the child is missing while they’re in hospital” (Participant 3).

The implementation of a pre-school service within a hospital setting.
In order to successfully provide equal continuous education for all, all nine hospital school staff members reported the importance of providing a pre-school service within a paediatric hospital as a major component towards supporting children under four years of age. Participants corroborated the attitude of the benefits and importance of providing a pre-school service, with all participants calling it a fundamental service. Two participants stated that: “I would see the need for it as
essential” (Participant 2), and “I think that it would be a fantastic resource for the children to have access to a pre-school setting” (Participant 7). Another participant reiterated this necessity of the service stating that the pre-school years “are critical foundation years for their future developments...we’re essentially denying them the skills that they will rely on in the future” (Participant 1), while another participant mentioned the high demand for such a service:

There are a lot of the three and four year old age bracket within the hospital who would benefit from an early years programme. I meet a lot of parents who ask about the school, and inquire when their child would be eligible for participating in our school and I think that that’s an area that we definitely could service (Participant 3).

Thus, there was consensus among all participants who cited the importance for a pre-school service for children who are ill, yet their views and wishes towards where and how the service would be run varied slightly.

Out of the nine hospital school staff members interviewed, seven made their wishes clear that they would like a pre-school service to be part of the existing hospital school, “I’d like the continuity of the whole thing together, because children don’t one day move from pre-school to hospital school, and even the framework is continued on, it’s all about continuity” (Participant 6), whilst two participants noted that they would like to see the service as a separate entity in a dedicated pre-school space “what I’d like to see is a space dedicated entirely to early childhood education” (Participant 1).

Four participants mentioned that a pre-school service is required for long term and recurrent children only, with one participant stating that: “I have witnessed children waiting to come to school in the hospital. You know that three and a half to
five year old, that’s probably the most optimum age” (Participant 8) and another adding: “any of our children who are there long term, they definitely could be looked after” (Participant 6).

Significantly, eight out of the nine staff members interviewed noted that they would like to see a pre-school service staffed with fully qualified pre-school educators, with one participant emphasising the possible collaboration between an ECCE sector and the hospital school: “I would like it to be part of the hospital school and to have the expertise of early childhood educators as part of the school team” (Participant 6). In contrast, one participant believes that the current teaching staff could organise the implementation of a new pre-school service within the hospital school, and there is no need for early years educators. “I do feel that the staff we already have who particularly focused their own studies on the early years would be great at running that. I don’t think it would be necessary to bring in early years educators” (Participant 3). This participant sees a need for extra staffing within the hospital school: “Possibly an extra SNA, and then the teachers that were responsible for this section of the school would then obviously need to be replaced within the other areas of the school” (Participant 3).

Various participants highlighted different features they would like to see within a hospital based pre-school service. Three participants mentioned that they would like the service to be fun and interactive with lots of play and movement, while two other participants placed an emphasis on basing the service around an Early Start Programme similar to those in DEIS schools. Here there would be an emphasis on “storytime…Aistear…water, sand and messy play” (Participant 5). There was a consensus amongst staff that pre-school sessions should be divided up between whole group classroom based sessions and one-to-one sessions on the wards for
children who are in isolation. Participants would like ward sessions to include story stacks, toys based on various Aistear (NCCA, 2009) themes and plenty of fun resources.

Providing a pre-school service would ensure that pupils are “reaching the appropriate milestones at the appropriate age” (Participant 4), exploring “strategies to develop resistance and resilience” and being provided with opportunities “to develop friendships and relationships” (Participant 1). According to French (2007) active learning, positive relationships between the adult and the child, social interactions with others and experiencing a challenging and interesting environment are crucial factors in the child’s early stages of learning and development.

**Conclusion**

This chapter presented the findings of the research data collected from semi-structured interviews with nine hospital school staff members. These findings are presented within the context of relevant literature. The key objective was to determine the views of a selection of hospital school staff with regard to early childhood care and education for children with chronic medical conditions.

Themes generated fell into three broad categories and were titled: *Contributors to academic challenges for children with chronic medical needs; Challenges affecting the social and emotional development of children with chronic medical needs;* and *Access to early childhood care and education within a hospital school.*

Findings from this study illustrate what participants perceive to be the contributors to challenges for chronically ill children of all ages and their families. Challenges affecting academic, social and emotional development are accentuated for chronically ill children who have access to education, and even more so for those
who don’t. It was found that all children with medical needs suffer from academic struggles and underdeveloped social and emotional skills. Data shows that children with medical needs who also experience infrequent attendance of ECCE, experience additional challenges due to the lack of an educational input.

The findings from this study also demonstrate participants’ views and recommendations towards the establishment of a pre-school service within a paediatric hospital setting. Detailed insights into participants’ views towards the preferred location, staffing, resources and the age range of pupils to possibly attend a pre-school service were examined and depicted categorically. To successfully provide equal continuous education for all students, all participants expressed the importance of providing a pre-school service within a paediatric hospital as a major component towards supporting children under four years of age.

The concluding chapter will serve as a summary of the main aims and findings of this research study.
Chapter Five: Conclusion

Introduction

The purpose of this research study was to examine the educational needs of chronically ill children who do not have access to ECCE within a hospital setting in Ireland. A further aim of this research study was to identify the challenges and impact infrequent attendance of ECCE can have on a chronically ill child’s life from the perspectives of hospital school teachers and SNAs employed in two Irish paediatric hospital schools.

A qualitative design approach was employed to address this study. Semi-structured interviews conducted via videoconferencing applications were conducted with nine participants currently working in hospital schools. The valuable insights and personal experiences of the participants were audio recorded with a portable Dictaphone and analysed using TA to address the following research question and it’s sub-questions:

What are the views of a selection of hospital school staff with regard to early childhood care and education for children with chronic medical conditions?

a) What impact does absence or limited access to early childhood care and education have for children when they attend hospital schools?

b) What are hospital school staff’s feelings with regard to early childhood care and education within a hospital setting.

The findings of this research study support previous research in this field regarding the provision of ECCE for chronically ill children while also providing valuable insights into policies and practices previously undocumented from an Irish
perspective. This chapter will summarise the main findings and outline academic, social and emotional challenges for chronically ill children.

**Summary of Findings**

Many children with acute or chronic illnesses experience ongoing difficulties with school, mainly long term or recurrent school absenteeism. These children may be immunosuppressed and if so, they must be hospitalised even with a slight common cold. Public places, including regular classrooms, bring about potentially dangerous exposure. Furthermore, a child’s return to school may be postponed due to ongoing out-patient appointments for follow-up care, physical limitations and potential for infection.

One of the main findings that emerged from this study is that practically all children who attend a hospital school encounter academic, social and emotional struggles due to their medical conditions and associated treatments. The medical condition itself is a major key element to consider when reflecting on the impact it may have on a child’s academic development. However, the participants were clear that the treatments for conditions also contributes to these difficulties. The data collected informed us as to why chronically ill children have a more problematic engagement with education than their healthy peers.

Participants agreed that all children within hospital settings experience significant academic challenges. While each patient is different, there was general agreement that most children face significant barriers to their learning. It was found that medical conditions and their associated treatments affect a child’s learning due to ongoing sickness, fatigue, low mood and feeling anxious and fearful of the unknown. All hospital school staff reported that medical conditions can have long term damaging effects on a child’s motor skills, neurological skills and cognitive
development. Strokes, flare ups of the joints and underdeveloped fine and gross motor skills are only a number of defects chronical illnesses can cause.

There was consensus among the participants of this study that without ECCE, children who are chronically ill experience similar difficulties to their ill peers, yet with extra challenges. Participants reported that these children under four years of age are at risk of being developmentally delayed in comparison to their peers. During the data collection process, participants noted that children were unable to zip up their own coats, to put their shoes on or to sit in a chair. Underdeveloped fine and gross motor skills were extremely common as well as the inability to make simple jigsaws, to hold a pencil, to recite numbers, to match objects, to engage in a nursery rhyme or song, or to identify common colours. Poor language acquisition and communication skills were also noted as prominent concerns by many participants.

Findings from this study illustrate countless challenges encountered by parents and families of chronically ill children, and their ability to get through life in a hospital setting. By placing their lives on hold to care for their ill child, they are willingly putting their child’s needs before their own. Despite an uncertain future, hospital schools are providing a sense of normality and continued hope for children with medical needs and their families.

There was consensus among the participants of this study that underdeveloped social and emotional skills are a considerable issue for all children who are acutely or chronically ill. Numerous participants agreed that being too unwell to socialise with home school friends or to attend their base school was damaging to any child, especially a chronically ill child who is residing in a hospital bed for the majority of its young life. Being immunocompromised and immunosuppressed can lead to a child being isolated from their familiar setting, daily visitors and hospital
school peers and so can induce anger and upset. Additionally, for children who have not previously attended a formal pre-school service the social and emotional difficulties have further consequences. These children lack the ability to follow instructions and directions with ease, they are unwilling to share or take turns and they can struggle to socialise and to be around other children. As a result of residing in a hospital setting for long periods of time, young children can become accustomed to exclusively socialising with adults on a daily basis. Emotional regulation was highlighted as a major issue as these children are unable to regulate their emotions due to their lack of experience of a classroom routine and setting.

According to the data presented, due to the absence of a pre-school service within our national paediatric hospitals, if a child of three or four years of age is hospitalised prior to beginning junior infants, or the equivalent, they are instantly at a disadvantage to their peers. Participants noted that the education of children under four years of age is not catered for in Irish paediatric hospitals. Early childhood is perhaps the most critical period in a child’s development as it nurtures each individual child’s curiosity, resilience, creativity, confidence and potential (INTO, 2016). The data shows that there is a large cohort of children who are being deprived of this vital service.

The findings from this study also represent participants’ views and recommendations towards the establishment of a pre-school service within a paediatric hospital setting. Detailed accounts of each participants’ desire towards their preferred location, staffing allocation, resources used and the age range of pupils to attend such a service were examined and depicted categorically. To successfully provide equal continuous education for all students, all participants expressed the importance of providing a pre-school service within a paediatric
hospital as a major component towards supporting children under four years of age. Four participants stated that a pre-school service is required for long term and recurrent children only, while seven participants cited that in order to have continuous education within the one department, they would like a pre-school service to be part of the existing hospital school. Additionally, eight out of the nine participants interviewed expressed their desire to have a pre-school service staffed with fully qualified pre-school educators, while one participant favoured a collaboration between an ECCE sector and the hospital school. This participant recommended hiring an extra SNA to assist the current hospital school staff to establish and operate a pre-school service. Participants specified that they would like the pre-service to be fun and interactive with lots of play and movement, while two participants placed an emphasis on basing the service around an Early Start Programme similar to those in DEIS schools.

Conclusion

Children represent approximately one-third of the population of Ireland. They represent the future of Ireland but they are reliant on the present for experiences that will enhance their future (Hayes, 2002). Children are a vulnerable social group. Hayes (2002) states that they are spoken on behalf of but rarely have an opportunity to speak for themselves. The voice of the child and it's parents are crucial to a study like this. In the context of the time afforded to this study due to it being part of a master's programme, access to parents was not achievable yet further research in this area of ECCE for chronically ill children is necessary. This study was limited to data collection from two out of the nine hospital schools in Ireland. Future research undertaken could explore the lack of ECCE, from staff, parents and children’s perspectives from all nine hospital schools in Ireland, or indeed abroad.
Complex, real thought needs to be given to the expansion of ECCE provision. Policies, guidelines and recommendations need to be established for the implementation of an ECCE setting within a hospital context. In order to provide an equal education for all, a pre-school service co-located within a hospital school and staffed by fully qualified early childcare professionals would accommodate for an equal, invaluable and continuous education for all.
References


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Appendices

Appendix A: Participant Information Sheet

Dear Participant,

I wish to invite you to participate in a research study that investigates the impact the absence of early childhood care and education can have on a chronically ill child’s education. From this, I intend to research the demand, or lack thereof, of an early childhood care and education service within a paediatric hospital setting in Ireland. In order for you to fully understand why this research is being undertaken and what would be required of you as a participant, I would appreciate you taking the time to read the following information carefully. Should you have any questions, require further information or indeed clarification on any aspect of the study, please do not hesitate to contact me.

I am currently in my second year of an MES in Early Childhood Education in Marino Institute of Education, Dublin. As I am in my dissertation year, I am required to conduct research to inform my thesis. The area I have chosen to investigate is that of early childhood education for children with chronic medical needs. As there is limited literature on this topic, particularly in Ireland, I feel it is necessary to conduct
research in this field that will inform practice and add to the limited research available to date.

There is one part to this study: a semi-structured interview. Due to the ongoing global pandemic of the coronavirus disease, my original data collection method of face to face interviews within a hospital school setting will have to be adapted. Interviews may be conducted through a video conferencing call or via a phone call. In total it will take 30-40 minutes to complete the interview. Confidentiality is of paramount importance to me and I am acutely aware of your right to privacy. For this reason no aspect of your interview will be discussed with any other members of staff. You are under no obligation to complete the interview, or to answer all of the questions. If you come to a question you do not wish to answer, we will simply skip it.

I would like to ask you about your experience, or lack thereof, of working with children in the early years, how medical conditions may impair a child’s development and ability to learn and your opinion on school readiness.

I hope you will be willing to participate because your responses are important and a valued part of the study. Your participation will remain strictly confidential. Your name will not be attached to any of the data you provide. You are welcome to discontinue participation in the study at any time, should you wish to do so. The risks of participation in the study are very low and of a social or reputational nature. The interview will be kept in a secure location and on an encrypted device without your name attached to it. The interview will be retained only for the purposes of the current study. Once the study is completed, the interview will be destroyed on the
basis of the schedule outlined in the Institute’s data retention schedule. If you would like more information on how long the interview data will be retained for, please don’t hesitate to contact me directly. There are no risks or direct benefits in participating in the interview. You will be asked to sign a consent form (below) indicating agreement to participate in the study, and I will endeavour to retrieve this at a later date.

If you agree to participate please contact me in one of the following ways:

- Via telephone: ______________
- Via email: ______________

If you are willing to participate, it would help me greatly to know this as soon as possible so that your participation can begin as soon as possible.

This study has been approved from an ethical perspective by the Marino Ethics in Research Committee. Should you have any questions or concerns about the ethical approval or conduct of this study, please contact ______________.

Yours faithfully,

____________________________

You will be given a copy of this information to keep for your records.
Appendix B: Pilot Interview Schedule

1. Can you talk to me about what it’s like to work in a hospital school?

2. Would you mind telling me about some of the children you work with?

3. Following on, can you tell me about your experience with 3 and 4 year old patients in the hospital?

4. In your experience, how would you know if a child is ready to start junior infants?

5. Would you usually be aware of a pupil’s previous educational experience prior to them being inpatients in the hospital?

6. I am interested in the impact formal pre-schooling has on children with medical conditions. If you think about the junior and senior infants you have worked with, how would you know if a child has had ongoing formal pre-schooling or not?

7. In your experience, are there particular medical conditions or associated treatments that may impair a child’s ability to learn?

8. Can you think of the infants who are in your hospital school at the moment - for bedside sessions or in the classroom for a whole group session. Would many of these children have had a disrupted pre-schooling due to illness, hospitalisation or other factors?
9. Can you describe the impact long term or recurrent hospitalisation may have on a child’s social development within the classroom/during school sessions?

10. How do you feel the lack of a pre-school service could be addressed within the context of a paediatric hospital?
Appendix C: Revised Interview Schedule

1. Can you talk to me about what it’s like to work in a hospital school?

2. Would you mind telling me about some of the children you work with?
   • Would you regularly come across children who are long term patients in the hospital?
   • Can you talk to me about the parents you would usually meet on a daily basis?

3. Following on, can you tell me about your experience with 3 and 4 year old patients in the hospital?

4. In your experience, how would you know if a child is ready to start junior infants?

5. Would you usually be aware of your pupil’s previous educational experience prior to them being inpatients in the hospital?

6. I am interested in the impact formal pre-schooling has on children with medical conditions. If you think about the junior and senior infants you have worked with, how would you know if a child has had ongoing formal pre-schooling or not?

7. In your experience, are there particular medical conditions or associated treatments that may impair a child’s ability to learn?
   • If so, how do you become aware of how a particular health condition may impact a child’s ability to learn?
8. Can you think of the infants who are in your hospital school at the moment, be it for bedside sessions or in the classroom for a whole group session. Would many of these children have had a disrupted pre-schooling due to illness, hospitalisation or other factors?
- How has this pattern of disrupted pre-schooling impacted on the child?

9. Can you describe the impact long term or recurrent hospitalisation may have on a child’s social or emotional development within the classroom/during school sessions?
- Emotional development? Developmental - fine/gross motor skills?
- Would this be less of an issue for children that you know would have had continuous formal pre-schooling?

10. How do you feel the lack of a pre-school service could be addressed within the context of a paediatric hospital?
- What would you envisage this service to look like within your setting?
Appendix D: Letter from School’s Board of Management

Ms. Jennifer Hogan,
Teacher,

16th October 2019

Dear Jennifer,

Further to your letter of 14th October 2019 requesting ethical approval for your dissertation research project leading to a Masters Degree, I am pleased to approve same under the conditions outlined in your letter and in conjunction with the terms outlined below:

• the approval is subject to the continuance of the approval already obtained from Trinity College Dublin

• the location of the proposed interviews will be at all times on School’s premises

• the collection and storage of personal data will be in accordance with current GDPR legislation enacted on 25th May 2018.

I wish you well with your research work.

Yours sincerely,

____________________
Chairperson
Board of Management
Appendix E: Principal Request Letter

Marino Institute of Education

XX/XX/XXXX

Dear Principal,

I am currently in my dissertation year of my MES in Early Childhood Education in Marino Institute of Education, Dublin. As part of this programme I am conducting research in the area of early childhood care and education in a hospital setting. My research is under the supervision of __________ and is entitled “A broken start? An examination of the impact of chronic illness and hospitalisation on the early childhood care and education careers of children attending hospital schools in Ireland.”

The purpose of this research is to examine the educational needs of chronically ill children who do not have access to early childhood care and education (ECCE) within a hospital setting. This study aims to identify the challenges and impact infrequent attendance of ECCE can have on a chronically ill child’s life. This research further aims to identify the impact complete or partial disruption of ECCE due to recurrent or continuous hospital admissions can have on children when they attend hospital schools. Hospital school staff members’ feelings and views with regard to ECCE within a hospital setting are explored and examined. The data collection for this study will include compiling information from the country’s two tertiary paediatric hospital schools, detailing the organisation and structure of the hospital school, and will include conducting semi-structured audio-recorded interviews with the teachers employed in this setting. It is anticipated that the interviews will last between 30-40 minutes each. It is hoped to complete the interviews during school hours but outside of class time and on school grounds, thus preventing disruption to the school day.

I am aware that this is a very busy time of year for you and your school and I would greatly appreciate your assistance with this project. I can foresee no risks associated with individual and school participation in this study beyond those experienced in everyday life. The information gathered will be treated with the appropriate privacy and anonymity. Your school and the participants will not be identified in the research. All information will be stored safely with access only available to myself, my
supervisor and examiners. Data retrieved will be destroyed after a period of 13 months after completion of the thesis examination process. The anonymised results will be included in a thesis and may be discussed at conferences or published in academic literature. As your school would be the site for data collection, a copy of the results can be made available to you upon request.

Please note that your school and staff are under no obligation to participate in this study. If at any time a participant wishes to withdraw from the study, they may do so at any time, without having to give a reason and without prejudice.

If you have any further questions regarding this research, please do not hesitate to contact me using the email address listed below. Finally, I would like to thank you for taking the time to consider my research. Without your generous participation, conducting such research would be impossible.

Kindest regards,

____________________

Email:

Phone:

____________________

Supervisor email:

Supervisor number:
Appendix F: Letter to the Marino Institute of Education's Ethics Committee

XX/XX/XXXX

To whom it may concern,

I am requesting ethical approval to change the data collection format for my research study. I was originally planning on conducting face-to-face interviews with participants, yet due to nationwide school closures in response to the worldwide COVID-19 pandemic this is not feasible. Via audio recorded, semi-structured interviews conducted through the videoconferencing applications Zoom or Google Hangouts, participants will be asked to recall how their chronically ill students engaged with education during and after medical treatments.

The purpose of this research is to examine the educational needs of chronically ill children who do not have access to early childhood care and education (ECCE) within a hospital setting. This study aims to identify the challenges and impact infrequent attendance of ECCE can have on a chronically ill child’s life. This research further aims to identify the impact complete or partial disruption of ECCE due to recurrent or continuous hospital admissions can have on children when they attend hospital schools. Hospital school staff members’ feelings and views with regard to ECCE within a hospital setting will also be explored and examined.

A participant’s information sheet has been re-drafted and amended, as has the method of gaining consent. Verbal consent will be obtained from interviewees at the beginning of each interview and participants will email their written consent. Interviews will be digitally recorded with a Dictaphone recording device placed on the desk next to the laptop and transcribed verbatim. Participants will be contacted
individually via phone calls with detailed information sheets sent to their work email addresses. Participants willing to participate in the interviews will contact me via phone or email with their suggestion of a suitable interview time.

Upon compilation of an interview schedule, a pilot interview will be conducted with a primary school teacher currently teaching in a hospital school located within a paediatric hospital in Dublin, Ireland. The pilot interview will set out to identify potential ambiguities in the phrasing of questions, redundancy of questions or to determine the appropriateness of the questions to the needs of this study. The questions will be revised for clarity and repetition and re-drafted prior to conducting case study interviews.

Remaining acutely aware of the potential for bias from the research method adopted, credibility, reflexivity and subjectivity in this qualitative research were valued greatly throughout the data collection and analysing process.

Sincerely,

____________________
## Appendix G: Coding Levels 1 - 4 Tables

### First Level Coding

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<td>Effects of disruptive pre-schooling</td>
<td>Reference to the effects disruptive pre-schooling can have on a child</td>
<td>EDPS</td>
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<td>Signs of formal pre-school education</td>
<td>Reference to signs a child has received formal pre-school education</td>
<td>SPS</td>
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<td>Signs of no formal pre-school education</td>
<td>Reference to signs a child has not received formal pre-school education</td>
<td>SNPS</td>
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<tr>
<td>Importance of a pre-school service in a hospital setting</td>
<td>Reference to the importance of a pre-school service within a paediatric hospital setting</td>
<td>IPSH</td>
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<tr>
<td>Under pressure to provide a pre-school service</td>
<td>Reference to hospital school staff being under pressure to provide a pre-school service to children under four</td>
<td>PR</td>
</tr>
<tr>
<td>Visions and wishes for a pre-school service</td>
<td>Reference to hospital school staff members visions, opinions and wishes towards a pre-school service within a paediatric hospital setting</td>
<td>VWPS</td>
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<td>Topic</td>
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<td>Early Start Programme</td>
<td>Reference to the Early Start Programme</td>
<td>ESP</td>
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<tr>
<td>Resources</td>
<td>Reference to school resources</td>
<td>RE</td>
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<tr>
<td>Aistear</td>
<td>Reference to the Aistear: The Early Childhood Curriculum Framework</td>
<td>AIS</td>
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<tr>
<td>Inclusion</td>
<td>Reference to child inclusion</td>
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<tr>
<td>Settling into a new setting</td>
<td>Reference to children settling into a new setting and meeting new people</td>
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<tr>
<td>Educational sessions</td>
<td>Reference to medical education sessions</td>
<td>EDS</td>
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<tr>
<td>Multidisciplinary team meetings</td>
<td>Reference to any collaboration with MDT</td>
<td>MDT</td>
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<tr>
<td>Other hospital schools</td>
<td>Any reference to liaising with other hospital schools</td>
<td>HS</td>
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<tr>
<td>Playroom</td>
<td>Reference to ward playrooms</td>
<td>PR</td>
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<tr>
<td>Play specialist</td>
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<td>Feelings and emotions</td>
<td>Reference to a child expressing feelings and emotions through play</td>
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<td>Behaviour issues</td>
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<td>Developmental development</td>
<td>Reference to the developmental needs of a child</td>
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<tr>
<td>Teacher Ratio</td>
<td>Reference to number of students being taught</td>
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<tr>
<td>Wellbeing</td>
<td>Reference towards a child’s wellbeing and mental health</td>
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### Second Level Coding

#### Engaging and supporting children during hospitalisation

<table>
<thead>
<tr>
<th>Category</th>
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<tr>
<td>Hospital school environment (HSE)</td>
<td>Providing hope (PH)</td>
</tr>
<tr>
<td>Building relationships (REL)</td>
<td>Communication with students (COMMS)</td>
</tr>
<tr>
<td>Teaching environment (TE)</td>
<td>High interest activities (HI)</td>
</tr>
<tr>
<td>Communication with student (COMMS)</td>
<td>Engagement (ENG)</td>
</tr>
<tr>
<td>Continuity in education (CE)</td>
<td>Bridging gaps in education (BG)</td>
</tr>
<tr>
<td>Long term student (LT)</td>
<td>Short term student (ST)</td>
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<tr>
<td>Recurring admission (RA)</td>
<td>Multi-Grade (MG)</td>
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<tr>
<td>Bedside teaching (BS)</td>
<td>Classroom teaching (CR)</td>
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<tr>
<td>Special Educational Needs (SEN)</td>
<td>Special needs assistant (SNA)</td>
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<tr>
<td>Accessible equipment (AE)</td>
<td>Communication with base school (COMMA)</td>
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<tr>
<td>Information gathering (IG)</td>
<td>Educational sessions (EDS)</td>
</tr>
<tr>
<td>Teaching environment (TE)</td>
<td>Multidisciplinary team meetings (MDT)</td>
</tr>
<tr>
<td>Classroom teaching (CR)</td>
<td>Other hospital schools (HS)</td>
</tr>
<tr>
<td>Special Educational Needs (SEN)</td>
<td>Playroom (PR)</td>
</tr>
<tr>
<td>Accessible equipment (AE)</td>
<td>Play specialist (PS)</td>
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<td>Communication with base school (COMMA)</td>
<td>Wellbeing (WB)</td>
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#### Families of children with a chronic illness

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<th>Category</th>
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<tr>
<td>Parents (PAR)</td>
<td>Living in the hospital (LH)</td>
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<td>Normality (NORM)</td>
<td>Communication with parents (COMMP)</td>
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<tr>
<td>Anxiety (ANX)</td>
<td>Stressful environment (SE)</td>
</tr>
<tr>
<td>Vulnerable children &amp; families (VCF)</td>
<td>Relationship with parents (RPAR)</td>
</tr>
<tr>
<td>Home tuition (HT)</td>
<td>Home environment (HE)</td>
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#### Challenges experienced in a hospital school/paediatric hospital

<table>
<thead>
<tr>
<th>Category</th>
<th>Codes</th>
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<tbody>
<tr>
<td>Challenges for children (CHC)</td>
<td>Challenges for teachers (CHT)</td>
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<tr>
<td>Bereavement (B)</td>
<td>Assessment (ASS)</td>
</tr>
<tr>
<td>Time pressure (TP)</td>
<td>Educational experience (EE)</td>
</tr>
<tr>
<td>Barriers to education due to medical conditions, treatments and hospitalisation</td>
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<tr>
<td>Disadvantaged due to illness (DI)</td>
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<tr>
<td>Peers (P)</td>
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<td>Friendships (FR)</td>
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<td>Falling behind (FB)</td>
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<td>Disengagement (DISN)</td>
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<tr>
<td>Isolation procedures (ISO)</td>
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<td>Socialising with adults (SA)</td>
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<tr>
<td>Effects of medical conditions (EMC)</td>
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<td>Inclusion (INC)</td>
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<tr>
<td>Settling into a new setting (NS)</td>
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<td>Emotional regulation (ER)</td>
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<td>Expressing feelings and emotions (EFE)</td>
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<td>Behaviour issues (BI)</td>
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<table>
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<tr>
<th>Characteristics of an effective hospital school routine</th>
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<tr>
<td>Attitudes (ATT)</td>
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<tr>
<td>Teaching experience (TE)</td>
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<td>Daily routine (DR)</td>
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<td>Management and administration (MA)</td>
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<td>Everyday is different (EDD)</td>
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<td>Range of abilities (RA)</td>
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<td>Database (DB)</td>
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<td>Enjoyable aspect (ENJ)</td>
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<td>Flexibility (FX)</td>
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<td>Rewards for teachers (RWT)</td>
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<td>Communication with medical staff (COMMS)</td>
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<td>Communication with colleagues (COMMC)</td>
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<td>Collaboration with colleagues (COLL)</td>
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<td>Mental health (MH)</td>
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<td>Rehabilitation (REHAB)</td>
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<td>Teacher ratio (TR)</td>
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Early Childhood Care and Education

Montessori teacher (MT)
Montessori method (MM)
Montessori resources (MR)
Hospital funding (HF)
Child led learning (CLL)
Multi-Sensory Room (MSR)
Multi-Sensory Equipment (MSE)
Pre-school activities (PSA)
Junior infant programme (JIA)
Early intervention (EI)
School starting age (SSA)
School readiness (SR)
Experience with the early childhood education (EECCE)
Admissions and enrolment policies (AP)
No pre-school service in a hospital setting (NPSE)
Communicating with three-year-olds (COMM3)
A right to education (RTE)
Early childhood care and education (ECCE)
Benefits of ECCE (BECCE)
Disruptive pre-schooling (DPS)
Effects of disruptive pre-schooling (EDPS)
Signs of formal pre-school education (SPS)
Importance of a pre-school service in a hospital setting (IPSH)
Under pressure to provide a pre-school service (PR)
Visions and wishes for a pre-school service (VWPS)
Early Start Programme (ESP)
Resources (RE)
Aistear (AIS)
Language development (LD)
Social development (SD)
Emotional development (ED)
Developmental development (DD)
## Third Level Coding

<table>
<thead>
<tr>
<th>Theme: Engaging and Supporting children</th>
<th>Subthemes</th>
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<td>Information gathering</td>
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<td>Engagement</td>
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<td>High interest activities</td>
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<td>Families of chronically ill children</td>
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<td>Craving a sense of normality</td>
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<td>Ongoing communication and building relationships with hospital school staff</td>
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<td>Vulnerable</td>
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<td>Disadvantaged/advantaged backgrounds</td>
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<td>Home tuition</td>
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<td>Chronically ill children/families missing out on life events of family and friends</td>
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<td>Challenges experienced Challenges for children</td>
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<td>Time pressure of school sessions</td>
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<td>Educationally falling behind peers</td>
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<td>Lack of friendships with due to hospitalisation</td>
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<td>Lack of a childhood</td>
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<tr>
<td>Challenges for hospital school teachers</td>
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<td></td>
<td>Bereavement</td>
</tr>
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<td>Emotional/tense work environment</td>
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<td>Assessing a child’s base line</td>
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<td>Time pressure of school sessions</td>
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<tr>
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<td>Lack of prior knowledge of a child’s educational experience</td>
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<td>Lack of continuity of school sessions with students</td>
</tr>
</tbody>
</table>
| Barriers to education | Effects of medical conditions | EMC | • Fatigue  
• Sickness  
• Disengagement  
• Falling behind peers at school  
• Behaviour issues/Anger  
• Anxiety  
• Self-conscious of appearance/medical equipment |
|----------------------|-------------------------------|-----|----------------------------------|
| Isolation procedures | ISO                           |     | • Inclusion  
• Not mixing with peers  
• Lack of friendships with due to isolation  
• Socialising with adults  
• Emotional regulation  
• Expressing feelings and emotions  
• Behaviour issues |
| Early Childhood Care and Education | No pre-school service in a hospital setting | NPSE | • School starting age  
• School readiness  
• Experience with the early childhood education  
• Admissions and enrolment policies  
• No pre-school service in a hospital setting  
• Communicating with 3-year-olds  
• A right to education |
| Signs of formal pre-school education | SPS                           |     | • Benefits of ECCE  
• School readiness  
• Language development  
• Social development  
• Emotional development  
• Developmental development |
| Disruptive pre-schooling | DPS                           |     | • Effects of disruptive pre-schooling  
• Emotional regulation  
• Behaviour issues  
• Socialising with adults  
• Peers  
• Friendships  
• Falling behind  
• Disengagement |
| Visions and wishes for a pre-school service | VWPR                          |     | • Importance of a pre-school service in a hospital setting  
• Under pressure to provide a pre-school service  
• Early Start Programme  
• Early intervention  
• Continuity in education  
• Pre-school as part of a hospital school  
• Resources |
<p>| | | | |</p>
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<tr>
<td>• Aistear</td>
<td>• Child led learning</td>
<td>• Hospital funding</td>
<td>• Bedside and classroom sessions</td>
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<td>• Early childhood educators</td>
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<td>• Primary school teachers</td>
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<tr>
<td><strong>Contributors to academic challenges for children with chronic medical needs</strong></td>
<td>Academic challenges (caused by medical conditions and long term treatments)</td>
<td>ACADEM</td>
<td></td>
</tr>
</tbody>
</table>
|  |  |  | • Fatigue, Sickness, Low mood, Anxiety  
• School attendance  
• Disengaging from school  
• Lack of concentration  
• Effects of treatments  
• Medical conditions having long term damaging effects on a child’s motor skills, neurological skills and cognitive development  
• Children who have not had access to ECCE:  
• Extra challenges  
• At a further disadvantage to their peers  
• DES rules of 4years + to be enrolled on school rolls  
• Poor language and communication skills  
• Developmental delays - fine and gross motor skills |
| **Challenges affecting the social and emotional development of children with chronic medical needs** | Social and emotion difficulties | SOCEMO |  |
|  |  |  | • Children who have access to education  
• Hindered social and emotional development  
• Peers  
• Isolation status – temper tantrums  
• Children who have not had access to ECCE:  
• Socialisation - mixing with adults/peers  
• Emotional regulation  
• Separation anxiety from parents  
• Behaviour issues  
• Poor language and communication skills |
| **Familial and social** |  | FAMSOC |  |
|  |  |  | • Children/families missing out on life events  
• Living in the hospital  
• Building strong relationships  
• Seeking normality  
• Craving a sense of normality  
• School room is a medical free zone  
• Normal school environment and resources  
• Stress and Fear |
| **Access to early childhood care and education within a hospital school** | Continuity in education | CE |  |
|  |  |  | • Continuity in education  
• A right to education for all |
| **Parents desire for a pre-school service** |  | PARPRESCH |  |
|  |  |  | • Parent’s desire for pre-school service |
| **The implementation of a pre-school service within a hospital setting** |  | PRESCH |  |
|  |  |  | • Hospital school teachers’ and SNA’s aspirations and thoughts towards the establishment of a pre-school service within the hospital |