ANGLIA RUSKIN UNIVERSITY

FACULTY OF ARTS, HUMANITIES AND SOCIAL SCIENCES

HEARING THE SILENT SPEAK – AN EXPLORATION INTO THE SILENT SPIRITUALITY OF SEVERELY DISABLED CHILDREN

SUSAN ELIZABETH PRICE

A thesis in partial fulfilment of the requirements of Anglia Ruskin University for the degree of Doctor of Philosophy

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ABSTRACT

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I argue that the spirituality of severely disabled children is silent and silenced. My research explores this under-researched area to investigate how these children express their spirituality and how that might be recognised and understood by others, especially within a healthcare context.

This is a theological qualitative research project. My literature review explored how 'religion' and 'spirituality' are understood within the societal and healthcare contexts that surround the children, their families and staff. I reflected on the Christian Doctrine of *imago Dei,* in the light of Children's Spirituality and Disability Theology. I explored a relational understanding of this doctrine and proposed that the study cohort could reflect *imago Dei* through their spirituality expressed in their relationships.

My over-arching methodology of attention and contemplation was applied to the methods used for the fieldwork. This involved spending time with six severely disabled children in their own homes. The data from these visits was analysed using adapted forms of Content and Thematic Analysis. The severely disabled children in the study were shouting out their spirituality, living a difficult life ordinarily, in meaningful relationships with themselves, others and God, living in the present moment. Attention and contemplation were necessary to hear and see their embodied, relational spirituality.

I concluded that these children's embodied spirituality is best described through an understanding of the relationality of *imago Dei,* seen in their relationships with themselves and others and God. Their relationships were expressed and formed through their languages of play and silence. Each child in the research had their own personal spiritual signature. The findings can be used as theological offerings to support healthcare practice in a deeper understanding of person-centred care, recognising the prophetic nature of the children and healthcare and through a recognition of hospitality as spiritual care.

Key words: children, severely disabled, spirituality, Practical Theology

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Abbreviations used:

BIAPT	British and Irish Association of Practical Theology
DeTrin	Augustine: On the Holy Trinity
EACH	East Anglia's Children's Hospices
HCPs	Healthcare Professionals
IASCUFO	Inter-Anglican Standing Commission on Unity, Faith and Order
IoEp	Augustine's Homilies on the First Epistle of St John
ISE	Interpretive Spiritual Encounters
PMLD	Profound and Multiple Learning Disabilities
NRSV	New Revised Standard Version of the Bible
RJ	Research Journal
SEND	Special Educational Needs and Disability
TA	Thematic Analysis
WFD	Westminster Faith Debates

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Chapter 1 Introduction

I deliberately chose to use 'exploration' in the title of my thesis. The point of any exploration is to search and discover, perhaps finding something previously unknown. To go on an exploration is to go on a journey. There have been other explorers, on these paths, such as Frances Young and Henri Nouwen who have searched for a theological understanding of profound learning disability, drawing on their personal experiences and reflections. Through their journeys they have discovered new insights that have contributed meaningful responses to their experiences of disability.

My research journey has followed a different trajectory. I have searched for meaningful responses to the experience of spirituality for a group of children who happen to be severely disabled. My thesis is that the spirituality of severely disabled children is silent and silenced because they do not use verbal language. The non-verbal languages they do use are not understood or recognised as a means of conveying their spirituality. Their voice, expressed through "the rich tapestry of their non-verbal communication", is not heard (Kellet, 2009 p.2). Voice, as Mary Kellet proposes, "is the right to express one's views freely, including an entitlement to be listened to" (2009 p.2). Through my research, I propose to show how healthcare professionals working with these children and society more widely, need to hear these children's spiritual voices. As I will demonstrate, these children have something important to say. To hear and listen to these children appreciates who they are, deserving to be heard in the same way that every person does and because they have a prophetic message for all to hear.

The research journey has not only led me to discover new insights into the under-researched area of severely disabled children's spirituality. It has also been a personal spiritual journey. The research process has become, as Slee proposes (2013 p.26), ingrained into my own spiritual practice as I have searched for meaning and understanding in all that I have encountered whilst undertaking this study. I have drawn on my own commitment, as a practising Christian in the Roman Catholic tradition, working as a Practical Theologian. This is the place where I encounter the "infinite mystery of God" (Cameron and Duce, 2013 p.23). Liberation Theology is an important influence in my approach with its emphasis on Gospel ideals of service, paying particular attention to the poor.

The Church, through its social teachings, has always focused on the poor and marginalised. However, the emphasis can appear to be 'top down', the teachings coming from the hierarchy of the institution. Liberation Theology, within the Latin American context out of

which it arose, sought to understand and act on the issues from the 'bottom up', with theology developing out of the context. In previous research,[1] I reflected on my own context, working with disabled children in healthcare in the light of Liberation Theology's understanding of a preferential option for the poor. I realised that for me, the poor are the silenced. I identified that children are silenced, the ones most silenced being the non-verbal and severely disabled children who are totally reliant on others for all their needs. Applying a Liberation Theology stance, this silencing becomes a matter of injustice. Liberation Theology seeks ways of giving voice to the voiceless. I argue it is imperative that these children's voices are heard, listened to and acted upon, for, as Gustav Gutierrez points out, the task of liberation theology is to work towards constructing a society that eliminates poverty and injustice, a society that respects and values those considered to be the weakest and insignificant (Gutierrez, 2007 p.25). However, their voices will only be heard if they are given preference.

In order to be given preference, they need to be paid attention. An underlying approach throughout my research has been Jane Leach's model of theological reflection: "Pastoral Theology as Attention" (2007). Leach's model pays particular attention to 'voice'. Using Leach's model supported me to identify the areas I needed to hear, pay attention and give voice to. Through striving to find the voice of these silenced children, I have been able to articulate something of my own voice.

Within recent Liberation Theology studies, there is a recognition for the need for what Jon Sobrino, Liberation Theologian, has termed "secular inventiveness." (Petrella, 2007 p.168). Sobrino identifies the need to draw on other disciplines, such as the social sciences, to find interconnections and inform theological thinking. I have used "secular inventiveness", drawing on a variety of different disciplines to inform this research. I am also applying a theological lens to the work of a secular organisation which, I propose, can help the organisation to understand spirituality. I acknowledge there are tensions that can cause difficulties for a theological voice to be heard within such a setting. Attention to the sensitivities surrounding the understanding of spirituality and religion within secular settings is required to prevent a silencing. I also propose that the research demonstrates the gifts practical theology can offer a secular setting, as well as the gifts a secular setting can offer practical theology. Having outlined my theological influences on this project, I now turn to the

[1] Dissertation for Certificate in Theology for Ministry awarded by Cambridge University, 2014

context out of which this research arose, which provided the presenting issue for my research questions.

1.1 The Context

My concern for disabled children's spirituality developed through my experience of working in a children's hospice. I worked in the hospice for six years, in the dual role of occupational therapist and chaplain for the first five years, then for concentrating on the chaplaincy role in my last year. I am a state registered Occupational Therapist, holding a professional qualification (Diploma of Occupational Therapy, awarded 1990) and registered with the Health Professions Council, required for the Occupational Therapy role. I have twenty years specialist experience as a Children's Occupational Therapist.

The Chaplaincy role within the hospice had no requirement for formal ministerial or faith-based training or background. Rather, the role, initially named 'the Spiritual Care Advisor', emphasised the spiritual, however that term was understood. The role was to support staff to identify spiritual needs in the children and families being cared for, to create relationships with local faith and life philosophy communities, to signpost individuals to appropriate external services and to be part of the support network for staff. There was a clear distinction between religious and spiritual needs, with the expectation that religious needs would be provided by volunteer faith chaplains. Spiritual care was considered to be part of everyone's role, specialist support for this provided by myself as the Chaplain. My qualifications for the Chaplaincy role came from my personal commitment and previous Theological Study (Certificate in Theology for Ministry, awarded 2014). I was also a member of the Association of Hospice and Palliative Care Chaplains.

It is not easy to convey the essence of working in a children's hospice. The hospice is one of three, providing palliative care to children within East Anglia. It is open all year round, supporting families and children with life limiting and life-threatening conditions. The children receive palliative care, meaning there is no cure for their complex conditions. All the children receive appropriate treatment and interventions to support them to live as fully as possible. This means, in contrast to adult hospices, many of the children and families are known to the hospice staff for several years. Children could be referred from birth and are eligible to receive hospice support until they are eighteen years old. Short breaks are offered to the children and families. The children, and sometimes their families, could stay at the hospice, enjoying all the facilities, with clinical care provided by the Care team. Other support includes physiotherapy, occupational therapy, Arts therapies, counselling and bereavement support, specialist symptom management advice and limited internal chaplaincy support. It

is important to appreciate that the hospice is a secular organisation, with no affiliation to a specific faith tradition or life philosophy.

Unlike adult hospices, death does not occur on a daily or weekly basis as the majority of the children are not in an 'end of life' phase, nor likely to die within a very short space of time. Recent medical developments mean that some children, although their underlying condition is untreatable and life limiting, are likely to live into early adulthood. The hospice supports 12 – 14 families a year through the end of life journey for their child, either in the child's home or at the hospice.

1.2 The Children

First and foremost, the children in the study were children. Therefore, it would appear to be appropriate to describe them as "children with disabilities" or "children with profound and multiple learning disabilities", emphasising that they are children first. However, I acknowledge the sensitivities present within contemporary disabilities studies concerning the labelling of disabled children. The preferred term is "disabled children". (Mallet and Runswick-Cole, 2014 p.5) The argument, as explained by Karen Wells, (Wells, 2018 p.98) is that "person first terminology [i.e. child with disability] implies that [the condition] is an appendage to the person…" Throughout the thesis I have tried to adhere to this preference, except when clarity or the need to emphasise the importance of the children as children has dictated otherwise.

Within healthcare and educational contexts, it is customary to describe the study cohort as profound and multiply learning disabled. (PMLD.) This is a category within the Special Educational Needs and Disability (SEND) criteria, used to describe children who are non-verbal, with severe physical disabilities requiring the use of a wheelchair, who have sensory impairments and complex medical conditions (Department of Education, 2015). Their complex learning needs mean that the children do not read, write, draw or use mathematical skills. Their comprehension is limited, their physical disabilities affect their co-ordination skills. These children require a very high level of support for all their personal care, medical, play, communication and learning needs and are very unlikely to achieve standard developmental milestones. They are the children who have "limited or no autonomy, power, freedom or choice, and as such are essentially both vulnerable and dependant" (Swinton, 2016 p.89). Other terms used to describe this group are "profoundly learning disabled" (PLD) or "profound intellectual disabilities" (PID).

Throughout the thesis I refer to the study cohort as PMLD or as being non-verbal and severely disabled. It is important to note that the children were not diagnosed as autistic.

This is a differentiated category within SEND criteria and not applicable to the study cohort. It is also important to note that although all the children involved in the research had a life-limiting/life threatening diagnosis, none of them were in an end of life phase.

1.3 The Research Questions

Leach, (2007), proposes that the starting point for her theological reflection model is a pastoral situation that raises questions. My starting point of reflection, culminating in my research questions, arose from a conversation at the hospice concerning the difficulties of recognising and recording children's spirituality. The chaplaincy team, of which I was a member, proposed a way of talking about spirituality using coloured beads to represent different spiritual aspects. We proposed inviting the children to create a bead bracelet to show aspects of their spirituality. One nurse summed up the position succinctly: 'that is all very well, but most of the children don't talk, how relevant is this to them?' This became a question that haunted me. There needed to be a way of hearing the voice of the non-verbal children. It was also evident the care staff were unsure and unclear about discussing spirituality with the children, and unclear about processing insights they received.

I chose to explore these issues through qualitative research, acknowledging the subjectivity of this approach, looking for meaning in people's experiences, which is difficult to quantify. As it is subjective, exploration and description are required to interpret different situations. As John Mcleod states: "Qualitative research is concerned with describing, uncovering, understanding and explaining processes through which meaning is co-constructed in relationships and purposeful activity between people" (2011 p.47). I frame this theologically, by way of Swinton and Mowat's understanding of the qualitative research task: "to describe reality in ways which enable us to understand the world differently and in understanding differently begin to act differently." (Swinton and Mowatt, 2016 p.45) I identified that there was a need to understand spirituality differently so that a different and more meaningful approach towards spirituality could be embedded within the care team. I crystallised these reflections and concerns into the following research questions:

- What is it that enables severely disabled children's spirituality to be heard and recognised?
- What enables those practicing in a healthcare context to recognise spirituality and so respond to it meaningfully?

1.4 Outline of Chapters

I will now outline the research journey for this project which begins with a literature review. This highlights the limited amount of research regarding the spirituality of severely disabled children, which, in comparison to the literature available on spirituality in general, equates to a grain of sand. Chapters Two, Three and Four explore the contextual layers surrounding the children, revealing the confused and diverse understandings about spirituality within healthcare and wider society. This confusion I suggest, contributes to silencing the children's spiritual voices. My aim, by exploring spirituality in these wider contexts, is to pay attention to the current reality and to gain an understanding of how spirituality is perceived. Through attention to the issues involved, I consider how spirituality could be understood differently to enable the children's voices to be heard.

Chapter Two is an exploration of how religion and spirituality is seen within wider society. By this I mean the society that surrounds the children and their families, and the staff working at the hospice. This wider context influences and informs people's understanding of religion and spirituality. I explore what I name the complex landscape in the literature, where there are continuing efforts to define both concepts. I discuss how society has moved from the position of religion and spirituality being seen as coterminous to one where for some, it is binary and for others there is an appreciation of the inter-connectedness of the two concepts. In response, I argue for the need of a multi-dimensional, pluralistic religious/spirituality framework which uses description rather than definition. I will propose an adaptation of Sahaya Selvam's matrix which accommodates the complexities of religion and spirituality within a contemporary post-secular societal context. Without such a tool, the complex landscape and the ongoing search to understand religion and spirituality through definition contributes to the silencing of these children.

In Chapter Three I review the literature concerning the understanding of religion and spirituality within healthcare. This is important as health issues dominate the lives of the children in the study cohort due to their complex disabilities. I identify the dominance of nomothetic language and knowledge within healthcare which, I propose, has a major influencing factor on how religion and spirituality are understood within healthcare contexts. I explore how religion and spirituality is understood within the nursing profession as this is the largest work force within healthcare and within the hospice. I also explore how religion and spirituality is perceived within my own professions of Occupational Therapy and Chaplaincy. Within healthcare contexts, the emphasis is on defining spirituality, devising

assessment tools for spiritual care and on competency training to enable staff to deliver spiritual care. I conclude that trying to define and assess spirituality is an impossible task. Instead I propose that all staff can be supported to become 'story hearers', working with ideographic language and knowledge. I conclude this chapter with a description, which can be expanded and diversified, rather than a rigid definition, of spirituality. I propose this description to be a more appropriate way to recognise spirituality in a healthcare context. However, the voice of severely disabled children remains silent within the healthcare literature.

Chapter Four brings the focus onto Children's Spirituality. However, there is minimal qualitative published research concerning the spirituality of severely disabled children meaning that their voice is barely heard within the literature. I begin by considering a theological view of Children's Spirituality by exploring a relational understanding of *imago Dei*. I propose this can inform and support an understanding of spirituality within children. I draw on educational and social science research as well as theological studies to support this exploration. I highlight the significance of play, of non-verbal language and of silence as key features of all children's expression of spirituality. I conclude this chapter with a detailed description of what I consider to be children's spirituality which, I propose, is based on relationality.

Chapter Five details my methodology, which centres on attention and contemplation as the overarching influences for this research. Attention is needed to hear the silent spirituality of these children which I propose is expressed through their play, their silences, their relationships and their non-verbal language. Contemplation is needed to ponder, reflect and to be reflexive, to begin to understand what is being revealed as spirituality by these children.

The ontological position (my understanding of the nature of the social world) that I have adopted is interpretive and critical. It is an interpretive position, as I see the social world "constantly being constructed through group interactions" (Hesse-Biber, 2017 p.6). This means that social reality is a dynamic process. It changes and shifts the understanding of truths as groups work together to find meaning. As illustrated in the first three chapters of this thesis, there is continual interpretive work within academia, aiming to understand the nature of religion and spirituality and what that means for the social world. However, I adopt a critical position as I identify that this group of children's voices are not significantly valued or included within the search for meaning about religion and spirituality. A critical position is

consistent with a liberation theology approach critiquing society and society's attitude to excluded groups.

I detail the ethical issues involved, the ethical procedures followed and the methods of data collection and analysis. My data analysis has used adaptations of both Thematic and Content Analysis, combined with contemplative reflection of the data and my own research journal. I explain the process used for the data analysis, the results of which are offered in the following three chapters.

In Chapter Six I give a portrait for each child, followed by what I have come to understand to be their unique spiritual signature, developed through the semantic analysis of the data. These portraits and spiritual signatures have been shared with the parents of each child, and the feedback received indicates that the parents agree with and value these reflections.

Chapter Seven takes the data analysis a step further, looking at the latent information resulting from a detailed examination of the data, searching for common findings from the encounters with the children. This brings the data analysis into conversation with the literature explored in Chapters Two, Three and Four. There are eight findings from this analysis, the most important one concerning the significance of the presence of the children's primary carer to enable the children to form relationships with others. It emerges that recognising how these children play and use silence are also significant in understanding their spirituality. I explore an appreciation of what their relationship with God could be. This chapter is aimed at answering my first research question.

Chapter Eight explores how these findings can be transferred into the wider context of healthcare settings, in particular that of a children's hospice. This works towards answering my second research question. This chapter has recommendations for practice that could support all staff to engage with spirituality and providing spiritual care. I identify three proposals that I propose could enable spirituality to be recognised and responded to meaningfully, with essential support from chaplaincy, within a healthcare setting. These proposals are a relational understanding of 'person'; an appreciation of the prophetic nature of the children, chaplaincy and the potential prophetic nature of healthcare settings; and a deeper understanding of hospitality.

In my concluding chapter, I summarise the whole thesis research, identifying contributions to new knowledge about severely disabled children's spirituality, acknowledging the limitations of my own research and identifying areas for further research.

I am aware that I am able bodied, verbal and educated to postgraduate level, diametrically opposed to the children involved in this research. I am also aware that it is essential that I attempt to present these children's realities from their perspective as truthfully as possible. It would not be right or ethical to cause harm by committing, as Courtney Goto names, "epistemic violence…the harm done to an individual when her understanding of her reality is ignored, obscured and over ridden by another person (or persons) who in words and actions redefine(s) that reality." (2018 p.179) I acknowledge the challenge this presents, working with a group of children who do not understand their reality through verbal language. They come to know their reality through experience, expressed non-verbally. I have, as honestly as possible, worked to understand these children's reality to enable their spirituality to be acknowledged, become clear and not overridden by my words or actions. In turn, I hope that this research enables others to recognise the depth of severely disabled children's spirituality, and in the recognition of it, be able to respond meaningfully, so that the spirituality these children are shouting out is heard.

Chapter 2 Exploring the Wider Context for this Research

2.1 Introduction

The purpose of this chapter is to explore the understanding of religion and spirituality within the wider context. This exploration is important as it is about the wider world which surrounds the children. Their families, the healthcare staff and volunteers come from this context which, I suggest, influences their understanding of religion and spirituality. Appreciating the background influences contributes to identifying the difficulties of recognising and responding meaningfully to spirituality in severely disabled children.

I begin by reviewing the current position within Britain, drawing on multi-disciplinary resources. I review some of the issues caused by this position and the impact this has on how people identify themselves in terms of religion and spirituality. I discuss the shift in society identified by Charles Taylor, whereby five hundred years ago it was ‘‘impossible not to believe in God,” (2007 p.15) to the situation where society is a mixture of belief and unbelief in the Christian God, or God as seen in other faiths or other life philosophies. I consider, in a limited way, how this position arose and how it is continuing to unfold. I propose that instead of multiple definitions of religion and spirituality, a multi-dimensional descriptive matrix is a more useful and inclusive way to understand these concepts.

2.2 The religious and spiritual world the children live in

It could be said my own position, of a practising Christian whose own religious beliefs inform my spiritual life, is a counter-cultural one. It is now common parlance to hear people describe themselves as ‘spiritual but not religious.’ Courtney Bender’s research (2010) shows how this phrase has become an identifier for people who no longer wish to affiliate themselves with formal religion. Taylor’s seminal work, *A Secular Age* (2007) explores this situation in depth. He reflects on what has happened during the last five hundred years resulting in a “titanic change in our Western society” (Taylor, 2007 p.12), whereby belief in God is no longer the default position. Taylor’s analysis of current patterns of belief is borne out by The Commission on Religion and Belief in British Public Life’s 2015 report *Living with Difference*. The report describes the current position regarding religion and spirituality in Britain as a “changing landscape” (The Commission on Religion and Belief in British Public Life, 2015 p.6). In my own view, that phrase is an understatement, it is not only changing, but has dramatically shifted, and there is now a complex landscape through which to navigate. Statistics, available from the Annual Population Surveys (APS) give an indication of how this landscape is changing. (Office for National Statistics, 2016)

Table 1 Figures extrapolated from the APS surveys

APS survey	No religion	Christian	Muslim	Other religions
2011	28%	62.4%	4.6%	5%
2015	33%	56%	5%	6%

These figures suggest that there are an increasing number of people who identify as having no religion and that there is an overall decline in Christian affiliation, belief and practice. The figures also indicate that there is a steady increase in non-Christian faith traditions, which the 2015 figures suggest totals 11% of the UK population. However, these statistics do not give any indication of those who would identify as 'spiritual but not religious.'

The Commission (2015 p.16) investigated the way people identified and described their beliefs and values in terms of religion and spirituality by using evidence from a 2013 YouGov Survey conducted for the Westminster Faith Debates (WFD). The results are shown in Table 2.

Table 2 Results of WFD Survey 2013

WFD 2013	Spiritual	Spiritual and religious	Religious	Neither spiritual nor religious
	15%	10%	8%	48%

The figures from Tables 1 and 2 support my view that it is a complex and changing landscape. It is evident that the terms religion and spirituality have a multitude of meanings, making it difficult to compare like with like, but they support Taylor's view that the default position within western society can no longer assumed to be based on belief in God (Taylor, 2007 p.12). As the title of Taylor's book suggests, he identified the context for western society as secular, seen in declining church attendance and a shift from belief in God as the norm to "one in which faith...is one human possibility among others." (2007 p.2).
The Commission's evidence also highlights that the words 'religion' and 'spirituality' are seen by some to mean two different concepts, by others to be related or the same, and by others to have no meaning at all. The complexity caused by the lack of a universal understanding of the words 'religion' and 'spirituality' is evident. It seems reasonable to suggest that the lack

of a common understanding is connected to societal changes. In the pre-reformation society where “it was impossible not to believe in God” (Taylor, 2007 p.15), the understanding of ‘religion’ and ‘spirituality’ as separate concepts was not necessary. The need for a different understanding developed as western society became increasingly secular.

This view is supported by social science research, such as that carried out by Zinnbauer and his team in the late twentieth century (Zinnbauer, et al., 1997). They suggested that in a fast-changing world, there was a need for a separation of these two concepts. Their research, carried out in the USA, using self-rating questionnaires, investigated the perceived differences between ‘religious/religiousness’ and ‘spirituality’. Their findings showed that religion and spirituality, although considered to be distinct concepts, were seen to be interrelated, with an understanding that religion incorporated a spiritual side. The research highlighted that for the respondents, in both concepts, the term ‘sacred’ was important.

What I perceive from Zinnbauer’s work, is that religion and spirituality have moved from being understood to be coterminous, to a position where religion and spirituality are now seen to be distinct yet inter-related concepts. ‘Religion’, in Zinnbauer’s research, was seen to be concerned with a system of beliefs, within an authoritative hierarchy, using rites and rituals in a communal, institutional setting. From this understanding of religion, it could be assumed that it is possible to be religious without having spirituality.

In contrast, ‘spirituality’ was seen as new age, concerned with the individual and mystical experiences. The respondents stated spirituality was a sense of getting away from past hurts within more formal religious settings (Zinnbauer, et al., 1997 p.561). This implies that it is possible to have spirituality without religion. However, the importance both concepts place on needing the sacred suggest that there is an interrelationship between the two. Zinnbauer acknowledges that for social sciences’ research of religion and spirituality, both concepts need to be understood as broadly as possible. His solution is to call for better definitions for spirituality and religion to help “Unfuzzy the Fuzzy”, the title of his paper (1997 p.563).

Zinnbauer’s work is based in the United States, which colours the understanding of ‘religion’ within that specific context. However, his ideas about ‘religion’ and ‘spirituality’ can be applied to the Commission’s findings. The Commission acknowledges that ‘religion’ is involved in complicated ways with a person’s identity, culture and upbringing. The Commission’s figures indicate that for a significant proportion of the population, religion no

longer has an identified part to play in their formation. 'Religion' has become understood within the narrow construct identified in Zinnbauer's research. This gives further insight into the changing landscape within the United Kingdom.

Whilst acknowledging that the Commission's findings show many people would no longer consider they had a religious affiliation, it is appropriate to explore how the word 'spirituality' has moved from being solely associated with religion to being used in far wider contexts and with a broader range of meanings. Taylor considers that the shift from religion forming the backbone of identity, culture and upbringing has been going on for the past five hundred years, not just the past decades. There are new conditions of religious belief influencing how believers and unbelievers come to understand their experiences, with the possibility of a non-religious understanding of these. This, Taylor proposes, is having a profound effect on society's attitudes. He states: "the coming of modern secularity in my sense has been coterminous with the rise of a society in which for the first time in history, a purely self-sufficient humanism came to be a widely available option" (2007 p.18). I propose that this development of a "purely self-sufficient humanism" is a major factor in the separation out of the two concepts of 'religion' and 'spirituality'.

Religion, as described by Taylor, was historically seen as public and communal. It created a sense of belonging through the collective worship of the whole community (Taylor, 2007 p.514). It also influenced individuals' faith development. The starting point was religion, from which personal spiritual practices developed, such as meditation, pilgrimage, or particular spiritual exercises. This deepened a sense of belonging and belief through a shared communal experience. Spirituality grew from a religious starting point. The assumed position today, as proposed by Taylor, suggests religious belief is no longer the default position, therefore there has to be a presumption of religious unbelief (Taylor, 2007 p.13). However, the goal of human flourishing is still at work, instead of starting from religion, it starts from the individual. The search for flourishing becomes a means of expressing spirituality. It is an inward journey that may lead an individual to religious belief. (Taylor, 2007 p.515). As a result of this position, religion and spirituality continue to be separated out into two distinct concepts. A further shift is also developing in that belief and religion seem to be becoming increasingly the concern of the individual and therefore private.

Taylor's proposal is supported by research conducted in a variety of settings. Gavin da Costa proposes that it is worth investigating universities, suggesting they are "like modern

secular societies in England … [with] a strong commitment to liberal pluralism: cultural, intellectual and religious diversity" (2005 p.3). This is corroborated by Matthew Guest's research, conducted amongst British university students, supporting D'Costa's contention that British universities reflect what is happening within the wider context. Guest's research identified students' approach to Christianity as being "more personal and autonomous, often less visible than conventional church going and more distant from religious institutions and authorities…" (Guest, et al., 2013 p.209).

Guest's research suggests that within Britain, although the formal ties to Christianity may not be strong, there remains a religious influence. Guest's findings echo those of Bender, (2010) who identifies that despite the continuing separation of spirituality and religion into two distinct concepts, spirituality is "deeply entangled in various religious and secular histories, social structures and cultural practices" (Bender, 2010 p.182). Both pieces of research illustrate that although religion and spirituality are seen as separate concepts, they influence each other, as well as cultural practices. The national celebration of Christmas illustrates the cultural influence of religion, for this feast can be celebrated independently of religious belief, although its foundation is religious. The practice of exchanging gifts has a religious origin and can also be seen as an expression of spirituality, which does not rely upon the religious origin. However, is also worth noting that for many, the entangled religious influences are ignored when they identify themselves as 'spiritual but not religious.' Bender also suggests that spirituality is influenced by society placing high importance on the individual, valuing individual's experiences, so that spirituality becomes an individualistic rather than a communal shared experience and concern.

The statement: 'I am spiritual but not religious' is important to understand as it is a phrase I regularly encountered amongst staff and families associated with the hospice. I noticed there was often a sense of apology as people were concerned they no longer identified with a religious affiliation. It seemed to stem from their past stories as disclosures were frequently made to the effect 'I was brought up a Christian and attended Church, but I no longer hold with any of that...' This anecdotal evidence is in line with Zinnbauer's findings that spirituality was connected with a need to get away from hurtful encounters with formal religion (1997 p.561) and reflects the entanglement Bender describes between religion and spirituality. However, the frequent identification of people as 'spiritual but not religious' is an indicator that 'spirituality' and 'religion' were understood to be two separate concepts amongst the population served by the children's hospice. Moreover, there appeared to be a

polarization between the two concepts. It is necessary to investigate the possible reasons for a separated understanding of religion and spirituality to provide further background for my research. It is this that I will explore in the next section.

2.3 'Religion' and 'spirituality' as separate concepts

Although Taylor identifies the separation between religion and spirituality beginning over five hundred years, he sees the 1960s as a particular hinge point whereby it became possible to discuss spirituality separately from religion. (Taylor, 2007 p.473.) His view is supported by theologians such as Diarmund O Murchú and Philip Sheldrake. O Murchú, in his article "Spirituality, daring new horizons" (2015), identifies spirituality emerged as an area of study in its own right from the 1960s onwards. He proposes from this point there was a counter-cultural 'upsurge' that challenged and rebelled against formal religion, which was seen as legalistic and staid. Alternative values based on experience rather than formal teaching, began to be explored, along with an increasing awareness of the sacredness of nature, reflected in contemporary environmental movements.

The movement away from formal religion has been termed the 'subjective turn' to spirituality by Paul Heelas and Linda Woodhead. Their ethnographic research of a small town in the north of England, concluded that within that setting, there was a distinct turn from life lived by rules, duties and roles of the local religious settings to life being lived subjectively from personal experiences. Individual authority was valued rather than the authority of the religious institutions (Heelas and Woodhead, 2005 p.2). Sheldrake provides an explanation for the 'subjective turn' (2014 p.7), identifying that from the 1960s onwards increasing globalisation and migration occurred, bringing influences from other cultures into the country. Heelas and Woodhead noted the increased availability of yoga classes and of Buddhist meditation lessons became increasingly popular as church attendance declined (Heelas and Woodhead, 2005 p.173). The same trend is noted by Bender in her findings (2010).

O Murchú describes this movement as spirituality breaking free from the confines of religion (2012 p.554). As part of breaking free, spirituality began to be explored in different ways by a variety of people, discussed and studied away from Christian theological circles. An example of spirituality breaking free from formal religious settings is that of Alistair Hardy, a zoologist. His research proposed that humans developed the capacity for belief as part of the evolutionary process. (Hardy, 1966; Hardy, 1979; Hardy, 1984) He claimed that: "Spirituality is an innate survival mechanism, universally found in humanity" (1979 p.2). It needs to be acknowledged that Hardy wrote as a scientist with a declared Christian faith. He also used

the word ‘religion’ very broadly, interchangeably with ‘spirituality’. Hardy used language more associated with a contemporary understanding of spirituality, for example: “Religion is not rational, it is essentially emotional; if it is to be real and to work, it must be as deep and sincere as human love…” (Hardy, 1966 p.175). This description of religion does not fit the narrow definition as understood from Zinnbauer’s research in 1997, where religion is concerned with the institution. Although Hardy’s use of language makes it difficult to compare his work with others, as his distinctions between religion and spirituality are not as definite as others such as Zinnbauer, his work is important for it illustrates how these concepts are being used in different areas of study. Hardy’s approach tries to match up scientific reasoning with a belief system, to prove that spirituality and religion were specifically linked to evolutionary theory. Although the theologian Nicholas Lash criticises Hardy for being too vague and for not substantiating his claims, Lash recognises the importance of bringing evolutionary scientists and theologians into conversation (1988 p.98).

Hardy’s work continues to be cited as evidence for spirituality being part of human nature in other spirituality studies. David Hay continued and developed Hardy’s research work, conducting a longitudinal study, between 1987 and 2000, surveying people’s religious experience. Hay’s results showed that although there was a significant decrease in attendance at places of worship, there was a significant increase in belief in a spiritual reality which was not connected to religious practice (Hay and Hunt, 2000). Hay’s findings substantiate the movement of spirituality out of religious settings, and support Hardy’s contention that spirituality is innate in everyone. Within research referenced to support educational approaches, (e.g. Hay, 1994; Hay and Nye, 2006; Adams, Hyde and Woolley, 2008; Watson, 2017) Hardy’s position regarding innate spirituality underpins the discussion on children’s spirituality, which I explore in more detail in Chapter Four.

Zinnbauer and Pargament, from a psychological viewpoint, adopt Hardy’s position in their later work. Their joint chapter on Religiousness and Spirituality, in *The Handbook of the Psychology of Religion and Spirituality*, opens with the statement: “Religiousness and spirituality have been a part of human experience throughout the length and breadth of human history” (Zinnbaur and Pargament, 2005 p.21). Whilst I agree with their statement, I note that they do not attempt to substantiate it. It is presented as an accepted truth. Hans Joas makes the same assumption: “human beings are anthropologically primed for religion” (2014 p.2). This adds to Lash’s concern about the vagueness of these statements, but also illustrates that there is debate regarding the innateness of spirituality as different disciplines

work towards a shared understanding. Hardy, Zinnbauer, Pargament and Joas' assumptions are one way of thinking about spirituality and religion but are difficult to prove scientifically.

Whilst these assumptions can be taken as true, they illustrate the continuing difficulty of understanding what is meant by the words: 'religion' and 'spirituality'. Joas' assumption seems to suggest a wider understanding of religion that includes spirituality, whereas Zinnbauer and Pargament are assuming that there are two different concepts that may overlap. Within academic disciplines, (e.g. Zinnbauer, et al., 1997; Bregman, 2014; Watson, 2017) there is a continual call for the need to distinguish between religion and spirituality and to be able to define both concepts, the recommendation made by Zinnbauer at the end of his paper.

O Murchú proposes that "religion tends to be defined in terms of creed, ritual and moral code" (2012 p.554). This concurs with Zinnbauer's definition (1997). These definitions are consistent with a narrow understanding of religion, focusing on authority, doctrine and behaviours. Religion, within this understanding is limited to 'doing.' The definitions for spirituality, developed since the 1960s, as the two concepts became separated, tend to focus on the individual, experience and a way of being. As O Murchú proposes "Spirituality heavily emphasizes a more authentic quality of relating among diverse peoples, cultures and aspects of the created universe" (2012 p.554).

Spirituality, as a concept is now present in multiple aspects of human experience, making it, as Sheldrake suggests, "a concept that defines our era" (2016 p.16). As well as the subjective turn identified by Heelas and Woodhead, I propose that there is an organisational trend at work resulting from the adoption of spirituality by a broad range of organisations, claiming spirituality as part of their business practices. I suggest this trend is a driver for the continual search for a definition of spirituality as organisations appear to favour definitions which can assist in explaining their purpose.

The search to define spirituality has been investigated in detail by Lucy Bregman in *The Ecology of Spirituality* (2014). In a wide-ranging review, considering the use of the word 'spirituality' in a variety of settings such as healthcare, leisure, business and education, she concludes that 'spirituality' is impossible to define. Bregman references Unruh, Versnel and Kerr's research paper (2002) which concluded that there were at least ninety-three definitions of spirituality. This paper, written by a group of Canadian Occupational

Therapists, challenged their professional body's decision to state that 'spirituality' was at the core of Occupational Therapy. They pointed out, for Occupational Therapists, 'occupation' is at the core of their practice. Spirituality may well need to be considered within occupation, but it is not what defines occupational therapists. Occupational Therapy focuses on enabling people to function within their environment to the best of their ability. As an occupational therapist myself, I support this challenge, instead proposing spirituality may well be significant to enable people to function within their environment.

Bregman uses this example to highlight not only the confusion involved in trying to define spirituality, but also to point out how spirituality is being used in far wider contexts, not necessarily appropriately. She proposes that this is due to the attempts professional bodies and individuals are making to search for meaning, their "sense of yearning for wholeness" (Bregman, 2014 p.2). Interestingly, Bregman dates the phenomenon of the increasing use of spirituality in wider contexts from the mid-1980s onwards, later than O Murchú's suggestion. I think her dating is particularly significant in the healthcare context, a point I explore further in Chapter Three.

I propose that this "yearning for wholeness" identified by Bregman correlates with Taylor's understanding of how humans are orientated to a "place of fullness". Taylor describes this place as one where "life is fuller, richer, deeper, more worthwhile, more admirable, more what it should be" (2007 p.5). While Taylor's statement does define spirituality, it does suggest a description of the purpose of spirituality, as a quest or search for that place of fullness, where humans can flourish. Taylor points out for those with religious beliefs the search for fullness will concentrate on finding fullness in God, whilst for those without religious belief the search is within themselves (2007 p.7).

Sheldrake adds a further dimension to spirituality, acknowledging its relationship to different belief systems that could be religious, philosophical or ethical. He points out that spirituality is: "primarily concerned with how to live our lives meaningfully, reflectively and usefully" (2014 p.55). A consistent theme is beginning to emerge through the literature, which, as well as describing spirituality as living meaningfully, acknowledges that it is about living in relationship with others, incorporating a sense of the sacred and acknowledging the importance of experience (Zinnbauer, et al., 1997; Pargament, 1999; Sheldrake, 2007). I connect Sheldrake's theological insights with those of psychologist Robert Emmons. His contributing chapter to Mikhail Csikszentmihayli's book, *A Life Worth Living*

(Csikszentmihalyi, 2006) is titled “Spirituality: Recent Progress” (2006). Similarly to Hardy, Emmons recognises spirituality as a general trait seen in all humans, suggesting it is the motivating force giving people their goals in life. Furthermore, he suggests that spirituality is seen in emotional responses such as “wonder, awe, gratitude, humility, love and hope” (2006 p.124).

There are several factors of interest here. The inclusion of a chapter on spirituality in a book principally concerned with wellbeing, illustrates the continuing movement of spirituality out of theological fields and into increasingly secular settings. It also shows that spirituality is seen as a fundamental part of wellbeing. The language Emmons uses to describe evidence of spirituality is reminiscent of the biblical language used by St Paul to name the fruits of the Holy Spirit: *“*love, joy, peace, patience, kindness, generosity, faithfulness, gentleness and self-control.” *(*Galatians 5.22. NRSV) There is a suggestion here, I would argue, that spirituality needs to draw on religious language in order to articulate what it means to be spiritual. It is evidencing the religious heritage as the source of thinking and describing spirituality within a Western context. This is why, as Sheldrake and Taylor, amongst others, argue Christian religious traditions are part of our Western history and culture and therefore cannot be totally ignored (Sheldrake, 2007 p.7; Taylor, 2007 p.515). They are part of our common heritage or as Bender describes it, the entanglement of religious and secular histories (2010, p.182).

Emmons also acknowledges the difficulty of defining spirituality. As with O Murchú and Sheldrake, Emmons describes religion as “belief systems, full of doctrines, practices, rituals and symbols” (2006 p.136). In contrast, he proposes spirituality is taken to mean: “something spontaneous, informal, creative, universal; it means authentic inner experiences and freedom of individual expression, of seeking, even of religious experimenting” (2006 p.126). Interestingly, although Emmons sees spirituality as separate from religion, he is acknowledging the part religion may play within spirituality. Emmons proposes that the majority of contemporary meanings for spirituality distinguish between religious, natural and humanistic spirituality (Emmons, 2006). Sheldrake proposes three slightly different distinguishing approaches – classic, esoteric and non-religious/secular (Sheldrake, 2014 p.12). Both academics are trying to categorise and organise spirituality, one from a psychological point of view, the other from a theological view. By doing this I suggest that both are trying to find a way of understanding the motivating spirit that drives us to reach out for the other, for that which is beyond ourselves.

One way of recognising that need to reach out for the other can be found by applying the further four broad types of spirituality proposed by Sheldrake, which work in conjunction with his three broad approaches. He suggests spirituality can be seen as either ascetical, mystical, practical or prophetic. He proposes the ascetical focuses on self-denial and rejection of materialism, mystical focuses on a way of knowing that "transcends purely rational analysis" (2014, p.14). Practical spirituality focuses on finding "God or the Absolute in everyday existence" (2014 p.14) and prophetic spirituality incorporates social justice issues into the spiritual quest. These are part of an interpretive framework explaining what it is to be spiritual, whether as an individual or as an organisation. The language of Sheldrake's framework, using approaches and broad types of spirituality, may be more appropriate for academic study. However, his framework is helpful, as it contextualises spirituality within the search for meaning arising from experience, recognising that experiences can be negative as well as positive. There is a concern, as Taylor identifies, that spirituality can concentrate solely on positive feelings and making things better. Taylor names this as "the therapeutic turn" (2007 p.618) where spirituality can become misused within wellbeing and therapy situations. This trend is echoed in Bender's (2010) research and elsewhere, such as that of Christopher Turner. Turner, working as a chaplain to asylum seekers, considers spirituality to be about enabling people to find their own spiritual meaning from within the experience, it is not about healing or transforming a situation – to do so is to "fill the space with a therapist." (Turner, 2017 p.346)

I support this concern; viewing spirituality in therapeutic terms with the focus on positivity, not only adds to the polarisation of spirituality and religion, it also makes it difficult to find meaning in negative experiences. My experience of working in a Children's Hospice regularly challenged a view of spirituality that solely focused on positive emotions. Spirituality, in order to enable life to have meaning, needs to be able to hold and integrate the negative and positive experiences. This, I suggest, is needed to find what Taylor refers to as 'fullness". As well as Emmon's list of awe, wonder, and so on, how people make sense of the death of a child, the challenges of caring for and living with severely disabled children with complex medical conditions also need to be part of spirituality. This adds to the continuing difficulty of trying to define 'spirituality' to ensure it reflects the reality of people's lives.

I propose that one of the issues with the continual striving to define 'spirituality' (and 'religion') is the risk that the words become meaningless. Peter la Cour's Danish study concluded that "a common understanding of the term spirituality does not exist, at least in a modern secular setting" (la Cour, Ausker and Hvidt, 2012 p.63). He recommends that the word 'spirituality' is always used with an expanded phrase to denote the context or area of research. For example: '"spirituality, meant as an inner striving", "spirituality, understood as lived belief", "spirituality, understood as contacting invisible worlds and energies".' (2012 p.78) As with Sheldrake's framework, describing spirituality this way may be appropriate within academic circles. However, this language is not how people communicate ordinarily.

La Cour does, however, make the point that future research into spirituality may need it to be understood "as a context bound experience of relatedness to a vertical transcendent reality" (2012 p.80). La Cour understands 'vertical transcendence' to mean the "possibility of another reality than that already known" (2012 p.80). I understand this to mean spirituality is connected to an outward movement to something other than oneself. Within a religious understanding of spirituality this would be a connection to God. Within a secular understanding, this could be understood as a connection to something outside oneself, such as a connection with nature. I consider that there is more than the one dimension to spirituality that la Cour suggests, and I propose this is hinted at in his suggested way of understanding spirituality. Looking at the *context* of an experience suggests another dimension, the inward dimension and the effect of that experience upon the individual. Looking at the *relationships* within that experience suggests a horizontal dimension. It suggests that people's relationships, with themselves, with others and to the experience is also part of spirituality, therefore, spirituality needs to be understood multi-dimensionally. La Cour's work considering what spirituality might mean within a secular context provides an important descriptor relevant for this project, that of 'relationship', highlighting that within a description of spirituality, the context of an experience is relevant and needs to be considered.

2.4 The continuing attempts to define spirituality

La Cour's research supports my proposal that the ongoing attempt to define and categorise spirituality continues to complicate the situation and does not 'unfuzzy the fuzzy', to borrow Zinnbauer's phrase. It is argued by social scientists and psychologists, such as Zinnbauer, that definitions are needed in order to be able to study spirituality properly. This illustrates the influence of scientific thinking which uses a positivist approach, counting, ordering, categorising and defining the objects of research. However, despite the best efforts over

the last fifty years or so, it is now recognised that “a single, generic, comprehensive definition of ‘spirituality’ is impossible precisely because it has such diverse expressions” (Sheldrake, 2016 p.20). Defining religion is also problematic. Taylor summarises the problem thus: “What is religion…this famously defies definitions, largely because the phenomena we are tempted to call religious are so tremendously varied in human life” (2007 p.15).

Kenneth Pargament (1999 p.9) points out that there is a serious risk that all religion is seen as negative and all spirituality seen as positive. Not only can this cause issues when spirituality is linked with wellbeing as discussed above (2.3), it also creates a polarization. This can be further extrapolated into a polarization between the institution and the individual, between regulation and authority, and free choice. This becomes dualistic and a potentially rigid framework. It is this binary that has become part of the perceived culture of western society and researched as such (e.g. Carrette and King, 2005; Heelas and Woodhead, 2005; Walach, 2017). Martin Marty describes previous debates as revolving “around binary categories: societies were *either* secular or religious; worldly *or* other worldly;…favouring immanence *or* transcendence…”(2003 p.42).

Ongoing research has found that the experience of many people is far more complex than a simple binary option of being one thing or another. Nor has ongoing research been able to support the proposal that religion would cease to exist. Jűrgen Habermas calls the time that we live in now “post-secular” (2006 p.4). He understands the need for the complex interplay between religion, secular thinking and spiritualties, “to conserve all cultural sources that nurture citizens’ solidarity and their normative awareness” (2010 p.111). Religious and secular communities need to learn from each other. This is not necessarily straightforward. As Jacqueline Watson, writing from a secularist viewpoint, concerning the need for interdisciplinary approaches to children’s spirituality states: “we are faced with a more complex, post-secular, spiritual landscape than even Habermas envisioned” (2017 p.7). It is interesting to note that Watson, whilst acknowledging the complex reality in which we now live, still continues to advocate for a definition of spirituality to enable a shared understanding. Watson does not provide a definition, instead suggesting key elements that such a definition would need to contain. Watson’s four elements are: a broad, inclusive account of spirituality; a recognition of human rights and voice; a positive challenge to consumerism, marketization and performativity; and spiritual practices to be valued and taught (Watson, 2017). This supports la Cour’s suggestion that the word ‘spirituality’ needs

to be used with a phrase that explains its context. However, it also illustrates the continued difficulty with defining spirituality. I propose that the search for a definition is self-defeating. Instead a different way of thinking is needed to enable a shared understanding of what is meant by these words.

Within the complex landscape of Britain, reflected in the microcosm of the hospice, there needs to be a way of recognising the situation where belief is one option among many and where spirituality can be seen as "native to everyone" (Sheldrake, 2016 p.17). There also needs to be a way that is non-judgemental, providing "individuals with the freedom to decide in favour of the secular option or the option of faith" (Joas, 2014 p.7). There is a need for a framework that allows for inclusive plurality. This is the issue to which I now turn.

2.5 Creating a multi-dimensional, pluralistic, inclusive framework

In a joint chapter in their later work, Zinnbauer and Pargament tackle this issue. They acknowledge that whilst many psychologists have carried out research in this field, there is little consensus about the definitions used for religion and spirituality. They also note that there is increasing crossover between descriptions once used for religion now being used to discuss spirituality. One conclusion that they reach is that wider research is needed, using wider definitions so that how religion works on an individual and how spirituality works within a wider cultural context can be studied. The polarization that Pargament identified in his earlier work (1999) is not only hampering research but is not reflective of the real world that people live in. Both Zinnbauer and Pargament acknowledge that religion and spirituality evolve over a lifetime and therefore "multidimensional, multilevel, complex constructs" which will "change and develop over time" are needed for the study of religion and spirituality (2005 p.29).

While both of them agree that religion and spirituality need to be considered within the same framework, Zinnbauer sees spirituality as the broader construct, where spirituality is the personal or group search for the sacred, religion being one way in which this can be achieved. Zinnbauer's view is comparable with that of Taylor's third definition of 'secular' where belief is one option among many in the search for meaning (Taylor, 2007 p.15). In contrast, Pargament's view is that religion is the broader construct, being the search for significance in ways related to the sacred. He sees spirituality as being a core function of religious life incorporating the search for the sacred. (Pargament, 1999; Zinnbaur and Pargament, 2005 pp.35-36). Since Pargament's earlier paper, although his view of religion and spirituality has not changed, he now no longer sees the need to separate 'religion' and

‘spirituality’ into differing constructs. I suggest that Zinnbaur and Pargament’s work highlights the complexities involved within research into spirituality and religion, requiring, as they now recommend, a multidimensional approach.

The recommendation for a multidimensional, multilevel complex construct is echoed in James Murphy’s paper ‘Beyond Religion and Spirituality’ (2017). Unlike Zinnbauer and Pargament, he sees religion and spirituality to be part of the same broad category that works towards creating a meaning making system. His particular interest focuses on lived religion, acknowledging that “religion as actually practised, rather than taught by theologians, is usually far more complex” (2017 p.2). He argues for the need for this more complex paradigm to include cultural and “idiosyncratic elements” (2017 p.2). As he states: “meaning systems are idiosyncratic, with individuals drawing on a broad range of experiences and cultural influences. They also go far beyond any explicit belief systems” (2017 p.3). This echoes Habermas’ demand that religious and secular communities need to learn from each other as well as illustrating Bender’s observation concerning the entangled histories of spiritualty and religion.

The way religion and spirituality are researched is also critiqued by other academics. Within the field of sociology of religion, Matthew Wood is calling for more robust research methodologies, that take into account not just what people say they do, but the wider discourse so that “social practice, social interaction and the broader social contexts of people’s lives and biographies” are taken into account (Wood, 2010 p.283). This echoes the Four Voices approach used in Theological Action Research which considers the Espoused voice which looks at what people say they do, the Operant voice which researches what people actually do, and the Normative Voice that considers the guiding traditions that inform the operant and espoused voices. The fourth voice is the Formal as expressed by the academics of the tradition (Cameron, et al., 2010 p.53). Both Woods and Theological Action Research advocate investigating what is real for people. The approach is to go beyond the surface, trying to allow people to express what they actually believe rather than what they think academics or formal voices want to hear.

Nancy Ammerman’s research has used just such an approach as suggested by Woods as she investigated what it meant to be spiritual. Her research, based in the USA, used a variety of methods, including asking people to take photographs of important places, keep an audio or written diary, and be interviewed. She wanted to find out how spirituality was in

used in everyday life. Her findings showed that “the sociological study of religion is not neatly contained in binary categories of organized vs individual, religious vs spiritual, theistic and transcendent vs nontheistic and immanent” (2014 p.276). Ammerman’s research not only supports the need for a multidimensional, multilevel paradigm as proposed by Zinnbauer and Pargament for understanding spirituality. It also shows that doing so can be more challenging and enlightening. Her research also builds on Marty’s earlier work, in which he concluded that a blend of religion and secular is found in the actual experience of how people live. Marty proposes that most academics and researchers have underestimated “the strength and durability of its religious components” (2003 p.45). Marty sums up the situation as the world is “neither exclusively secular nor exclusively religious, but rather a complex combination of both…with religious and secular phenomena occurring at the same time in individuals, groups and in societies around the world” (2003 p.42).

A multidimensional matrix of religion and spirituality that can show the complex interplay between religious and spiritual components has been developed by Sahaya Selvam. It must be noted that he is speaking from an African perspective. He posits that within non-Western societies the distinction between religion and spirituality is not as stark as within Western ones. He points out that within African Traditional Religion the sacred and the profane are combined, it does not make sense to separate them within that context. He proposes a model that can “accommodate a global, multicultural and interreligious approach to the study of religion and spirituality” (Selvam, 2013 p.130).

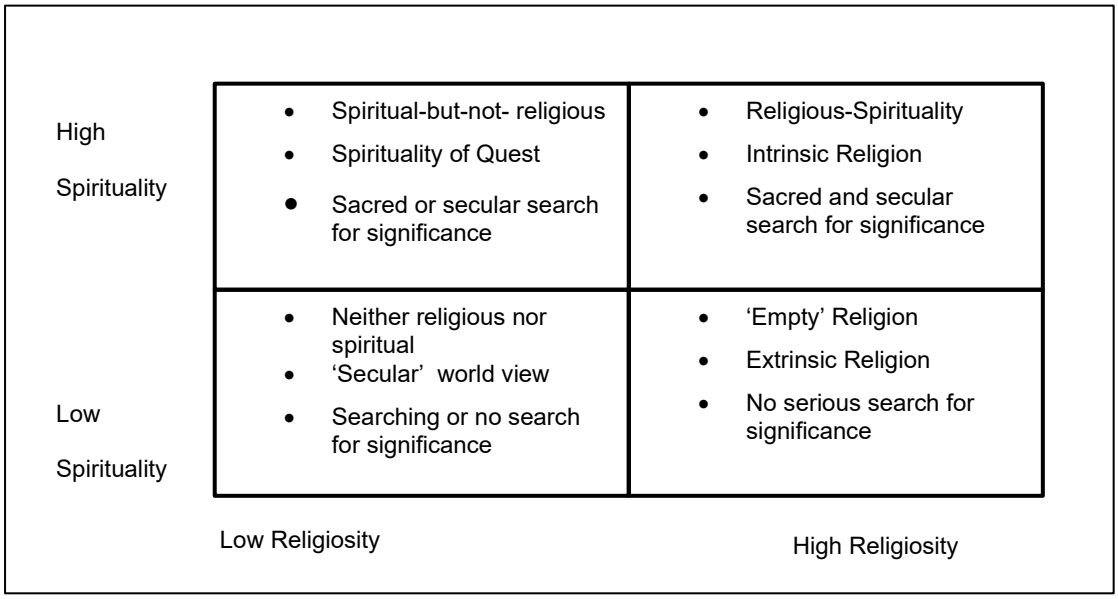


Figure 1 Multi-Dimensional Matrix for Religion and Spirituality (Selvam, 2013 p.138)

Whilst acknowledging Taylor's view that within the West "our societies…will forever remain historically informed by Christianity" (2007 p.514), Selvam's arguments also need to be incorporated to recognise the influence of other faith traditions on contemporary society. The point being everyone, to a greater or lesser extent, is influenced by religion. In the same way, following the arguments developed by Murphy, Sheldrake and Taylor, everyone is engaged in spirituality. This can be seen as combining Murphy's understanding of the need to find meaning making systems with Sheldrake's understanding that spirituality is about living meaningfully.

Selvam's matrix accommodates the blending of complexities that Marty (2003) identified as required. Using spirituality and religiosity as the vertical and horizontal axis on a grid, four quadrants are created. I suggest the descriptors Selvam provides enable everyone to be able to locate themselves within the matrix. It is worth noting that Selvam is using some of the critical descriptors of sacred, inclusive, quest, significance as identified by Zinnbauer, Pargament, Murphy and Watson in their search for definitions for religion and spirituality. There is an interplay between different influences in each quadrant and an acknowledgement of the importance of the secular. This becomes a more useful way of thinking about religion and spirituality and fits with Marty's understanding of the complex relationship between the secular, religion and spirituality. As Joas identifies, secularization needs to be seen in all its diversity, acknowledging its influence on the contemporary world, as well as acknowledging that demographically, the world is becoming more religious. (Joas, 2014 p.3) Selvam's multi-dimensional matrix is a useful and realistic model, illustrating the dynamic relationship between spirituality and religion.

Incorporated into the matrix is Selvam's view of religious-spirituality, whereby three dimensions of spirituality are seen to be at work. These are described as three movements: towards the self, towards the transcendent/sacred and towards others and the world. (Selvam, 2013 p.142). This elaborates and, in my view, gives a more holistic approach to spirituality than that of la Cour who only talks about a vertical transcendent reality. To me, 'movement' in this context implies relationship, a significant element of spirituality.

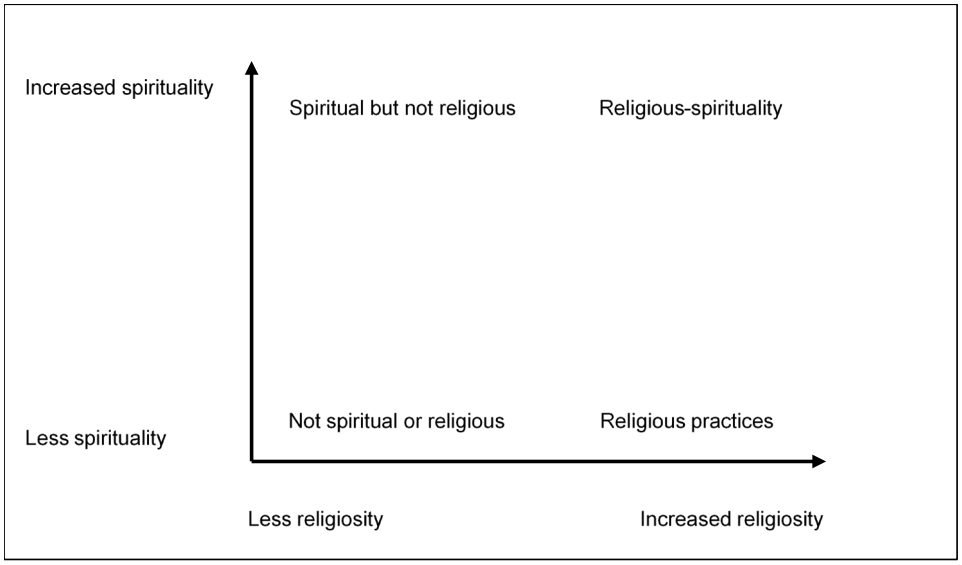
2.5.1 Adapting Selvam's matrix

Selvam's matrix was devised for the academic study of religion and spirituality. It therefore has demarcation lines between the different quadrants. Although it is inclusive, and allows for plurality, it does not appear to be a dynamic model for it seems to imply that the position

within the matrix is fixed. I also note that the words 'low' and 'high' used to denote levels of spirituality or religion could be considered metaphorically and therefore have value judgements attached to them. 'Low' being associated with negative (such as low self-esteem) and 'high' being associated with positive (such as 'held in high regard'). Selvam's division of quadrants may be useful for the study of religion and spirituality as it helps define the way people identify themselves. I question whether it is sensitive enough to capture the movement encountered within people's lives between religious and spiritual experiences. I also consider the use of 'low' and 'high' could be seen as a value judgement.

Selvam is influenced by the work of James Fowler, seeing a connection with Fowler's stages of faith development that happen over a lifetime and Fowler's 'religious –spirituality' category. (Selvam, 2013 p.141). I discuss the issues concerning staged developmental approaches, especially when applied to the children in the study cohort, in Chapter Four. I agree with Fowler's proposal that faith develops over a lifetime as events will affect how people respond to religion and spirituality. (Fowler, 1981) This is seen in healthcare practice, such as a children's hospice, where significant life events happen. I propose that Selvam's (2013) matrix can be adapted to provide an inclusive and equitable tool that will promote an understanding of religion and spirituality allowing for more fluidity, accommodating the movements people may make at different times of their lives.

Figure 2 A dynamic Spirituality/Religion Framework



By removing the demarcation lines, my adaptation of Selvam's matrix allows for movement between the different quadrants. It allows everyone to be identifiable within the matrix and by removing any hierarchy, equality and inclusivity are promoted. The use of the words 'less' and 'increased' are an attempt to find words that are value free but give an indication of where a person might identify themselves. By only using the spiritual/religious labels that Selvam uses, and leaving space around them, I aim to show that there is the possibility of movement around the spaces.

I suggest my adaptation encompasses the three movements of spirituality identified by Selvam. It acknowledges that the degrees of religiosity and spirituality will change as people's experiences and contexts change. By promoting the use of this matrix, it may become possible to move beyond the phrase 'I'm spiritual but not religious' and move towards a shared understanding that everyone is spiritual to a greater or lesser extent and everyone is influenced by religion, to a greater or lesser extent.

2.6 Summary of Chapter Two

The purpose of this chapter was to explore the wider UK context concerning religion and spirituality and how those two concepts are understood within that context. I have reviewed the current situation in Britain and shown that the situation is changing and complex. I have noted that the complexity arises from the movement over the past five hundred years from the assumption that everyone had a belief to the current position where belief is now understood to be one option among many, described by Taylor as 'The Secular Age.' This continues to change and develop, with contemporary western society now being described as "post-secular" (Habermas 2006).

The understanding of 'religion' and 'spirituality' mirrors this movement. When the assumption was that everyone believed in God, religion and spirituality were understood to be the same concept. The cardinal point of the 1960s has been identified as the time when religion and spirituality began to be understood as two separate concepts as the secular age evolved. However, recent work has acknowledged the lived complexity of religion and spirituality in a post-secular context. It is now becoming more readily accepted that religion and spirituality need to be seen within the same framework, demonstrating, I suggest, that society has moved from a binary understanding of religion and spirituality. This is the position that I hold, although to signify the shift in understanding, I will term it 'spirituality and religion.'

It has become evident that there is little benefit to contribute to the ever-growing list of definitions for spirituality and religion. Instead, I have argued that it is far more helpful to consider descriptions that include words such as sacred, quest, searching, relationships and meaning making. In turn these can help identify descriptors or critical elements such as awe, wonder, hope, humility, love that could contribute towards a way of describing how spirituality and religion is expressed. I propose that my development of Selvam's (2013) Multi-Dimensional Matrix for Religion and Spirituality can also be used to enable people to identify their own meaning making system, each person's position will be influenced to a greater or lesser extent by their understanding of spirituality and religion.

This chapter has highlighted the complex issues involved in understanding spirituality and religion within a wider societal context. I suggest the complexities involved contribute to silencing the children; it is noticeable that their voices do not feature in the literature explored so far. The children in the study cohort have serious medical conditions necessitating considerable healthcare support. Therefore, how healthcare understands spirituality and religion needs to be explored, as it is a further influential context surrounding severely disabled children. My adaptation of Selvam's matrix offers a framework that could be used within healthcare settings to discuss spirituality and religion.

Chapter 3 Exploring Spirituality within the Healthcare Context

3.1 Introduction

This chapter explores how religion and spirituality are understood within NHS healthcare, a dominant context surrounding the children in my research. I suggest healthcare settings can be seen as microcosms of the wider context discussed in Chapter Two, mirroring secular movements within society. In a recent paper, Anke Liefbroer, Ruard Ganzevoort and Erick Olsman's research has shown "integrating spiritual care into healthcare in a highly pluralised, spiritually diverse context is challenging" (2019 p.256). I identify that one of the challenges comes from historical religious influences on healthcare. I briefly review these influences, noting the movement from religious foundations to highly technical specialist institutions.

I briefly consider the delivery of spiritual care, looking at the roles of Chaplaincy, Nursing and Occupational Therapy as this is the same as my former work situation. I critique the use of Spiritual Care assessments, proposing there is limited validation for their use. I review how interdisciplinary working has the potential to develop an organisational understanding of spirituality. I discuss how healthcare settings work in a scientific, nomothetic way, where definitions are static statements or boundaried classifications of disease and illness.

For the purpose of this thesis, I am advocating the need to stop defining spirituality and instead use descriptions and descriptors to explore the concept of spirituality. I am viewing 'descriptions' and 'descriptors' very broadly, not only using adjectives, but also including adverbs, nouns and attributes that indicate aspects of life which people understand to be spiritual. This allows for a dynamic and fluid understanding of spirituality, which, I propose, fits within the multi-dimensional pluralistic spirituality/religious framework as outlined in Chapter Two. (2.5.1)

This chapter does not intend to review the theology of healthcare contexts. As a Practical Theologian, I take a pragmatic approach to review the impact the religion and spirituality binary identified in Chapter Two has on healthcare practice. This chapter provides further contextual background for Chapter Four in which I focus on children's spirituality, which will draw on resources from the disciplines discussed in this chapter to inform my theological perspective, that of a Practical Theologian, finding God in everyday experience.

3.2 The religious and spiritual background to healthcare

3.2.1 A brief historical overview

Within general healthcare contexts, the medical professions dominate, with allied healthcare professions such as Occupational Therapy considered as part of multi-disciplinary teams. Chaplaincy services are recognised providers of religious and spiritual care but are not necessarily acknowledged as an integral part of the multidisciplinary team.

Historically, this was not the case. The role of 'healer' and 'carer for the sick' was entwined with religious ritual and ceremony in antiquity. This is illustrated in ancient texts describing Greek and Roman healing temples and evidenced in the early Christian and Islamic healthcare institutions (Risse, 1999 p.58). Early Christianity connected caring for the sick and dying to living out the Christian calling. The model of healthcare such as the Basiliados founded in the late fourth century C.E. by Basil of Caeserea (Watkins, 2012 p.422), was based on ancient Egyptian and Jewish models of social welfare. Spiritual and physical needs were brought together in an organised and institutional way. (Risse, 1999 p.73) This illustrates the significance and influence of religion within the history of healthcare, similar to the influence both religion and spirituality have had on society as discussed in the previous chapter. However, as Risse points out, tensions now arise as hospitals have moved from being houses "of mercy, refuge and dying" in the Byzantium period, to houses of "high technology" in the 21st Century (Risse, 1999 p. 675).

3.2.2 Moving from 'mercy, refuge and dying' to 'high technology' – the professionalisation of healthcare

Being rooted in religious traditions gave a particular nuance to working in healthcare. The work was seen as vocational, a profession to which individuals or organisations were called by God, to carry out the function of nursing the sick. This is evidenced by the work of the monastic orders in medieval times, and with the foundation of religious nursing orders in the eighteenth, nineteenth and twentieth centuries. (Risse, 1999) This could be described as a spirituality of caring, illustrating the development of a spirituality from a religious starting point, as proposed by Taylor (2007, p.514).

The modern hospice movement has its roots in religious foundations. St Joseph's Hospice Hackney, the first dedicated modern hospice, was founded by the Irish Daughters of Charity in 1904. (St Joseph's Hospice, undated website) The experience of working there influenced Dame Cecily Saunders' founding of St Christopher's Hospice in 1967. She established it as

a Christian foundation, with the aim of being open to those of all faiths and none. For Saunders, this was vocational work, a call from God. Saunders' vision was of a community, formed by the staff and patients, where everyone had a contribution to make. The spirituality that underpinned the work was love, shown by the care given, skilful nursing, thoughtfulness, prayer and silence (Bradshaw, 1996). Here too is the pattern of spirituality developing from a religious foundation, a practical spirituality of caring for the sick and dying.

Similarly, the Children's Hospices movement grew from a religious initiative. Helen House, founded in 1982 by Sister Dominica, was the first children's hospice in Britain. (Helen and Douglas House, 2018) My own former workplace, EACH Milton, is one of the older children's hospices in the country. Although not established as a religious foundation, its beginnings were linked to the local church, as the parish had gifted property. From this base, the EACH charity grew, with a remit to provide services to those of all faiths and none.

These examples act as a continual reminder that culturally, informed by Christian traditions, religion had a part to play in healthcare that cannot be denied. Within the original foundations of healthcare, spirituality and religion were inseparable. The move away from hospital care based within religious settings began with Florence Nightingale, the pioneer of modern nursing. Although she saw her work as Christian vocational service, Nightingale saw the need to move nursing "into the ordinary, the world not associated with religion" (Bradshaw, 1994 p.139). However, it is interesting to note that the language used within the nursing hierarchy reflected religious influences. The nurse in charge of a ward was called 'Sister', a term associated with female religious orders. This designation only changed in the mid 1990's when more male nurses entered the profession. Ann Bradshaw, nursing historian, also suggests that up until the mid-1960s, it was commonplace for 'Sister' to lead prayers every morning on her ward (Bradshaw, 1994 p.145).

One consequence of the move away from religious foundations was the increased professionalisation of nursing. Bradshaw suggests that, as nursing became more professional and more scientifically based, causing it to focus on functional output, unconsciously, the sense of vocation began to shift. Bradshaw does not dispute the need for increased professionalisation of nursing. However, she strongly argues that as a result, the sense of vocation and connection to religion and spirituality has been lost, to the detriment of healthcare. She describes this shift as a move from "values inspired by religion towards values inspired by science" (Bradshaw, 1994 p.141). Bradshaw dates this shift from the

1980s. This saw the introduction of training through science-based degrees, emphasizing scientific values and reasoning, for nursing and allied healthcare professions.

Healthcare has become very technical and reliant on nomothetic knowledge. This is factual knowledge, which must be “falsifiable, replicable and generalisable” (Swinton and Mowatt, 2016 p.39). Falsifiable means that, in theory, it is possible to disprove the fact, replicable means that the fact can be reproduced elsewhere, generalisable requires the application of factual knowledge within a wide range of contexts. In other words, healthcare could be said to take a positivist, functional approach to the delivery of care. Assessments and outcome measures are key tools to ensure that factual evidence supports the care delivered. To enable staff to work in this way, the National Health Service in Britain has developed a framework that sets out the knowledge, skills and competencies required for every post. (Agenda for Change Project Team, 2004).

The emphasis on competency training has several merits. It breaks down what is involved for a specific task providing a functional analysis that can be followed and provide a measurable outcome. It provides consistency in training and a benchmark which can be used to measure people’s skill development. However, as Ewan Kelly points out, competency-based training does not necessarily encourage the “professional artistry in healthcare” (Kelly, 2012 p.435). That is, the skill of understanding the interrelationships between different tasks and the subsequent consequences on the spiritual, physical, psychological and social aspects of health.

This raises the question: how does religion and spirituality fit into this professionalised, ‘high tech’ setting? I suggest healthcare contexts maintain the position where religion and spirituality are seen as separate concepts. I propose that Bradshaw’s dating of the 1980s (1994 p.141) provides a worked-out example of Bregman’s (2014 p.10) identification of the point at which there is an increasing separation between ‘religion’ and ‘spirituality’ (2.3). As a result of this separation, religion is rendered as private, although it is acknowledged that individuals will have religious needs and are entitled to ask for those to be met. (Department of Health, 2003 p.8)

Spirituality, on the other hand, is playing an increasingly important part within healthcare and is publicly acknowledged as being important. The ‘holistic approach’, the contemporary term used in healthcare, is understood to mean seeing the patient as a whole, understanding the

interconnections between physical, psychological, social and spiritual needs. (McKenzie, 2002 p.25) Roderick McKenzie proposes that the move to holistic nursing from the scientific model evident in the 1980s is due to a more humanist philosophy being prevalent within today's society and therefore influencing healthcare. (McKenzie, 2002 p.24) This suggests that spirituality and spiritual care can be easily recognised and provided within healthcare.

However, I perceive a tension within the holistic care approach. Physical, social and psychological domains lend themselves to a nomothetic knowledge base. Healthcare professionals working in these domains can evidence success and achievement through goal setting and outcome measures. The work required can be easily identified and ordered into a process driven, task orientated system. This is not so easily done for spirituality, which, as Swinton discusses, works from an ideographic knowledge framework. That is: "meaningful knowledge …discovered in unique, non-replicable experiences." (Swinton, 2014 p.100) Spirituality does not fit into a neatly defined, scientific, positivist epistemology.

Swinton sums up the situation well: "In order to understand spirituality it will be necessary to let go of our positivistic desire for absolute certainty, neat definitions and universally applicable categories, in order that we can enter into an aspect of human experience which, in many respects, transcends final categorization." (2001 p.13) How spirituality is understood and how spiritual care is delivered within general healthcare practice are the areas that I will now explore.

3.3 Delivering spiritual care in healthcare settings

As highlighted in Liefbroer, Ganzevoort and Olsman's research (2019) there are fundamental questions being asked of all involved within healthcare, concerning whose role it is to deliver spiritual care and what are the necessary competencies required in delivery. There is a clear expectation from the Department of Health that a universal service is to be provided: "Meeting the varied spiritual needs of patients, staff and visitors is fundamental to the care the NHS provides." (Department of Health, 2003 p.5) However, how it is to be delivered and by whom continues to be the subject of debate and research. There is also an underlying tension between what can be seen as a functional approach and a faith-based approach focusing on vocation. In this section I will review the challenges and issues raised for chaplaincy, nursing and occupational therapy in providing spiritual care.

3.3.1 Hospital and hospice chaplaincy

Christopher Swift, writing as a hospital chaplain exploring hospital chaplaincy in the Twenty First Century, makes the point that up until the 1960s, there were ordained hospital chaplains. These people were usually appointed by their faith community (Christian and most likely to be Anglican) and paid for by the NHS. Since the 1960s, the term 'chaplaincy' has evolved. This reflects the cardinal point identified by Taylor (2007), Sheldrake (2007) and O Murchú (2015) (2.3), illustrating how the increasing secularization of society is mirrored within healthcare. This has affected the role of the chaplain and the understanding of religion and spirituality within these settings.

The traditional chaplain role was rooted in a religious point of view. However, with the introduction of chaplaincy teams (Department of Health, 2003), reflecting the changing faith affiliations of the populations served by a hospital, the emphasis has changed. Chaplaincy teams are usually made up of a mixture of ordained and lay chaplains, paid and volunteers, representing different faiths, denominations and life philosophies. Their role is described as taking part "in the spiritual and religious care of patients and staff" (Swift, 2014 p.155). With the development of 'chaplaincy', the language has changed to now include 'spirituality' as something separate from 'religion', illustrating the emergent understanding of spirituality as separate from religion.

The distinction between what is considered to be spiritual and religious care is defined in the *Spiritual and Religious Care Capabilities and Competencies for Healthcare Chaplains* (Foggie, Macritchie and Mitchell, 2008 p.3):

- "**spiritual care** is usually given in a one to one relationship, is completely person centered and makes no assumptions about personal conviction or life orientation;
- **religious care** is given in the context of shared religious beliefs, values, liturgies and lifestyle of a faith community."

The way these definitions are presented, I suggest, not only implies that people need either spiritual care or religious care, it also boundaries and limits what is considered to be either spiritual or religious care, ignoring the potential movement between these two concepts. This contrasts with how religion and spirituality are becoming to be understood within the societal context explored in Chapter Two. (2.5) It would appear that healthcare is fixed in the binary of religion or spirituality with the subsequent risk that chaplaincy work could be forced into the same rigid thinking.

This concern is raised by Peter Berger, sociologist and theologian. He points out, “for most religious people in the world the situation is much more complicated: they cope with reality in both secular and religious terms” (2015 p.410). Whilst I concur with Berger’s concern, I do not accept his binary of ‘secular and religious’. I argue it is not as simple as that as demonstrated by my proposed religious/spiritual framework. (2.5.1) which can accommodate the complexities of reality. Nor do I consider he has been as inclusive as necessary for a pluralistic society. Therefore, I want to expand this point further and suggest that for non-religious people, it is equally complicated. As Laurence Lepherd points out, at times of major life challenges such as severe illness, reflection on religious and spiritual issues is likely to happen. (2015 p.566).

An outcome of the movement into chaplaincy teams has been increased academic study of chaplaincy and a recognition that this is an area of pastoral theology meriting research (Orchard, 2001; Swinton and Mowatt, 2016). This not only reflects the increasing professionalisation of chaplains, it has also brought about a professional identity (Swift, 2014 p.3). As part of that professional identity, and to align the role of chaplains with other healthcare professions, considerable work has been undertaken to produce capabilities and competencies required by chaplains in hospital and hospice settings (Mitchell and Gordon, 2003; NHS Education for Scotland, 2008). Competencies fit successfully into a nomothetic framework as they measure how well a particular task is undertaken. Therefore, it is relevant to consider the task of hospital chaplains.

Christina Puchalski, in her forward to *Spiritual Care in Practice: Case Studies in Healthcare Chaplaincy* (Fitchett and Nolan, 2015) proposes that the task of chaplains is to help people tell their story: “Chaplains don’t label. They listen intently to the person” (2015 p.10). Swinton, in his afterword to the same book, expands on this idea by proposing that “Listening to, negotiating and working with stories forms the heart of the task of healthcare chaplaincy” (2015 p.301). Therefore, chaplaincy, unlike the rest of healthcare, is primarily working with ideographic knowledge.

Turner, working as a chaplain with people who have experienced trauma, understands spirituality to be linked to physiology, the study of the body and its reactions. His approach recognises that trauma affects the body, therefore trauma affects spirituality. The body’s reaction is going to be unique to each person as it is experiential. It is not going to be

possible to generalize, replicate or falsify the experience because it is ideographic. The experience of how the body reacts to trauma, when seen holistically, contributes to the spiritual narrative. It connects the physical, psychological and social domains with the spiritual domain (Turner, 2017). Turner's understanding of the role of chaplaincy is similar to that of Andrew Todd, who describes chaplaincy as the ability to "join the dots" of a patient's story (Todd, 2015 p.79). However, Todd also points out the professionalisation of chaplaincy moves it from a ministry of presence, into another specialism within healthcare, emphasising the functionality of chaplaincy. There is a consequent risk of the dots not becoming joined if the specialists do not communicate with each other.

One way of illustrating the connecting dots is through case studies, demonstrating how chaplaincy operates. This approach is advocated by George Fitchett, writing as a healthcare chaplain (Fitchett and Nolan, 2015). However, because Fitchett's approach works in such a different and alternative way to formal medical assessments it presents a challenge to other professionals within the multi-disciplinary team. It does not easily fit with a scientific outlook. This, I propose, explains Swift's view that "chaplains present an implicit challenge to their employers by the counter-cultural nature of their endeavours" (Swift, 2014 p.165). It also explains why considerable work has been undertaken to try to make chaplaincy fit into the overall secular and scientific framework within highly technical hospitals. It may also explain why there is, as I am told anecdotally, the constant need for chaplaincy departments to prove they are needed. Evidence from Jackie Thomas' research concluded that "to a management concerned with financial stability, the anecdotal nature of spiritual care and its use of vernacular language do not appear to justify its existence" (2015 p.69). Léon van Ommen's review of four books in this field highlights the same tension: "spiritual caregivers [are] increasingly under pressure to defend their presence in the care setting and on the balance sheets" (van Ommen, 2018 p.44). This project does not have the scope to consider in depth the impact on spirituality of the increasingly difficult financial position within healthcare, but the implication is that it is affected.

I suggest that this is why so much of the academic output concentrates on devising spiritual care assessments, definitions of spirituality and papers attempting to prove the efficacy of healthcare chaplaincy. Hospital Chaplaincy works on a referral system which is reliant on other professionals understanding its role. There is a further challenge here, as Galek et al's research found: "chaplains' professional relationships with those in other disciplines tends to vary with each discipline's perspectives about religion and spirituality" (Galek, et al., 2007

p.364). There is no guarantee that the chaplaincy team will be seen as part of the multi-disciplinary team supporting the patient. As Todd suggests "chaplaincy has had an ambiguous relationship" within multi-disciplinary teams who, within their own defined professional standings, are not clear whether chaplains are healthcare professionals and thus to be accorded the same respect (Todd, 2015 p.79).

I propose that part of the underlying issue here is that spirituality, despite being accepted as part of the holistic needs approach, continues to be seen as completely separate to the physical, psychological and social domains. This means that an important part of a patient's story may be missing.

3.3.2 Chaplains as 'story hearers'

A key theme emerging from the literature is that of seeing healthcare chaplaincy as 'story hearers' rather than story tellers. To be open to the experiences of others, to be able to hear their stories, demands the skill of active listening. Thomas' research interviewed hospice chaplains working in adult hospices in the UK (Thomas, 2015). Her research showed that chaplains saw their work as "finding a language that enables patients …to tell their story and in so doing, to re-engage with their own spirituality" (2015 p.65).

Thomas, quoting one of her interviewees, suggests that: "spiritual care means really listening, with all the senses, in order to hear the patient's spirituality and 'meet him where he's at and love him' " (2015 p.65). Active listening requires self- awareness and reflexivity. This is another consistent theme in the literature (Mitchell and Gordon, 2003; Clayton, 2013; Swift, 2014). Unless one is self-aware, it is difficult to be open to the experiences of others. Swift describes it as being "empty handed" (2014 p.184). I suggest that this means that in order to be totally present to the person encountered, it is important that one's own story does not get in the way. As Swift suggests, this is essential for all involved in chaplaincy: "To be effective, the chaplain must know herself well and understand the processes occurring within" (2014 p.158). In reviewing the current situation for healthcare chaplaincy, Swift concludes that as well as needing self-awareness and an openness to other's experiences, there is a need to be able to "articulate a theology that is of practical relevance" (2014 p.150). This, I suggest, demands a deeper understanding of how religion and spirituality are understood within the wider context, as discussed in Chapter Two.

Stephen Pattison (2001) has consistently argued over the past few years for the need for faith based chaplaincy leaders, who are able to provide religious care as needed, and spiritual care for all. He maintains that this is required to provide faith-based leaders with a clearer identity within chaplaincy. I agree with this to a degree, but recognise that there is need for people who identify as 'spiritual but not religious', to be part of the wider chaplaincy team where all are able to attend to the spiritual. My reasoning for this is that a chaplaincy teams needs to reflect the pluralistic, multi-dimensional society we live in, as outlined in Liefbroer, Ganzevoort and Olsman's research (2019).

The task of chaplaincy is not about proselytizing, it is to meet people where they are and hear their story, so that they may be able to find or continue to find meaning in their lives. It is practical spirituality as described by Sheldrake (2014 p.14). The current healthcare context is dominated by scientific values and procedures. That is unlikely to change. Therefore, the challenge remains of finding ways of combining the narrative based ideographic knowledge of spirituality with the pre-dominant nomothetic language of medical care so that the whole story is heard. Using my proposed multi-dimensional, pluralistic framework gives a basis for this articulation. Spirituality and religion need to be seen together, as my framework illustrates, with an understanding that there is movement between these concepts. (2.5.2)

3.3.3 The nursing approach

Nurses comprise the largest workforce within healthcare settings. They therefore have a significant role in the provision of all aspects of care. There is common consent, within nursing publications, that spirituality is an essential part of holistic nursing care. (Narayanasamy, 2001; McSherry, 2001; McSherry, 2006; Carson and Koenig, 2008; Clarke, 2013; Timmins and Caldeira, 2017). This not only confirms the separation of spirituality and religion but also implies that nurses deliver spiritual care. In order for them to do so, it is considered necessary within healthcare organisations for nurses to understand what is meant by spirituality. It is not surprising, therefore, that the nursing literature concentrates on four issues: defining spirituality, delivery of spiritual care, assessing patient's spirituality and training nurses to be competent and confident to deliver spiritual care. I will briefly review the literature in each of these areas to investigate how spirituality is understood and responded to within the nursing profession, giving the context for my second research question.

3.3.4 Defining spirituality in nursing

'Every book and article I see about spirituality in nursing tells me how impossible it is to define spirituality. That's just not helpful.'' Hospice Librarian

The search for a definition of spirituality within nursing care has pre-occupied nurse researchers for many years. I consider this reflects the continued dominance of scientific reasoning that seeks clarity and precision. In 1999, Martha Meraviglia's paper, reviewing theological, sociological, psychological and nursing definitions of spirituality, found that there was no common definition, but there were common themes. She identified connectedness, faith, integration and the sense that spirituality was a unique dynamic process to be the similar threads in the reviewed literature. One advantage of her work is the multi-disciplinary sources reviewed to try and define spirituality. However, her conclusion was to create a further definition: "Spirituality is theoretically defined as the experiences and expressions of one's spirit in a unique and dynamic process reflecting faith in God or a supreme being; connectedness with oneself, others, nature or God; and integration of the dimensions of mind, body, and spirit" (Meraviglia, 1999 p.29). This seems a reasonable statement, however, it is more of a description of what spirituality entails. Meraviglia's definition is one of the earliest I have found in the literature and I note that this definition is not one that has been widely quoted subsequently. I speculate that this could be because God is named within it, reflecting the polarization of religion and spirituality, it also suggests that her definition did not answer the quest for a clear definition of spirituality, resulting in a continuing search twenty years on.

Wilfred McSherry, writing in 2003, suggests that finding a definition for spirituality is difficult because spirituality is based on individual understanding. This raises the point that a patient's and nurse's understanding may differ. McSherry raised the same concern as identified by la Cour et al (2012) that spirituality is becoming so broadly understood that it is in danger of becoming meaningless (2.3). McSherry concludes that "spirituality is associated with many descriptors making the formulation of a common or universal 'constant' definition theoretically impossible" (2004 p.156). His thinking develops in a later paper, recognising that "spirituality is not just concerned with matters of theology and existential beliefs but about the ordinary and the mundane." (2006 p.49). I understand him to mean that spirituality is lived out in everyday experiences which will have different meanings for each person. Therefore, McSherry and Cash argue, it is misguided to try to find a universal definition of spirituality (McSherry and Cash, 2004 p.159).

I agree with this suggestion, as I have explored in Chapter Two. Continuing to try to define spirituality does not help to understand what spirituality is about nor its purpose. The point about the word becoming meaningless is important. If the purpose of spirituality is clear, then it begins to make sense of why, within a healthcare context and as part of holistic and person-centred care, spirituality needs to be considered alongside the physical, psychological and social aspects of a person's life, in order to be able to hear their story. It is then not in danger of becoming meaningless. Developing a meaningful understanding of the purpose of spirituality seems to be a more worthwhile pursuit than the continual quest for a universal definition.

Laurence Lepherd, in his article 'Spirituality: Everyone has it, but what is it?' (2015) deliberately describes spirituality, rather than try to define it. His point is that spirituality "is an integral part of daily life" (2015 p.169). He describes spirituality as being about connectedness to oneself, others, or a higher being or significant places. Lepherd sees spirituality as multi-dimensional, expressed in a variety of ways, but recognises that central to spirituality is transcendence. "Transcendence sets spirituality apart from other psychosocial constructs" (2015 p.571). This, Lepherd implies, is the ability to find meaning in life's experiences. This approach, describing the purpose of spirituality is more helpful and I can see more appropriate to apply within healthcare settings.

However, for others the quest for a definition continues. Recent work, such as that conducted by Elizabeth Weathers, Geraldine McCarthy and Alice Coffey (2016) and P. Stephenson, D Sheehaan and G. Shahrour (2017) continues to focus on defining spirituality, because, they claim, similarly to Zinnbauer (2.3), it is first necessary to have a definition of spirituality to then be able to conduct further research into spirituality in healthcare. One conclusion reached is that spirituality is a complex and abstract concept, (Weathers, Mccarthy and Coffey, 2016 p.79) as well as the acknowledgement that "Unfortunately, a common definition of spirituality has not been achieved" (Stephenson, Sheehan and Shahrour, 2017 p.320). I propose this evidence supports my contention that the continual search for a definition is not helpful and needs to end. Instead, putting energy into describing spirituality enabling healthcare staff to recognise and become aware of their own spirituality, so that in turn, they could become able to recognise spirituality in those they care for, would be more useful.

Both the papers cited above, despite their aim of producing a definition, introduce the notion of attributes as a way of describing spirituality. Weathers, McCarthy and Coffey identity attributes of connectedness, transcendence and meaning as understood in real life (2016 p.94). Stephenson, Sheehan and Shahrour add beliefs and values to this list, the overall emphasis being on how all five attributes are framed in everyday life (2017 p.320). This links with Lepherd's (2015) emphasis on spirituality being integral to daily life, in that there is a sense of purpose in life experiences that echo the attributes of finding connectedness, meaning, value, beliefs and transcendence. I particularly value the emphasis in both papers on everyday experiences. This echoes other nurse researcher's views (McSherry, 2006; Clarke, 2013; Lepherd, 2015) and has a direct link with Ammerman's (2014) work (2.5), acknowledging that spirituality is rooted in everyday life. However, my concern with listing attributes is that the list can all too easily be turned into a checklist which is systematically marked off, especially for nomothetic demands. Spirituality is not about a checklist to be worked through; it is about finding ways of supporting people as they make sense of their experiences. As identified by Swift (2014) and Thomas (2015), it is about hearing the story and knowing what to listen for. Recognising different attributes within the story told may be a more helpful approach.

This brief overview of some of the current literature about spirituality in nursing highlights several issues. The search for definitions continues in order to support research but there is an indication that considering attributes would be a more helpful approach. The attributes listed are the same as descriptors and descriptions used in the wider context and in healthcare chaplaincy. I propose it would be more helpful therefore, if the literature focused on describing rather than defining spirituality thereby answering the librarian's plea, quoted at the start of this section. However, there seems to be little inter- or intra- disciplinary dialogue resulting in repetition and similar conclusions within different professions. This confirms the observation made earlier concerning the lack of 'joining up the dots' by different specialisms within healthcare to fully hear a patient's story. I propose this indicates the need for joint working and shared understanding between the different professions, so that spirituality is not seen as a uni-professional domain, but a concept embraced by all.

3.3.5 Nurses delivering spiritual care

The risk of spirituality being seen as the domain of only one profession is suggested by McSherry's chapter titled *Spiritual Crisis? Call a Nurse'* (2001). The attitude named in the title could imply that it is solely nurses who can deal with spiritual care matters. However,

McSherry argues, based on his research, it is not any one single profession that provides spiritual care, but it is “key individuals working together” (2001 p.114). It must be acknowledged that nursing teams have the most involvement with patients, providing twenty-four-hour care, seven days a week.

Janice Clarke advocates that by seeing spirituality as part of everyday care, all nurses are in an ideal situation to provide spiritual care (2013 p.101). Her approach is based on the relationship that builds between a nurse and a patient, recognising that spirituality’s themes of connection, transcendence and meaning (the attributes named by Weathers, McCarthy and Coffey, 2.3.4) can be met through the care given by a nurse. Clarke, in the same way as Turner working in a trauma setting, sees that this is an aspect of embodied life. Nursing is about caring for the body. Clarke, I suggest, is reclaiming the vocational aspect of nursing by proposing that spiritual care can be provided through good nursing care. It is practical spirituality at work. Her view echoes that of John Costello: “When I think of spiritual care, I am talking about truly caring for the patient and family by getting to know them as people and finding out how you can help them through the crisis they may be experiencing…. and responding with kindness, compassion and empathy” (2009 p.263).

Kindness, compassion and empathy are, I suggest, part of the vocational aspect of caring that is rooted in the origins of nursing care. This is echoed by other researchers. (Highfield, 2000; Timmins and Mcsherry, 2012). However, within that care relationship, it must be acknowledged and recognised that there is a power dynamic. One of the skills in providing good person-centered care is an awareness of where the power lies in the caring relationship. This calls for reflexivity, which is consistently recognised in the literature as an essential requirement to be able to deliver spiritual care (e.g. Highfield, 2000; McKenzie, 2002; Van Leeuwen and Cusveller, 2004).

Van Leeuwen and Cusveller make the important point that “spiritual care …also requires support of the nurse’s own spirituality” (2004 p.245). This links to the vision outlined in the NHS guidelines for Healthcare Chaplaincy and the role of chaplains to support staff as well as patients as outlined by Swift (2014). Obviously, people are free to choose how they receive their spiritual support. The point is that in order to provide spiritual care, people need to be in touch with and able to nurture their own spirituality, in religious and non-religious ways. There seems to be compelling evidence that providing spiritual care is a core component of nursing. But, the challenges of working with an increasingly scientific

nursing process, runs the risk, as Clarke points out, of care being reduced to being "problem-based, rationalistic and mechanistic" (2013 p.27).

McSherry raises the same concern, suggesting that far from holistic care being delivered, care has been reduced to focusing on a functional mechanism that can be fixed (2006 p.74). This approach loses sight of the person in the hospital bed, instead they can become identified by their illness or disability, labelled as 'the fractured spine in bed 2.' Swift, as a healthcare chaplain also has concerns: "despite the genuine and appropriate claims of the nursing profession to be the primary providers of spiritual care, spirituality for nurses is simply one of a multitude of tasks aggregated to their roles" (2014 p.1). I suggest the problem here is seeing spirituality as a functional task, on a checklist of other tasks that need completing. If spirituality is seen as a way of being, that is being kind, being compassionate, being caring then it is possible for nurses to provide spiritual care. I suggest that this is exactly what Clarke, Timmins and McSherry are advocating.

By 'being' in this way it could be possible for the descriptors for spirituality to be recognised. It may then be appropriate to offer a referral to the chaplain who may be able to explore issues further. It is obvious that there are more nurses than chaplains working in healthcare settings, so providing spiritual care needs to be seen as part of everyone's role, with the support of chaplains for whom this is their total focus. This goes back to McSherry's point about the need for people to work together.

I suggest that part of the issue about providing spiritual care is the assumption that spiritual care needs require assessment. I will be reviewing spiritual care assessments in more detail later on in this chapter. In this section, focusing on spirituality within nursing, I want to consider some of the implications this assumption has for nurses. Martha Highfield, who developed the SPIRITual interview (Highfield, 2000), proposes that nurses need to use standardised assessments. McSherry also considers using standardised assessments but critically asks: "can spiritual needs be identified by the use of assessment tools?" (2006 p.107). I suggest he asks a valid question. I do not think that spiritual care needs are best identified by formal assessment. Formal assessments operate well when working with nomothetic knowledge. For spiritual care, working from an ideographic starting point, formal

assessment is not suitable. It does not fit with the model of spiritual care provision that I consider most appropriate, that of 'being'.

The expectation that spiritual care is formally assessed continues to force spiritual care into being considered a functional task. It then becomes a task that is either not done, or one that is done with reluctance and the minimum of information gathered. This is possibly due, as McSherry's research found, to the fact that nurses do not have time to carry out in depth interviews, nor do they necessarily feel confident or competent to do so (2006 p.127). However, the profession seems to be very focused on providing training and competency lists with much research and curriculum development in this area to try to address the issue.

3.3.6 Nurse training and competencies for spirituality

McSherry (amongst others, e.g. (Narayanasamy, 2001; Mitchell and Gordon, 2003; Kelly, 2012; Timmins and Caldeira, 2017) identifies the need for appropriate training and competencies for nurses to deliver spiritual care. Various suggestions have been made within the nursing profession to consider how this might be addressed. René van Leeuwen and colleagues have identified six spiritual care related nursing competencies, which can be used to: "assess areas in which nurses need to receive training in spiritual care and to see if they have developed competencies." (2009 p.2857) The six areas focus on assessment, implementing spiritual care, professionalisation, improving the quality of spiritual care, considering personal support and patient counselling. The suggested competencies also consider how referrals to professionals are made, attitudes towards patient spirituality and communication skills.

Whilst I can see how these competencies may help with McSherry's concerns about lack of training, they appear to demand the same degree of competency as would be expected from a healthcare chaplain. Demanding such a level of competency compounds the point Swift makes, concerning additional tasks nursing is expected to undertake on top of providing nursing care. However, van Leuwen et al make the point that: "More discussion is needed about the role nurses play in spiritual care as well as the limitations of that role and its identification in relation to the task of hospital chaplains." (2009 p.2865). This is significantly important if the aim is to provide holistic care.

Nurses are in a good position to deliver a level of spiritual care, but I suggest that the continual debate about trying to define it and how to assess for spiritual needs hinders their

ability and confidence to do so. By supporting the core skills of nursing that focus on caring compassionately, and recognising descriptors of spirituality, nurses can deliver spiritual care as part of a multi-disciplinary team and not in isolation from other spiritual provision as part of holistic care. It is worth paying attention to the point made by Lenart Škof, in his article for *Nursing Ethics* where he proposes that at present "a genuine culture of attentiveness and care" is lacking within nursing. (2016 p.903). His solution is that in order to become attentive to the other, there is first the need to become attentive to oneself. Although Škof is not directly referring to spirituality within nursing, I suggest that it reasonable to assume that attentiveness and care connect with an underlying understanding of spirituality, which in turn provides compassionate, holistic care. By supporting nurses to develop self-awareness, as consistently identified as being required to provide spiritual care, (McSherry, 2001; Van Leeuwen and Cusveller, 2004; McSherry, 2006; Clarke, 2013) it may also be possible for nurses to deepen their own spirituality.

I now consider how my own profession, Occupational Therapy, views spirituality and the role it plays in the way Occupational Therapists work.

3.3.7 Occupational Therapy and spirituality

At the core of Occupational Therapy is 'occupation', defined by the Royal College of Occupational Therapy as those "practical and purposeful activities that allow people to live independently and have a sense of identity" (Royal College of Occupational Therapists, 2018). Occupational Therapists work with people of all ages, using a person-centred approach to support them to carry out those 'practical and purposeful activities'.

There is limited research within the Occupational Therapy field concerning spirituality. However, despite the acknowledged challenges of defining spirituality, it is accepted that "spirituality can be generally regarded as integral to the work of occupational therapists" (Wilson, 2010 p.438). Lesley Wilson, Lecturer in Occupational Therapy, also asserts that spirituality needs to be acknowledged "as having holistic importance in people's lives" (2010 p.439). Interestingly and refreshingly, Wilson does not advocate assessing spirituality, rather, by acknowledging its importance, if a patient identifies this as an area of occupation they wish to address, it will be appropriately supported.

Janice Jones, in her research examining how Occupational Therapists embed spirituality into daily practice, noted that this was achieved "by placing the patient central to the therapeutic

encounter" (2016 p.247). Her key finding from her research was that "Spirituality is more meaningfully described than defined for occupational therapy practice" (2016 p.248). Jones provides a detailed description:

> *"Spiritually competent occupational therapy practice engages a person, as a unique spiritual being, in occupations which will provide them with a sense of meaning and purpose. It seeks to connect or reconnect them with a community where they experience a sense of wellbeing, addresses suffering and develops coping strategies to improve their quality of life. This includes the occupational therapist accepting a person's belief and values whether they are religious in foundation or not and practicing with cultural competency."* (2016 p.85)

This is practical spirituality at work. Using my broad interpretation of 'descriptors' as outlined in the introduction to this chapter, the descriptors contained within it are similar to those already identified elsewhere. Jones refers to connection, meaning, belief and values. Relationship is also implied through the idea of connecting with community. The emphasis is on how the occupational therapist engages with the other, thus implying the need for relationship. This is a person-centred approach, focusing on the patient's needs not those of the therapist. It demands that the therapist accepts the person as they are, which in turn, identifies the need for self-awareness. This is implied in Jones' description and is consistent with the research outlined in healthcare chaplaincy and nursing.

However, Jones' description begins "spiritually competent…" As already discussed, I do not agree that spirituality can be an assessed competency and therefore suggest that "spiritually *aware* occupational therapy practice" would be a more appropriate phrasing. Jones uses the phrase: "practicing with cultural competency" (2016 p.85) It is not immediately clear what this means, and again, I have concerns with the word 'competency'. I interpret this phrase to mean that people are related to in a culturally sensitive manner and would therefore suggest that the description could be reworded to reflect this. Jones does not expand on this phrase; I would hope the intention is that when matters of religion and culture are acknowledged as significant, they are appropriately addressed.

Although I have concerns about the claim to address suffering, (Jones, 2016 p.85) as this may not be possible, I welcome the inclusion of the word 'suffering'. I am aware that suffering has not been mentioned within the literature reviewed so far, which could imply that suffering does not have anything to do with spirituality as seen in these contexts. There are significant issues to address concerning the role and meaning of suffering within spirituality, that I will explore further in the next chapter. As Dorothy Sölle, theologian, questions: "Does suffering …have any place left in a society fixated on performance and experience? …. Is it

really true that getting rid of or avoiding suffering is something for which no price is too high and no anaesthetic too precious?" (2001 p.137) My theological perspective is that suffering does have a place in society and in everyday life. It cannot be avoided. Therefore, I commend the way wellbeing and suffering are both seen as part of spirituality in Jones' description, providing a more holistic approach by acknowledging that suffering is part of spirituality.

It must be noted that Jones, in the same way as Wilson, does not propose the need for a specific assessment for spirituality. Occupational therapists have their own forms of assessment, using and interpreting them is considered to be a core skill of occupational therapy. I suggest this implies that by adopting a person-centred approach, similarly advocated by Wilson, if a patient wishes to address specific spiritual needs then this can be facilitated. Jones' description does recognise that spirituality is the starting point, appreciating that there may be religious involvement. This, I suggest, moves away from religion and spirituality being seen as binary, supporting my contention that both concepts need to be recognised within the same framework. This description fits well into the multi-dimensional, pluralistic framework for spirituality and religion that I am proposing.

I have considered how Healthcare Chaplains, nurses and occupational therapists are involved in delivering spiritual care. I have identified some of the tensions involved in the delivery of spiritual care, including that for the need of assessments. I will now directly critique some of the spiritual care assessments developed for use within healthcare settings.

3.4 Use of spiritual care assessments within healthcare

Assessments are an important part of healthcare; they are essential to provide the correct and appropriate diagnosis for medical conditions. It is a scientific, evidence-based approach which I suggest can work well to deal with physical, social and psychological issues but is not a suitable approach for spirituality. And yet, there are several spirituality assessments that have been designed, standarised and promoted for use within healthcare settings. The majority of these assessments have been designed in the United States, such as the FICA (Faith, Importance, Communities of Support, Addressing the issues) devised by Puchalski and colleagues in 1996, (published 2000) or the SPIRITual Interview (Spiritual belief system, Personal spirituality, Integration, Rituals practiced, Implications for medical care, Terminal events planning) published by Highfield (2000, p.117).

The USA has led the way in devising spiritual care assessments because, since 2003, every patient in a healthcare setting in the USA is required to have one. (Cadge and Bandini, 2015 p.433). The current position in the USA, according to Wendy Cadge and Julia Bandini, is that there are at least 40 different tools, devised by a large variety of professionals for use within their own profession. The assessments are language based and are designed to ask people about their belief systems. Their research also found that although much is written about these tools and how to teach them, there is very limited research into how these tools are used and experienced in practice. Within the UK, although these tools are referenced within the nursing education literature, there is little evidence to show that they are being used or that they can successfully identify spiritual needs. This seems to question the validity of these assessments. The evidence, I suggest, answers McSherry's question: "Can spiritual needs be identified by the use of assessment tools?" (2006 p.107) by saying 'no'. The answer that some academics then propose is to devise yet another assessment.

Fitchett, a chaplain and educator working in America, strongly recommends instead of devising yet more assessments, work is done to critically evaluate those existing to then disseminate best practice. He highlights there is limited research into the impact on clinical work as a result of spiritual care assessments. Significantly for this project, he points out tools validated to diagnose spiritual distress for adults are not validated for use with children (Fitchett, 2012 p.300).

The emerging picture is a confused one. The evidence suggests that each profession is devising its own spiritual assessment tool, with no reference to other professions working with that patient. Simultaneously, there is limited evidence to support the use of assessment tools or evidence demonstrating spiritual care is provided to patients as a result of these assessments. Fitchett is an advocate for using these tools. Despite calling for a halt to further spiritual care assessments being developed, he has devised his own: the '7x7 model,' linking seven aspects of holistic assessment to seven aspects of spiritual care (Fitchett, 2012 p.301). I suggest this contributes to the confused picture. I propose that the confusion is caused by the continual attempt to fit an ideographic experience into a nomothetic knowledge framework. Moreover, in a passing comment, Fitchett quotes Pargament "who writes that 'inviting clients to tell a story is the best way to learn about their spirituality' " (2012 p.302).

For my analysis, this is the key. Rather than formal assessments that involve forms, checklists and complicated mnemonics, the straightforward direct question of inviting someone to tell their story is far more effective. There are skills involved in this way of working, so that the appropriate trigger questions that open up the conversation are used. It may start with 'What is most important to you now?' and 'How can we help?' This is the approach advocated by Linda Ross and Wilfred McSherry in their paper, 'The power of two simple questions' (2018). They have found the second question often does not need asking because the answer to the first makes it obvious. Ross and McSherry correctly point out that asking these questions appropriately throughout a shift will identify the most pressing need of the moment which may lie within any of the four domains of holistic care. But, as Clarke (2013) points out, all good compassionate nursing care is spiritual. It is interesting that this approach has to be disguised and complicated by being turned into a nomethetic assessment tool called the 2Q-SAM. It is also worth being aware that this approach could be challenging as not all the answers will be neat and tidy, or straight forward. As Swinton suggests, to work this way, people "need to be comfortable with uncertainty and mystery" (2001 p.13).

Telling the story is a far more effective way of allowing someone to articulate their spiritual care needs which may also manifest as physical, psychological and social issues. People will choose to whom they will relate their story. The important point is that the 'story hearer' needs to be aware of the significance of what they are hearing, listening out for the descriptions and descriptors such as connection, values and beliefs. It is then important to know how to appropriately share that story. To do this effectively, interdisciplinary working that truly reflects holistic care is required.

3.5 Interdisciplinary working

Within a healthcare context, 'interdisciplinary working' refers to the different medical disciplines such as consultants, nursing staff, social workers, allied health professionals working together. Each of these disciplines will have their own professional language, roles and responsibilities. They will also have their own assessment tools and approach to spiritual care.

From my point of view, if spiritual care is first acknowledged as an attitude of care, as proposed by Clarke (2013), it is then straightforward to say everyone can and does deliver spiritual care, incorporated into the everyday care tasks that happen all the time within a healthcare setting. To support this, interdisciplinary working and training between healthcare

chaplains, nurses and other allied healthcare professionals needs to be promoted to develop a common understanding of the role of spirituality within healthcare. This may help address the issues identified by Galek (2007 p.364) (3.3.1).

There are further levels of spiritual care that become more specialist and that may be more appropriate for the chaplaincy teams to work with. This is the approach that the Marie Curie organisation has developed. (Mitchell and Gordon, 2003). It is acknowledged that everyone within the organisation: volunteer, facilities team, nurses and chief executive, all need to have an understanding of spiritual care. This is more helpful and supportive, offering a holistic approach whereby spiritual care becomes part of the overall ethos.

However, the Marie Curie Foundation support and promote this understanding of spiritual care through a competency framework. The first competency everyone is required to have is an awareness of their own spirituality. As I have argued when reviewing the issue of competencies for chaplains, and as illustrated by the level of competencies van Leeuwen (2009) outlines for nursing staff, I do not accept that spirituality and spiritual care fits within the nomothetic competency framework. Competencies are assessed, then signed off by a manager who deems the practitioner to be competent. To assess someone else's awareness of their own spirituality is intrusive and probably questionable from a legal point of view. Their awareness will be framed ideographically and therefore difficult to fit into a nomothetic competency framework. This issue is linked to my second research question which asks what is it that enables healthcare practice to recognise and so respond meaningfully to spirituality. I question whether formally assessing self-awareness of spirituality will enable the recognition of spirituality in others. I welcome the interdisciplinary organisational approach advocated by the Marie Curie Foundation but propose that spirituality and spiritual care need to be embedded in the overall ethos of an organisation in a different way.

The Interdisciplinary Spiritual Care Model, developed by René Hefti and Mary Esperandio, (2016), working from medical and theological backgrounds provides a way of embedding spirituality within an organization. Their model, based on research carried out in Brazil, acknowledges that spirituality is a key coping mechanism for many people, and within a Brazilian context this may well be expressed through religion. By the whole team recognising this as a support mechanism there is a shared understanding that everyone is responsible for spiritual matters, which are communicated within team meetings. The role of chaplaincy

is seen as integral to this whole team approach. The Chaplaincy Team is not invited in when identified as needed, but is part of the team from the start, supporting and teaching the wider team. Hefti and Esperandio advocate chaplains need to move beyond their own faith traditions and for all involved to be self-aware and in touch with their own spirituality. The work is about "accompanying the patient's journey through presence, words and humble acts of caring" (Hefti and Esperandio, 2016 p.32). Their model relies on a 'Spiritual History' being taken on admission (Hefti and Esperandio, 2016 p.29). Realistically this is not something that is done in this country and I argue, goes against the principle of patients choosing to whom they tell their story. However, their model supports the view that spiritual care requires a narrative approach which needs to be equally recognised within the interdisciplinary team.

I will now consider my own experience of working in a children's hospice, taking into consideration the challenges identified above for spirituality in healthcare practice.

3.6 My own context

A Children's Hospice is a place that combines some of the 'high tech' medical skills with being a place of refuge, calm and hospitality. My duel role as an Occupational therapist and lay Chaplain in a children's hospice gave a particular nuance to both roles. The hospice supported me to work in both roles, but it was not a condition of employment for either role. Just as I understand spirituality and religion as both belonging in the same broad construct, I saw my two roles as integrating into one. I did not suddenly stop being an occupational therapist or the chaplain at a given time, both roles influenced my attitude to caring, they were both part of the whole that is myself. By default, interdisciplinary work between occupational therapy and chaplaincy happened.

However, the interdisciplinary work between chaplaincy and the whole of the care team was harder to establish. There were practical reasons for this. As the 'Occupational Therapist', employed for three days a week, it was easier to work alongside the care team and families supporting the everyday care tasks. As the Chaplain, working one day a week, there was significantly less time to provide support and training to other staff as identified in Hefti and Esperandio's interdisciplinary model. Nevertheless, working this way helped to promote spirituality and spiritual care to be at the core of everyone's work. The underlying recognition within the hospice was that spiritual care was integral to the care provided, with respect and recognition that each individual would express their spirituality in their own way. Although

religion was not specifically mentioned, multi-faith resources were available as it was understood that for some, their spirituality would be expressed through religious practices.

What was evident during my time working in the children's hospice was the practical care shown to all who came into the service. Martin Clayton describes the practical spirituality of a children's hospice well, highlighting that it is not just about end of life care, but the ordinary everyday "forms of service" (2015 p.250). There was a real sense of hospitality within the hospice, the everyday forms of service that ensured refreshments were always available, all accommodation ready, and meals prepared, as well as highly skilled medical and wellbeing care. This is, I suggest, authentic human care giving, which as Ray Anderson, a practical theologian states, is "essentially spiritual" (2003 p.174).

Clayton, like Saunders, sees hospice as 'community.' For him, the unique community of a children's hospice is one that can heal "by helping sick children and their families find ways towards some sense of wholeness" (2015 p.259). Finding some sense of wholeness, is, I propose, a dynamic process that can take several years. It grows out of the hospice community that builds up through the relationships and connections families have with the setting. 'Relationship' and 'connectedness' are two consistent descriptors about spirituality within the literature. Using Clayton's insight, 'wholeness' is a further descriptor that can be used in this context.

Through their engagement with the hospice, it was possible to see these descriptors in practice as families lived with the consequences of their child's condition. Recognising these descriptors is a way of hearing the families' ideographic story. Through hearing the story, it becomes possible to hold the hope for the families (Clayton, 2015 p.3). I suggest that holding hope in this way recognises that spirituality is not just about wellbeing but acknowledges suffering too, as highlighted in Jones' (2016) description of spirituality, (3.3.7). For these families, 'ordinary everyday life' encompassed the continual challenge of caring for children with very complex needs. In the midst of those challenges, hope of wholeness can become hidden or lost. The spiritual care given, expressed through everyday acts of service, as well as through more specialised work, can help to hold the hope of wholeness.

Helping families find that sense of wholeness was an essential component of the underlying spirituality of the hospice. This informed the holistic person-centred approach taken when working with families to explore how the hospice could best support them. There was a

formal assessment and recording system which informed the care plans. The hospice did not use a standardised spiritual care assessment but provided space to record what was significant for the child or family. Frequently though, the sections for the child and family's spiritual and religious needs to be identified and noted were left blank. This anecdotal evidence bears out the findings from the literature that identifying spirituality and spiritual care needs is difficult because, I suggest, it is expressed ideographically. The family may well have been telling their story, but the hearer may not have been able to identify any explicit spirituality being shared because the expressions of spirituality did not neatly fit into a nomothetic understanding.

The staff, just as McSherry (2006) identifies, may have felt lacking in confidence and awareness of spirituality. Spirituality featured regularly in mandatory training. However, it was still an area of holistic care that appeared to be difficult for the care team to discuss with families. It must also be acknowledged that if this was difficult to do with children with verbal capacity, it was even harder to consider when working with children who were non-verbal. As a result, parental views were sought. These were valid views, but to be truly holistic and person-centred there needed to be a way of hearing the children's stories, hence this project.

However, I recognise that language that refers to 'holding the hope of wholeness' or that asks people to be a 'story hearer' is not necessarily language that will be helpful to the majority of the care team to ask about the spirituality of the children and families. What is likely to be more helpful are descriptions and descriptors that connect with everyday experiences. I will now consider how my proposal for describing rather than defining spiritualty could be applied within healthcare.

3.7 Describing not defining spirituality within healthcare settings

The evidence suggests that, similarly to my conclusion to Chapter Two for the wider societal context, the continual attempts to define spirituality within healthcare are no longer helpful. Certainly, as proposed by Jones (2016), description is a more useful way of understanding spirituality. Jones, due to the nature of her research, has limited this to Occupational Therapy. I am proposing the use of description can apply throughout the healthcare context.

It is important to consider what type of description will be most helpful. John Swinton and Stephen Pattison, practical theologians with considerable experience in this field, argued for a "thin, vague description of spirituality" (Swinton and Pattison, 2010 p.232). Their approach

was antithetical, highlighting the mysterious and prophetic nature of spirituality within healthcare, which does not fit into the dominant scientific language used in these contexts. However, I am not convinced that describing spirituality in 'thin' and 'vague' terms will promote understanding as they claim. I suggest that within the healthcare context, in the practicalities of working within a pre-dominantly scientific environment, 'thin' and 'vague' descriptions are easily ignored and missed.

Instead, I propose using the ethnographer's term of 'thick description' to help explore spirituality in the healthcare context. Clifford Geertz puts forward the following understanding of 'thick description': "a multiplicity of complex conceptual structures, many of them superimposed upon or knotted into one another, which are at once strange, irregular and inexplicit" (1993 p.10). I acknowledge that this project is not an ethnography, and I also acknowledge that people working within healthcare are not necessarily ethnographers. However, I propose that thick description is a tool that enables richer expressions of spirituality and acknowledges the wider complexities as discussed in Chapter Two. It allows for the inter-relationship between the spiritual, physical, psychological and social domains of holistic care to be taken into account. It encourages a movement away from factual, replicable, generalisable knowledge and allows for the valuing of individual experience. This is the conclusion Swinton came to in his later writings, clarified in an email he wrote to Gavanta, quoted in his endnotes: "we need … thick descriptions that reveal something of the richness and depth of human experience" (John Swinton, email to Bill Gaventa, January 6, 2015 in Gaventa, 2018 p.293). Swinton develops this notion further in later research, suggesting that 'thick description' aims to "capture the essence of a phenomenon…to convey all its fullness" (2016 p.123) I therefore suggest that substantial 'thick' descriptions are not so easily ignored, they are potentially linked to specific stories, feelings and encounters. This makes it possible for all healthcare professionals to recognise spirituality in a person-centred way. As William Gaventa remarks this involves "paying much more attention to what is important to the person…rather than the requirements of a care system" (2018 p.49).

I suggest Jones' description, quoted above, provides a starting point for thick descriptions of spirituality. As already discussed, it contains several descriptors that name how some people understand the spiritual in their lives. It hints at different conceptual structures that need thinking about and reflecting upon. In turn, this can be a way of developing self-awareness which has been identified as an essential part of spiritual care.

It remains a challenge to shift the focus from definitions to descriptions within the medical profession. I contend that it is not possible to create static, boundaried definitions of spirituality. Puchalski, a leading medical academic in this field, co-ordinated an international conference with the explicit aim of producing a consensus-based definition of spirituality. The interdisciplinary gathering of theologians and medics decided on the following as a definition:

> *'Spirituality is a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose and transcendence, and experience relationship to self, family, others, community, society, nature and the significant or sacred. Spirituality is expressed through beliefs, values, traditions and practices*.' (Puchalski, et al., 2014 p.646)

I argue, considering my broad use of description and descriptors, this is not a boundaried definition but, like Jones' description, this works towards creating a thick description. It encompasses much of the language used to discuss spirituality that I have identified elsewhere. By combining Puchalski's descriptors with the other descriptions, descriptors and attributes identified so far in connection with spirituality, a word cloud can be created. I propose that this may be a more useful way of illustrating the fullness of spirituality through thick description.

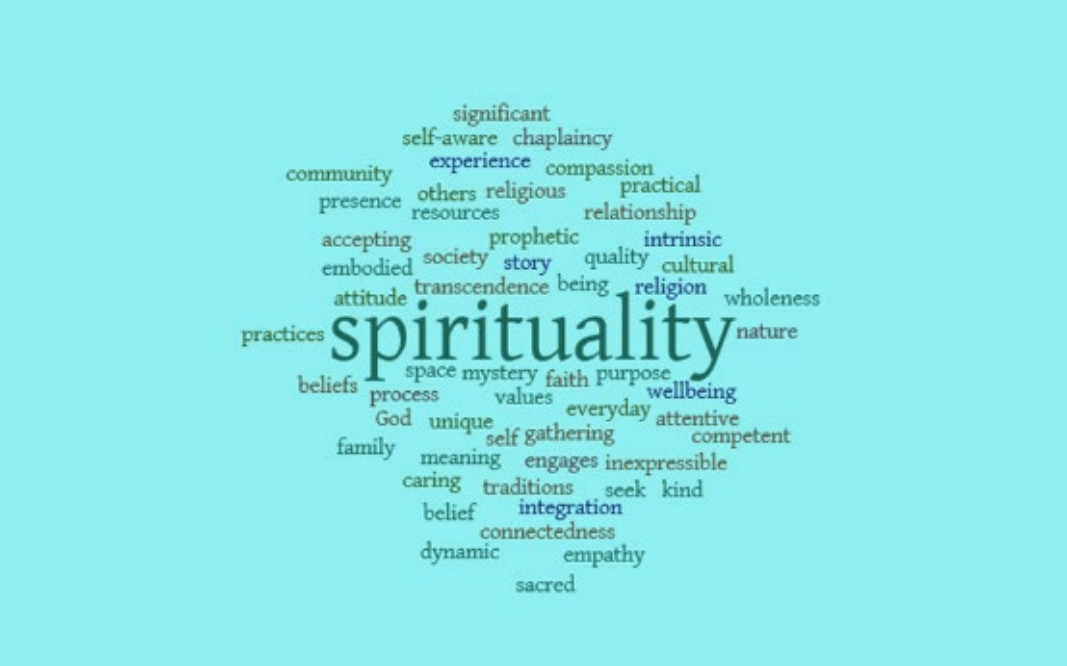


Figure 3 Word Cloud created using descriptors and descriptions of spirituality found in the reviewed literature

I suggest that using description as shown in the word cloud within a training programme has the potential to allow staff to appreciate the breadth of descriptions and descriptors used for

spirituality. They may well be able to add to the word list and be able to become more aware of their own spirituality. In doing so, through their own self-awareness, they may be supported in recognising spirituality within their work environment.

3.8 Summary of Chapter Three

This chapter has explored how religion and spirituality are understood within healthcare, with reference to a children's hospice, reflecting that it was a microcosm of the wider healthcare context. By reviewing the historical evidence, I have shown that religion has had a strong influence on healthcare, but there is now a prevalent understanding of religion and spirituality as binary which, I argue, is not helpful. This binary understanding appears to coincide with the increased professionalisation of healthcare.

I have discussed how spirituality does not fit into the scientific processes that dominate healthcare practice. Ways of incorporating the ideographic language of spirituality into nomothetic frameworks is required. Working in an integrated multi-disciplinary way such as the model described by Hefti and Esperandio (2016) could be a way of linking ideographic and nomothetic language. It could also become truly practical spirituality where chaplains, nurses, occupational therapists along with the other healthcare disciplines are the 'story hearers', providing spiritual care through a kind and compassionate presence to the person in front of them.

The evidence has shown that there is very limited validation for spiritual care assessments. There is also evidence that despite the continual attempts to do so, there is no universal definition of spirituality. By taking a very broad approach to what can be considered a descriptor, I am proposing that describing rather than defining spirituality is more useful within healthcare. The multi-dimensional pluralistic religious/spiritual framework I proposed at the end of Chapter Two accommodates the range of 'thick' descriptions and descriptors that I have collected. I suggest this framework could help all involved to become aware of their own spirituality and religious beliefs, supporting a shift from seeing spirituality and religion as binary, to a more dynamic understanding. In turn, multi-dimensional, multi-professional integrated teams working within healthcare could support spirituality as part of holistic care.

However, it is important to consider how the scientific adult world of healthcare can appreciate and understand children's spirituality, particularly that of non-verbal children. In the literature explored so far, their voices have yet to be heard. How to hear their story is the

purpose of this research. In order to begin to consider that, it is first necessary to explore the emerging field of Children's Spirituality, incorporating theological perspectives and creating a broad description. This is the task of the next chapter.

Chapter 4 Exploring Children's Spirituality

4.1 Introduction

Having considered religion and spirituality with the wider adult context of society and more specifically within healthcare, this chapter concentrates on children's spirituality, with particular reference to disability issues. I begin with a theological perspective, considering the Christian doctrine of *imago Dei*, the understanding that all persons are created in the image of God. I reflect on this doctrine in the light of disability theology and children's spirituality. I propose my study cohort contributes further perspectives towards the understanding of this central doctrine.

It is worth noting that children's spirituality as a distinct area of study emerged in the late 1980s. Rebecca Nye, a leading researcher in the field, pinpoints the 1988 Education Act as the starting point. This required educational authorities to "promote the spiritual development of pupils in schools and of society" (Nye, 2009b p.70). Children's Spirituality has become a multi-disciplinary area of study, with contributions from education, psychology, healthcare and legislation such as the UN Convention on the Rights of the Child (United Nations Assembly, 1989). Unlike historical thinking that discounted the possibility of children being spiritual, as Kesley Moore and colleagues point out, "findings suggest that children may have much more developed spiritual lives than was once thought" (2016 p.261).

Within the field of Disability Theology there is minimal qualitative research investigating the spirituality of severely disabled children. I propose that this particular group need "theological advocates", a term coined by Swinton (2016 p.193), to enable their voices to be heard. Theological advocates need to understand the alternative ways these children communicate their spirituality. This requires exploring the interrelation between several disciplinary perspectives such as psychology, education and healthcare as well as theology to develop a fuller understanding of children's spirituality.

The complex combination of these multi-disciplinary influences is akin to Geertz' understanding of 'thick description' which he identifies as the various complex and interweaving layers contributing to a conceptual structure. (1993 p.10) Geertz applies 'thick description' to specific contexts. I will use his principles to develop a broad description for children's spirituality combining my exploration of *imago Dei* with multi-disciplinary influences concerning children and disabilities. The aim of creating a broad description is to show the depth, breadth and richness of what I consider to be involved in all children's spirituality.

4.2 Catholic theology concerning *imago Dei*

God is love, and out of that love "God created humankind in his image, in the image of God he created them, male and female he created them." (Genesis 1:27 NRSV) This one verse from the Bible has given rise to considerable debate to determine what it means for human persons to be created in the image of God. Theological thinking originating from Augustine of Hippo and Thomas Aquinas continues to influence the way the concept of *imago Dei* is doctrinally understood. *Imago Dei* is an essential concept within Augustine thought. Augustine, in one of his sermons on the First Letter of St John, (IoEp. 8.iv.6) suggests "we ourselves therefore, *have* the image of God." (IoEp. 8.iv:9) (my italics) I interpret this to mean that within everyone, there dwells the image of God.

Aquinas uses a structured approach to the same question, reasoning that a human person "is said to be the image of God by reason of his intellectual nature" (STh I Q93 § 4 answer). Aquinas continues by stating that all humans possess a "natural aptitude for understanding and loving God" (STh I Q93 § 4 answer). In other words, humans are naturally drawn towards God, but for Aquinas this will be through their intellect which he considers to be a person's most God-like quality. Therefore, following Aquinas' reasoning, using intellect is constitutive of being made in the image of God.

At first sight, this appears to exclude children and anyone with disabilities, especially those with intellectual or learning disabilities. As Marc Cortez highlights: "The capacity for rational thought would not seem to apply to infants, (or) many disabled people…" (2010 p.20). This potentially dismisses my study cohort which appears to be in contradiction to the teaching that *all* human beings are created in the image of God. (My emphasis.)

4.3 Considering *imago Dei* and disability issues

It needs to be admitted that the Christian tradition has struggled with disability and disability issues (Reynolds, 2008 p.30). The World Council of Churches, meeting in 2005 to discuss Christian Perspectives on Theological Anthropology, suggested that there is an "unconscious assumption which pervades many of our cultures that only a 'perfect' person can reflect fully the image of God – where perfect means to be successful, attractive, young and not disabled" (World Council of Churches, 2005 p.8). Unfortunately, I suggest that this is a more conscious assumption, driven by societal conventions that demand success and perfection, along with an emphasis on individualistic experience. Along with an adherence to a literal interpretation of Aquinas' thinking concerning *imago Dei,* which prioritises the

intellect and rational thinking, this can lead to the false assumption that the image of God is only seen in the able bodied and intellectually able.

Miguel Romero's research, examining Aquinas' work in the light of disability, disproves and challenges this assumption. Whilst acknowledging that Aquinas did not write specifically about disability, Romero suggests that he wrote about "corporeal infirmity" which, Romero proposes, alludes to "a theology of bodily weakness" (2012 p.102). Romero's detailed examination of Aquinas' teaching on bodily weakness concluded that Aquinas considered "an impairment of that sort (i.e. learning disabilities) has no direct implication upon a person's capacity for relationship with God" (2012 p.123). Romero demonstrates this by pointing out that Aquinas co-opts Augustine's premise that within everyone, including those who do not have the use of reason such as babies, unconscious people and those with dementia, there is "a certain natural knowledge and love" (STh I Q93 § 8 reply to obj 4). Everyone has the capacity to know and love God (Romero, 2012 p.103). Anna Maliszewska uses this understanding of a universal capacity, applying it to understanding rationality and freedom by suggesting that rationality is the ability to come to know God, freedom is the ability to freely respond to God (2018 p.41).

However, not everyone has the capacity to be able to express their rationality and freedom intellectually or verbally. Medi Ann Volpe examines this issue by reasoning that those with intellectual capacity have a responsibility to use it in their relationship with God. Her point is that those with intellectual disabilities will not know God by using their intelligence, they will know God through God (Volpe, 2013 p.21). Her argument, I suggest, is in line with Augustine's understanding of each person having the image of God within them, with the desire to be in relationship with God. Romero and Volpe, who both have personal experiences of disability, have found a way of reasoning that, as Leonardo Boff puts it, builds "a trustworthy bridge between experience and theology" (1988 p.112).

Nancy Eiesland, in *The Disabled God* (Eiesland, 1994) makes her own bridge between her personal experience and her understanding of *imago Dei*. Eiesland, one of the first writers and campaigners in the Disability Theology field, was a sociologist, theologian and wheelchair user. Her thinking was influenced by the disability rights movement in America which proposed that society disables people. The disability rights movement gave rise to the social model of disability that suggests "the 'problem' of disability lies in society itself – in architecture, attitudes and assumptions" (Creamer, 2012 p.341). Contemporary disability

studies emphasise the social issues surrounding disability, rejecting models of disability that imply the problem is the individual, instead disability needs to be seen in terms of community and community interaction (Mallet and Runswick-Cole, 2014 p.4).

Eiesland discusses the need to re-think the symbols that are used for Christ. Referring to Paul Ricoeur's oft quoted phrase "symbols give rise to thought" (Ricoeur, 1967 p.11), Eiesland re-imagines God as disabled by focusing on the symbol of Christ Crucified. This enabled her to think through and discuss the image of God that connected directly with her own situation. She identifies three themes that emerge from her reflections: ordinary lives incorporate difficulties and disabilities, they are embodied; disability provides an alternative understanding of embodiment, recognising that the medical equipment, essential for a disabled person, is part of 'body'; and thirdly, disability is part of ordinary life (Eiesland, 1994 p.47). Seeing Christ, the "image of the invisible God" (Col 1:15) as disabled enabled Eiesland to articulate "a liberatory theology of disability that incorporates both political action and re-conception of symbols" (Eiesland, 1994 p.90).

I consider Eiesland to be proposing that disability issues expand an understanding of *imago Dei* by acknowledging difference and embodiment. Disability creates unease and uncertainty because it confronts society with difference. Eiesland was speaking from a physical disability viewpoint. I propose a greater challenge is presented by profoundly learning-disabled people, such as the children in the study cohort. They challenge through reflecting back a different view of perfection and wholeness. Hauerwas describes this profound challenge as being "prophet like", for as Hauerwas points out, they "remind us of the insecurity hidden in our false sense of self-possession" (1986 p.169). Disability issues also challenge the medical model where disability is viewed as a defect to be fixed, with an emphasis on individual pathology, suggesting that there is a lack or something at fault with the individual (Mallet and Runswick-Cole, 2014 p.4). The medical model has influenced the way society has, until relatively recently, dealt with disabilities. The children involved in this research cannot be 'fixed' within the medical model of disability. They are and always will be, profoundly physically and intellectually disabled.

The study cohort do have severe limitations if the focus is on what they are unable to do. Deborah Creamer proposes a 'limits model' of disability theology, starting with the acknowledgment that everyone is limited, some more than others. As she states: "Human life is…an experience of limits. This model observes that our notion of 'normal' is an illusion,

and a dangerous one at that" (Creamer, 2012 p.341). She advocates focusing on positive characteristics of disability such as "creativity, interdependence, or perseverance" (Creamer, 2012 p.341). While I commend Creamer for wanting to challenge the medical model mentality, my personal experience of working with this particular group of children and their families suggests that describing the continual deterioration of their children's conditions as a 'positive characteristic' is likely to be met with a negative reaction. Creamer appreciates that disabilities are on a "vast continuum" with no single perspective of what it means to be disabled (Creamer, 2009 p.18). Eiesland's understanding of disability as "living a difficult life ordinarily" is more helpful (Eiesland, 1994 p.14). This understanding allows for suffering to be seen as part of living. The extent of these children's disabilities does mean that despite the best efforts of all concerned they experience times of physical and emotional suffering.

John Swinton identifies in *Becoming Friends of Time* (2016) those who would advocate that these children suffer too much and therefore it is kinder for all concerned if they do not live. Along with Swinton, I cannot support this view. I propose an assumption to be made about suffering is that it is part of the human condition. In Jones' (2017) description of spirituality, (3.3.7), suffering is mentioned, recognising that it is part of being human. It is right and just for those who have the skills to do so to provide comfort and alleviate suffering as far as possible. But suffering cannot be denied, it exists. The point that Swinton along with others (Hauerwas, 1998; Reynolds, 2008; Reinders, 2014; Swinton, 2016) argues is that disability cannot be fully equated with suffering. As Stanley Hauerwas proposes, it is an oversimplification to suggest that all suffering can be prevented. The issue, he suggests, is not whether people, particularly those with severe learning disabilities, [2] suffer from having a disability. Rather, it is the suffering that society feels this group causes society (Hauerwas, 1986 p.167). Reinders develops this argument suggesting that for people with learning disabilities in particular, societal attitudes are potentially likely to cause more suffering through exclusion and false assumptions (2014 p.7).

Societal and personal attitudes towards profound learning disabilities are reflected in the work of Frances Young (2014) and Henri Nouwen (1997). Their deeply personal reflections search to find theological meaning in profound learning disability, highlighting the difficulties

[2] Hauerwas refers to people with complex learning disabilities as 'mentally retarded' or 'mentally handicapped'. This phraseology is not used in this country and is considered to be offensive. I have therefore chosen not to use Hauerwas' terms when referencing him.

in coming to terms with and finding meaning in profound learning disability. This is a different emphasis to my research which considers profound learning disability in the study cohort as a given, rather, I am seeking to find how severely disabled persons express their spirituality, which needs to be recognised and responded to appropriately.

To respond to the study cohort appropriately necessitates them being recognised as persons. There are those who argue that severely disabled children are 'non-persons' in a philosophical sense and therefore do not needed to be accorded the rights of a person. Romero (2015) names this trend, as does Pia Matthews (2011) who identifies Peter Singer as one of the antagonists. Singer's argument stresses the need for rationality, autonomy and self-awareness to be present for an individual to be considered a person. He proposes disabled infants lack these three attributes and do not have the potential to attain them. Therefore, in his view, whilst he recognises the factual and philosophical complexities involved, he proposes that "killing a disabled infant is not morally equivalent to killing a person. Very often it is not wrong at all" (Singer, 2011 p.167). Singer's reasoning raises the question: can the children I am studying be considered as persons? They cannot be considered so if rational thought, language, autonomy and self-awareness are assumed to be the pre-requisites for being a person. Their cognitive ability is severely impaired, their verbal skills are severely limited, they are totally reliant on others for all their needs to be met, and it is not necessarily easy to know if they are self-aware. Therefore, are they to be considered 'non-persons'?

Matthews, in her detailed examination of John Paul II's teachings and writings (Matthews, 2013) demonstrates how, from a Roman Catholic point of view, reasoning and arguments such as that proposed by Singer, cannot be accepted or tolerated. Profoundly disabled people are most definitely to be seen as subjects not objects. Appreciating disabled people as subjects is also stated in the UN Convention on the Rights of Persons with Disabilities, they are to be accorded the same rights as non-disabled persons (UN, 2006). Therefore, profoundly disabled people are to be considered as persons, even if they appear to be 'non-acting'. If, as Matthews suggests, others are not able to appreciate that, it is because they "have not fathomed how to engage successfully" with this group of people (Matthews, 2013 p.78). Matthews is challenging what it means to be a person and demonstrates that it is not solely reliant upon intellectual abilities. This challenges the reasoning that the image of God and the relationship with God is solely dependent upon intellect. I propose that Romero's work successfully demonstrates Aquinas' understanding, that a relationship with God does

not rely solely on intellect. Although Aquinas saw rationality as the highest form of having a relationship with God, he accepted that other ways were possible. Matthews, I suggest, is challenging those within the Church and society who have forgotten this.

4.4 Using other disciplines to develop an understanding of *imago Dei* in relation to profound disability

Matthew's concern about the need to engage successfully with people with profound learning disabilities is echoed in recent developments within education. It is an easy assumption to consider a child assessed as having a cognitive age of 18 months to be like a toddler. But as the educationalist Penny Lacey suggests, that ignores the thirteen years of experience any thirteen-year-old has, regardless of cognitive ability. (Lacey, 1995 p.64). Ben Simmons and Debbie Watson's research (2014) challenges a prevailing perspective within special education which suggests that PMLD children do not have a sense of self, others and the world, and therefore do not engage in purposeful, goal-directed activity. Simmons and Watson's concerns are based on their experience within specialist educational settings, where the focus is on correcting behaviours, rather than understanding that these behaviours are means of communication. This focus limits the "understandings of the richness of their being" (Simmons and Watson, 2014 p.198). Their idea of 'being' echoes Matthews' work. She argues that there is a sense of vocation in simply 'being', which is a richness in itself. As Matthews suggests "staying still, being apparently passive and allowing experience to come is a profoundly human activity" (2013 p.90). This is suggestive of contemplative practice, a sense of being in the present moment.

Matthews and Reinders, from a theological perspective, and Simmons and Watson from an educationalist perspective are all propounding the view that by not appreciating the richness of these children's lives, something significant is being missed. From a theological viewpoint, I argue this means a deeper understanding of *imago Dei* is incomplete if the understanding remains limited to rational thought and the intellect. Elizabeth Johnson's work, exploring *imago Dei* from a feminist perspective, offers a way forward that expands a limited understanding by suggesting that *imago Dei* is the "grammar of God's self-utterance…and…liberating care for this conflicted world and all its creatures" (Johnson, 1992 p.13). She argues that historically, women's theological identity has been ignored within discussions about the image of God. Recognising that a flexible approach is needed, her arguments have used a feminist lens to empower women "to make their own humanity as *imago Dei* historically tangible." In the same way, I want to use her flexible approach to

acknowledge severely disabled children, who do not use rational thought and intellect, as being made in the image and likeness of God.

Janet Martin Soskice's exploration of the image of God, like Johnson, considers gender issues. She proposes that "we learn love through the reciprocity of our human condition, through being in relation to others who are different from ourselves…" (Soskice, 2007 p.51). Soskice is highlighting two important aspects, that of 'being in relation' and of 'difference'. I understand her reasoning to be that humanity is created and desires to be in relationship. Humanity learns how to love through relationships. God is love; therefore, it is through relationships that humanity learns and discovers God as love. However, this relationship requires difference. For Soskice, this difference in relationship can be explored through the differences in gender. Taking a flexible approach as advocated by Johnson, I propose that this need for difference in relationships can be explored through being in relation with others of different ages, abilities and disabilities.

4.5 Exploring a relational approach to *imago Dei*

Soskice's thinking about a relational approach is echoed by Cortez who identifies that "human beings are fundamentally relational beings – related to God, to other humans and to creation…this is relationality that truly images a God who is himself a relational being" (Cortez, 2010 p.24). It is worth noting Cortez' list of relationships echoes that of the commonly used definitions of spirituality, as explored above (2.3; 3.3.4; 3.7) (e.g Meraviglia, 1999; Pargament, 2013; Puchalski, et al., 2014). These definitions of spirituality focus on the relationship with oneself, others, God or the Transcendent and creation/nature. The significant difference is that Cortez' list begins with God, whereas the definitions used in general and healthcare practice begin with 'relationship to self.' Cortez, by beginning with God, recalls the Christian teaching that "we love, because God loved us first." (1 John: 4.19 NRSV). In other words, humans love and relate to each other because they are created in the image of God as a relational being. As Carol Harrison points out, Augustine uses the language of relationships to talk about God; because to say the word 'God' invokes the threefold image of God, in which humanity is created (Harrison, 2000 p.43). Aquinas echoes this when he proposes that within humanity "there exists the image of God… as regards the Trinity of Persons" (STh 1 Q93 § 5.). Seeing God as 'trinity of persons' moves this discussion into a different area of relationality, that of God in relationship with God, as Father, Son and Holy Spirit.

It is not possible to discuss Trinitarian Theology in depth within the scope of this research. I acknowledge that the Trinity is unfathomable and unknowable, but I suggest that drawing on the language of relationships in Trinitarian Theology is relevant to this project, contributing to an understanding of the spirituality of PMLD children. All children, to be able to live, thrive and flourish need to live in relationships of love. The study cohort are in relationships with their parents and their extended networks of family, school and community. Cortez suggests there is agreement that "to 'image' God means to 'reflect' God in creation" (2010, p.16). Therefore, the children's relationships could be considered as a reflection of God. In an unpublished report by IASCUFO January 2020, it states: "…human beings, who are created in the image of God, are also to be known through their relations in the communion of life" (IASCUFO 2020 p.18). I propose that it is through those relations/relationships that Volpe's proposal of knowing God through God could be seen (2014 p.21).

One of the issues for contemporary society in considering Trinitarian theology is the understanding of the word 'person'. As David Cunningham points out, 'person' can be understood to mean the 'individual'. This contemporary thinking is at odds with the traditional Christian understanding of 'person' which implies community, for others (Cunningham, 1998 p. 171). This means to be able to appreciate the mystery of *imago Dei* needs careful exploration, to enable an understanding that to be made in the image of God "does not mean to be a copy of an individual divine person" (Fiddes, 2000 p.102). What is required is an understanding of God as community which moves the focus of the doctrine of *imago Dei* away from the contemporary understanding of 'person' as individual and away from intellect and rational thought. Instead, the focus of *imago Dei* is brought onto relationships. Cunningham describes the Trinity thus: "The Three exist in dynamic relationship with one another, giving to and receiving from one another what they most properly are" (1998 p.115).

Jürgen Moltmann discusses the complexity of the Three Persons of the Trinity in relationship with each other via the concept of '*perichoresis*'. This is the indwelling and inter-dwelling of and between God the Father, Son and Holy Spirit. *"Perichoresis* means reciprocal indwelling and mutual interpenetration" (Moltmann, 2009 p.288). It is how the Three Persons of the Trinity are completely in relationship between each other and are so indwelling in each other that speaking of one refers to the other two as well. This "dynamic relationship", as Cunningham calls it, (1998 p.115) as the image of God leads to exploring "what it might mean to dwell in and be indwelt by the lives of others" (Cunningham, 1998 p.165). In his interpretation, Colin Gunton proposes *perichoresis* "teaches that made in the image of God,

we are closely bound up, for good or ill, with other human beings… We all contribute to making each other what we are." (1993 p.169). The loving relationships within families can be a reflection of the dynamic relationship of the Trinity.

I acknowledge that the analogy of 'family' is complex as family life is not perfect. However, family is based on relationship, and the children in this study are based in families. This is explored by Boff, who sees 'family' as symbolic of the Trinity (1988 p.105). He describes the Trinity as being for the others, through the others, with the others and in the others (Boff and Burns, 1988 p.127). These dynamic relationships can be seen in families. Similarly, Fiddes sees *imago Dei* as being "called into a relationship with God which is like that between a son (or daughter) and a father (or mother)" (2000 p.102). By referring to *imago Trinitatis*, which Moltmann advocates, rather than *imago Dei*, the relationship and communal aspects of God and God's relationship with the world is emphasised.

Likewise, Cunningham accepts the virtue of participation in dynamic relationships, seeing this mirrored in the family, "where the relations among the members should…be marked by communion and participation in one another's lives" (Cunningham, 1998 p.169). Fiddes explores the metaphor of relationships further, by suggesting the Trinity is best understood as the "movements of relationship" (2000 p.72), emphasising the dynamic aspect Cunningham identifies. This, for Fiddes, is about participating in the Trinity: "it is in the relations between a mother and the baby in her womb, between children and parents…that are analogous to relations to God." (2000 p.50) Care is needed with this analogy, as already acknowledged above. However, good familial relationships, based on trust and appropriate desire and love for each other, participating in each other's lives, are a way of describing the experience of God, of what a relationship of God may feel and be like (Fiddes, 2000 p.38). They are a way of knowing God and experiencing something akin to *perichoresis.*

The "pure relationality" of the Trinity is emphasized by Johnson (1992 p.222). She is searching for alternative ways of discussing the ancient truths such as the belief that we are all created in the image of God. Although her focus is to introduce the feminist perspective, her insight that "the God who is thrice personal signifies that the very essence of God is to be in relation and thus relatedness rather than the solitary ego is at the heart of all reality" (Johnson, 1992 p.215) is of great significance for this project. It suggests that how the children relate to themselves and others and how others relate to them is an image of God. Through the experience of relationships, it is, I suggest, possible to experience the

movement of God in encounters with family, friends and community. This is perhaps, a glimpse of *perichoresis*, a hint of what is to come, of those moments when it feels as if there is a mutual indwelling in each other. Another way of describing these glimpses of *perichoresis* is to use Fiddes' term of "dwelling in relational spaces" (2000 p.49). God is revealed in relationships.

I am aware of the need for caution when describing the Trinity in these relational terms. Karen Kilby's critique of the use of social doctrines of the Trinity rightly points out that there is a risk of narrowing down the overall function of the doctrine of the Trinity into one particular aspect that solves the mystery of three persons-in-one. Rather, she proposes, the doctrine needs to be "taken as grammatical…a set of rules ... for how to deploy the 'vocabulary' of Christianity in an appropriate way" (Kilby, 2000 p.443). For this project, I am proposing the threefold image of God understood within relational terms, along with Johnson's flexible approach to *imago Dei,* provides the grammar required to explore the spirituality of this specific group of children.

Contributions from other disciplines, such as the social sciences, further expands the understanding of the importance of being in relationship with others. For this project, it is worth considering implications from child developmental studies. John Bowlby's work, in the 1950s, highlighted the importance to an infant of the relationship between themselves and their primary carers (Bowlby, 1998). That relationship significantly influences a child's concept of self. All children are dependent on their primary caregivers to have their basic needs met. This dependency relationship is described as 'attachment'. When those basic needs are met, the infant is in a secure position to explore and play. An 'attachment figure' is someone who "provides physical and emotional care, has continuity and consistency in the child's life and who has an emotional investment in the child's life" (Pearce, 2009 p.13). Examples of behaviours indicating attachment relationships are eye gaze with an adult, searching for an adult, seeking to be picked up, and smiling at an adult (Pearce, 2009 p.19).

These attachment behaviours correlate to Pierre Ranwez's work, cited by Nye (2009b). Ranwez was writing in the mid-1960s, studying the discernment of children's religious experience from a theological viewpoint. He proposed that the "first free act, however small it may be, can therefore be a formidable event in a human being's destiny" (Ranwez, 1965 p.48). He saw the 'free act' of a baby smiling at her mother as intentional and the beginnings of a spiritual relationship. Ranwez was appreciating that spirituality was to be

found in the everyday relational encounters between a child and its mother. Maliszewska, pointing out that for the Church, a human being is defined as being capable of knowing and loving their maker, alludes to Ranwez's understanding of this intentional act. She writes: "some theologians have understood the mother's smile to mediate the love of God to the infant and have therefore seen the infant's response to that smile as a response to God himself" (2018 p.41). Maliszewska also cites the Polish Jesuit priest, Zbigniêw Kubaki, who sees such acts from babies and infants as acts of faith: "solely through their will of living and simple gestures such as a baby's smile at his/her mother, it brings salvation, hence it is true and real" (Zbigniêw Kubaki, cited by (Maliszewsha, 2018 p.42).

This same small act, of a baby responding with a smile to her mother, can be seen in psychological terms as a sign of attachment, or in theological terms as an indication of spirituality. Moreover, recent work in neurophysiological studies, discussed by Stuart Brown in his work on play, has shown that the mother's (or primary carer's) appropriate response is significant in the ongoing development of a good relationship. When the primary carer responds with smiles and vocalisations, both the baby's and carer's brain waves are synchronized, they are in attunement, which enables both to experience "joyful union" (Brown, 2009 p.82). This echoes spiritual language, highlighting the importance of a deepening understanding of human relationships, which in turn adds to our appreciation of God as a relational being.

4.6 Exploring research into Children's Spirituality

As mentioned in my introduction to this chapter, it is only relatively recently that it has been acknowledged that children are spiritual. Early research in this field, such as that conducted by the child psychiatrist and psychoanalyst Robert Coles, concentrated on collecting anecdotal evidence of children's spirituality and expressions of religiosity. Coles' approach was important, he spent time with children, letting them tell their stories in their own way in settings that were familiar to them (1990).

David Hay and Rebecca Nye's seminal research in 1998 went further, investigating how spirituality was experienced and expressed by children. Working directly with verbal children, they analysed their results noting the attributes they listed were "normal processes forming the conventional content of child psychology…This firmly locates children's spirituality within the reach of the ordinary child" (Hay and Nye, 2006 p.113). Their research demonstrated children have a great sense of spirituality, expressed through the categories of Awareness Sensing, Mystery Sensing and Value Sensing (Hay and Nye, 2006 p.65).

Awareness Sensing includes the ability to be totally focussed and attentive to the 'here and now,' to be in a state of 'flow'. 'Flow' is the state defined by Csikszentmihalyi as one of "deep absorption in an activity that is intrinsically enjoyable" (Csikszentimihalyi, M. 1990, cited by Shernoff, et al., 2003 p.160). The absorption in the activity is so complete that it appears as if the individual is completely at one with it.

Mystery Sensing includes an appreciation of wonder and awe and using the imagination. Value sensing acknowledges delight and despair, as well as looking for meaning, and a sense of ultimate goodness. It is worth noting that these category descriptors echo descriptors identified by Emmons **(**2006**)** (2.3). These three categories were evidenced as happening all the time, as part of the ordinary lives of children.

Hay and Nye identified a further category from the conversations with the children. They noticed a definite 'shift' occurred when the children spoke about a significant experience. These experiences were connected to their relationships with themselves, others, nature or God. This 'shift' indicated a different level of consciousness and "added value to their ordinary or everyday perspective" (Hay and Nye, 2006 p.109). Hay and Nye named this shift 'Relational Consciousness', identifying it as "the rudimentary core of children's spirituality" (2006 p.109). Their work was ground-breaking as it gave the field of children's spirituality the gravitas and established the necessary academic rigour required for any research within Children's Spirituality to be taken seriously.

I propose that 'relational consciousness' has a correlation with a relational approach to *imago Dei.* Nye, in a later publication, summarises children's spirituality as being "especially about being attracted towards 'being in relation', responding to a call to relate to more than 'just me'…" (2009a p.6). This, she proposes, is children's natural capacity for 'relational consciousness'. I connect this natural capacity for relational consciousness with Augustine's and Aquinas' teachings concerning the natural knowledge and desire to love God that they identify as present within all human beings. Nye's research (2009b p.72) demonstrates how this can be recognised in children through their everyday experiences.

Nye's research has been substantiated by others, such as Elaine Champagne. Champagne, researching pre-schoolers, identified three different modes of being: being sensitive, being relational and being existential. (Champagne, 2003) These modes of being relate to Hay and Nye's categories. Hay and Nye's category of awareness and value sensing share the same

ideas as Champagne's 'being sensitive.' Champagne's 'existential mode of being' echoes Hay and Nye's category of Mystery sensing. It encompasses how the children are able to be in the world, living in the present moment. The separate mode of 'being relational' has a direct link with relational consciousness, although I propose that Hay and Nye's development of this concept is deeper than Champagne's mode of being.

Champagne's work found that these modes of being are seen in all that the children did. The three areas she identified: the embodiment of spirituality, the importance of play, and the importance of non-verbal language, have particular relevance to this project. Champagne suggests that children respond with their bodies in being sensitive, relational or existential. This, she proposes, is embodied spirituality. It might take the form of laughter or tears; it may be through movement such as running or jumping. Children are responding to others and the world through their bodies. This relates to Eiesland's understanding of embodiment. What I take from Champagne and Eiesland is that to be spiritual is the human condition and that spirituality is made manifest in many diverse ways.

Nye and Champagne, and others such as Adams et al, challenge the thinking that spirituality develops in a linear fashion, coming later in life once other developmental stages have been first attained. This linear thinking has been influenced by the work of developmental psychologists such as Jean Piaget (1896 – 1980). Piaget's work has made valuable contributions towards understanding how children cognitively learn. Piaget's work was also influential on Fowler's developmental work on stages of faith, referred to in section 2.5. But as Nye points out, "the major problem about developmental stage theories is their narrowness…" (Hay, Nye and Murphy, 1996 p.55). Nye, in later research, (2018a) asserts that the influence of Piaget's emphasis on cognition in child development studies has been detrimental to understanding Children's Spirituality. Cognitive developmental theories tend to ignore children's experiences and context, instead linking stages of development with patterns of thought and religious understanding. As Adams et al point out, child development theories are theories, "incomplete frameworks which should not become strait jackets" (Adams, Hyde and Woolley, 2008 p.42).

I agree with the challenge made by Nye and others to the linear cognitive approach to child development. I suggest that alternative models of child development are needed, that, as Nye suggests, show "the possibilities of children's spiritual strengths" (Nye, 2018b p.141). Approaches that take into account experiences are more relevant to the study cohort,

allowing for the different way PMLD children develop. Research concerning disabled children's childhood and development is an emerging field. One of the issues, as highlighted by Katherine Runswick-Cole and Dan Goodley is that children with disabilities are compared with typically developing children and as such are considered to be 'lesser', because they are different (2018 p.41). Disabled children do not all reach the standard childhood milestones in the same way as typically developing children. Runswick-Cole and Goodley identify this as a continuing legacy of the medicalisation of disabilities, which can reduce "human behaviours to narrow, individualising and at times pathologising concepts" (2018 p.43).

I suggest all disabled children develop their personalities, communication skills, memory and recognition skills in ways that are often unique to themselves, but valid none the less, although established in ways that do not conform to a linear progression. It needs to be acknowledged how the word 'development' can have negative overtones for their families, as there can be an implication of what the children should be achieving physically and cognitively. This may result in constant comparisons with typically developing peers concentrating on what they are unable to do, rather than the developments that they do achieve, in their own way. In contrast, by focusing on children's experiences of relationships and embodiment, as advocated by Hay, Nye, Ranwez and others, rather than the developmental milestones and intellectual abilities that prioritise verbal and physical skills and rational thought, it becomes possible to appreciate that all children have a capacity for spirituality. This holds true if, following Hardy's understanding of spirituality (2.3,) it is considered to be "a natural human disposition, or an innate quality" (Adams, Hyde and Woolley, 2008 p.14). Therefore, observing their disposition indicates a way that the spirituality of all children and especially those diagnosed as PMLD can be appreciated and valued. To be able to do this requires adults to be aware "that children are expressing something spiritual" (Adams, Hyde and Woolley, 2008 p.26).

4.7 The significance of play

Hay and Nye identified in their research that "languages of play and games were significant ways in which children framed their spirituality" (2006 p.120). This indicates that the role of play in all its forms is important to consider for children's spirituality. It was through using playful activities Hay and Nye (2006) recognised the categories of Awareness Sensing, Mystery Sensing, Value Sensing and Relational Consciousness. Champagne's research (2003) considering children's embodied spirituality was conducted through observations of pre-school children at play.

In the previous two chapters I have discussed the difficulty of trying to fit spirituality into boundaried definitions. Similarly, play has been described as difficult to define and "impossible to pin down" (Scarlett, 2005 p.4). Catherine Garvey, one of the first psychologists to study play describes it as "fuzzy" (1991 p.2). Interestingly, play has been described by Hugo Rahner, theologian, as an activity "undertaken for the sake of being active, meaningful but directed towards no end outside itself" (1965 p.7). Play is voluntary, it is engaged in because it is enjoyable and fun. Rahner further proposes that play is an activity which "engages of necessity both soul and body" (1965 p.6). For Brown, play is "the purest expression of love" (2009 p.218). Brian Edgar, applying Brown's work on play to his own theological research proposes that play is essential for creating relationships with others, which in turn means it is the "ultimate form of relationship with God" (Edgar, 2017 p.46). I conclude therefore, that spirituality and play are deeply connected.

Piaget, considering play as part of children's development, saw it as a staged progression, moving from non-symbolic to symbolic play, then onto imaginative stages (1951 p.148). However, just as with spirituality, play does not necessarily follow a neat ordered straight line of development. It does contribute to other areas of learning such as problem solving, language development and communication skills, (Garvey, 1991 p.5), but that is not the point of play. Play is not a rational, scientific product, play is play. As Johan Huizinga in his seminal work on play, *Homo Ludens,* states: "we play and know that we play, so we must be more than merely rational beings, for play is irrational" (1970 p.22). I advocate that this is a way of understanding Volpe's proposal that those with limited intellectual capacity or rational thought know God through God. God is relational, relationships are formed and created through play, play is therefore essential in spirituality. As Edgar suggests: "normal, everyday play is nothing other than a reflection of the relationship that God wants with us" (2017 p.x).

Jerome Berryman recognised the importance of play within spirituality, incorporating it into his religious education approach, 'Godly Play'. Although based on Christian teaching, Berryman saw this approach as a means of developing spirituality for all children, providing them with a language to describe their experiences. A feature of this approach is that after the structured teaching input, which encourages children to wonder and to play with ideas, there is a time for children to explore using a wide range of creative materials. This is non-directed time, allowing the children to work at their own pace on things that are significant to them at that moment. It is play. The end product is not important, it is the time of processing

through play that is significant. Nye, who introduced Godly Play to Britain, summarises play as “a vital creative process through which Christian (Spiritual) language can take root in a child’s life” (2009a p.78). Hyde, reviewing Berryman’s writings, describes how Berryman sees play as “at the edge of children’s being and knowing”(2013 p.11). Brown echoes this in his observation that children are “always in the process of changing and becoming” (2009 p.92). Through play, children are engaged in a creative process that enables them to develop relationships with themselves, others, nature and God. In other words, they are naturally involved in spirituality.

4.7.1 ‘Come and Play with me!’

The simplest way to create relationships with children is to move to their level and recognise and respond to the invitation to play. Play becomes a way to dwell in each other’s lives. It is a way of living out the dynamic relationship of the Trinity, as described by Cunningham, of “giving to and receiving from one another” which may allow them to become “what they most properly are” (1998 p.115).

To be able to do this requires the ability to recognise “the native language of play” (Nye, 2009a p.35) used by all children. Garvey’s research noted that smiles and laughter emerge in very young infants seemingly signalling an invitation to play – for example, playing ‘peek-a-boo’ (Garvey, 1991 p.15). Vasudevi Reddy’s research supports and develops Garvey’s findings, by highlighting that infant laughter comes from the engagement with others. It is through relationship that laughter and humour develop. As Reddy points out, an infant’s laughter “creates as much joy as it reveals” (2010 p.183). This highlights too, that play is mainly non-verbal, incorporating laughter and humour, as well as movement. This is the embodied spirituality as described by Champagne.

Understanding play as a non-verbal means of exploring children’s spirituality raises the issue of researchers using verbal language and cognitive ability to investigate children’s experience of spirituality. Chris Boyatzis realises that “verbal measures create the risk of studying not children’s experience but the language they use to describe it” (Boyatzis, 2005 p.136). If verbal measures are the only way of capturing children’s experience, then there are real difficulties with my own study cohort. Many children, including those in my study, will not have the verbal ability to put into words what is of significance and importance to them. The non-verbal language of play allows them to communicate meaningful and significant experiences in their lives. The conclusion I draw is that there is a serious need to

prioritise and recognise the significance of the non-verbal elements of play and what is therefore being communicated about spirituality.

4.7.2 Disabled children and play

Although there is an understanding that play is important for all children, there is limited research exploring how disabled children play. I am arguing that play in all its forms, provides an ideographic language to frame and express spirituality. Therefore, it is important to consider how my study cohort may play. Naomi Graham, a children's occupational therapist, interviewed parents of children with cerebral palsy to gain their views of their child's ability to play. Her findings highlighted that the children participated vicariously through watching and being with siblings and friends at play. Another finding, substantiated in her later work, showed that communication through word play and storytelling was also a play experience for this group of children (Graham, Truman and Holgate, 2014; Graham, et al., 2018).

There appears to be even less research investigating how severely disabled non-verbal children play. Debby Watson, working in education, promotes identifying playfulness in PMLD children. She suggests that "it is extremely rare to find a learner who does not express a 'playful disposition' in some form, be it a fleeting shiver of excitement, a blinking eye, an open mouth or a raised eyebrow" (2015 p.372). This demonstrates that these children do invite others to play. The signal that indicates playfulness is described as "a fleeting and fragile phenomenon that is easily missed" (Watson, 2015 p.372).

I submit that very skilful attention is required from everyone working with these children to recognise invitations to play. There is the danger of play becoming adult-led simply because it can be difficult to ascertain a child's choices. There are further complications caused by medical conditions – a child may be smiling or giggling but this could be an indication of seizure activity requiring medical attention, not an indication of playfulness. However, the introduction of technology, such as iPads and eye gaze systems, is having a significant impact on enabling choice and play activities for many of these children, as well as providing a means of communication. By using skilful attention, it is then possible to know a child's specific invitations to play to then identify a child's "individual signature of playfulness" (Watson and Corke, 2015 p.367).

4.7.3 Play and Silence

Play also includes silence. Nye acknowledges the importance of silence: “Children who choose not to speak are not spaces where ‘nothing’ is happening. Silence can be a way of saying something so important that it can’t be put into words” (2009a p.45). Applying Nye’s thinking to my study cohort makes me wonder how and if this group of children use silence. Is it used to disengage or is it a way of communicating something very important? Silence is more than an absence of sound, there can also be a quality of stillness. I wonder if silence becomes something different for non-verbal children. It may be necessary to recognise it as a language of its own, into which any gesture, suggestion of movement or the slightest indication of playfulness needs a response and careful interpretation. It is likely to be different for each child.

4.8 Spiritual signatures

Nye identified that each child in her research had their own, as she termed it, spiritual signature. She recognised the danger of putting children’s experiences into neat categories ran the risk of misrepresenting the children’s spirituality. “The practical implication is that one needs to enquire carefully about and attend to each child’s personal style if one is to ‘hear’ their spirituality at all” (2006 pp.97 - 98). I suggest that identifying a spiritual signature demands an awareness of each child’s play and playfulness and “to what they communicate with their whole body and person” (Champagne, 2003 p.45). This demands paying attention to verbal and non-verbal language, observing movement and reactions, awareness of interactions and responses. This also indicates a way that the spirituality of PMLD children can be heard. In later work, Nye questions whether it is necessary for children to be conscious of their spirituality. Her conclusion, drawn from psychodynamic research, is that it is not necessary. What is significant is the early relationships and “intense emotional interconnection which babies and young children co-create with their carers” (Nye, 2018b p.142). I propose this supports a relational approach to spirituality, seen through a relational understanding of person. This therefore has a bearing on each child’s spiritual signature for it will be created by and through the relationships and experiences that the children encounter.

4.9 The dependency and vulnerability of children

All children can be seen as dependent and vulnerable. The study cohort is particularly so as they will always be dependent and vulnerable. Children are living within a consumerist society that prioritises the pursuit of material wealth. There is a danger of exploitation for anyone considered to be vulnerable. Hyde proposes the danger comes from relationships

developing with material goods rather than with one's own self, others or with nature or God, restricting people to their superficial selves (Hyde, 2008 p.143). Hyde sees this as a particular risk for children's spirituality. Children are at risk of becoming objects, not subjects, in a world more concerned with materialism.

Studies have shown that severely disabled children are at very high risk of abuse and harm precisely because of their dependency and vulnerability (Friedrich, 2012; Ann Craft Trust, 2018). The adult world can very easily damage children's experiences "making children powerless and ultimately silent." (Richards, 2009 p.39) As Rowan Williams has reflected "children need to be allowed to be children, protected from being sexualised, projected onto or seen as burdens interfering with 'real' life" (2000 p.47).

There is an added vulnerability for the study cohort due to their complex health needs, requiring frequent medical interventions. Therefore, how severely disabled children's spirituality is viewed within healthcare needs to be considered. I do not intend rehearsing my arguments against the healthcare focus on assessment as discussed above. (3.4.) Assessments fit with the medical 'fix it' model of disability. Children's spirituality is not something to be fixed, but something that needs to be nurtured and allowed to flourish.

4.10 Children's Spirituality in healthcare

There are three pieces of research from healthcare practice that, despite working within nomothetic frameworks, are trying to broaden the approach to children's spirituality. Alister Bull, a children's hospital chaplain, finds the language of 'spirituality' unhelpful as it "produces a language that makes some suspicious, gives academics plenty to argue about and leaves practitioners ambivalent to what it means to both the carer and the patient" (2016 p.13). He argues for a common language to provide a shared understanding, which he describes as connectedness: "Connectedness is a diagnostic language that helps us all understand each other whatever the beliefs, the surroundings or the experience" (2016 p.95). His ideas are influenced by Vygotsky's understanding of zones of proximal learning, applying that to considering zones of proximal connection. He recognises the importance of enabling children to tell their own stories, advocating play and storytelling to enable this. He has devised story cards and Likert scales inviting the child to tell him what is most important to them whilst they are in hospital.

I welcome Bull's use of play and storytelling and appreciate how his approach links with that of Ross and McSherry, (2018) (3.4), focusing on what is important to the child at that

moment. However, I am concerned that by solely focusing on 'connectedness' this becomes a narrow approach. I suggest this approach could remain superficial, concentrating on what a child is connected to, which then can become a homogenous checklist for assessment purposes. As indicated by Nye with her emphasis on relational consciousness and spiritual signatures, it is more significant to consider how connections are made and the relationships that are then forthcoming, which contribute to a child's expression of spirituality. It must also be noted Bull's approach has been designed for verbal children. His approach gathers sensitive information a vulnerable child may not wish to discuss with a comparative stranger. The most vulnerable children on a ward will be those who are severely disabled and non-verbal. It is not obvious how Bull's approach would work for them.

Paul Nash, Katherine Darby and Sally Nash, part of the chaplaincy team at Birmingham Hospital for Sick Children have also developed a play-based approach which they have named Interpretive Spiritual Encounters (ISEs). They define an ISE as "the significant participative nature of the encounter that creates and offers the time and space for (children) to explore safely spiritual needs…or whatever is on their minds" (2015 p.31). A variety of activities are used to spark a conversation, as it is recognised that a standard set of questions is not appropriate. However, similarly to the issues with Bull, the aim of this work, whilst acknowledging that the children have a right not to participate, is to illicit information to be used as an assessment. I note that there is a prescribed list of activities which the team feel promote ISEs. This approach is adult led and runs the risk of focusing on the end product, not the processing within an encounter. I note that a feedback form is required to be completed after each encounter, which is a standard procedure within an outcomes focused organisation such as healthcare. However, I suggest having to complete feedback forms runs the risk of shifting the focus from the child and onto the adult's achievement, thereby potentially silencing the child. I also note that despite working in a hospital for sick children, Nash et al, make no reference to severely disabled, non-verbal children.

The assessment procedures described above do not allow for free spontaneous play, which is where, I am proposing, children's spirituality is best seen. Part of the problem may be a lack of recognition of the individual play signals used by PMLD children. Let an anecdote from my own work experience illustrate how play can happen. I was sitting next to a severely disabled young person with no voluntary movement whilst they were in their wheelchair. I was suddenly aware this young person was making a very quiet clicking sound with their

tongue. I clicked back. We had a 'click' conversation for a few minutes and a slow smile began to appear on the young person's face. We had begun to play.

My anecdote illustrates the value of attentiveness when sitting next to a child and the importance of simply being with them. This was one conclusion from a workshop run for community-based healthcare professionals (HCPs) working with life limited children (Llewellyn, 2015). It was realised that remaining alongside, being informal and 'being there' were key attributes required from healthcare professions. "This quality of informality appears to be intrinsic to spiritual care. It implies an authenticity and allows the nature of care to emerge in the relationship between HCP and families..." (Llewellyn, 2015 p.237).

Working on the relationship between professional and person is reflected in David Coulter's approach as a physician for PMLD patients, in America (Coulter, 2002). This is very different from other assessments reviewed. Coulter acknowledges that it is not easy to recognise spirituality for this group of people, but he maintains that it is present, stating that it is easier "to describe rather than define" (2002 p.2). He proposes that having first got in touch with one's own spirituality, it is necessary to look three times to recognise spirituality in this group. The first 'look' focuses on the person – who is this person, what is important to them, who do they love? The second 'look' asks that this person is seen as a human being, with their own point of view, acknowledging what each other has in common. The third 'look' Coulter suggests, rarely happens, but it is the moment when the observer is able to "see in the other person the ground of all being…to see the face of God in the other" (2002 p.7). Coulter describes this moment as being truly breath-taking, involving looking deeply into the other's eyes.

I relate Coulter's 'third look' to Nye's sense of relational consciousness. I speculate that the 'looking deeply' and the 'breath-taking moment' is when relational consciousness within PMLD children can be sensed and acknowledged. This needs to be sensed by the observer/listener because it is encountered non-verbally. Skilful attention that notices the most fleeting response is required. This emphasises the importance of self-awareness and reflexivity as identified by Coulter and Nye. This echoes the same prerequisites for spiritual care made by healthcare researchers (3.3.6, 3.3.7).

Whilst appreciating the constraints that Bull and Nash et al are working under and welcoming their understanding that play makes an important contribution, I am concerned

that their approaches could easily become adult led, prescribed and product driven. In contrast, Llewellyn and Coulter's approaches are person centred, emphasising the importance of being present, and recognising the dependency and vulnerability of the person.

4.11 Creating a broad description for Children's Spirituality

My multi-faceted exploration has been with the aim of creating a broad description of children's spirituality. I have argued in previous chapters that a definition of spirituality is not helpful, nor does it capture the depth and breadth of what is entailed in Children's Spirituality. I agree with Nye when she proposes that "it might be more useful to describe children's spirituality than to secure a definition" (2018a p.217). Acknowledging that my study cohort's complex needs may make it harder to recognise their spirituality, I advocate that the core of their spirituality is the same as for all other children. I propose the following as a possible description:

Children's Spirituality needs to be understood from within children's everyday experiences. From those experiences they become aware of themselves, others, the world around them, and what some would call God, others would call the Transcendent or the Other. They experience wonder and awe, delight and despair. They discover a sense of what is of value and significance to them. There is also the discovery of mystery and being able to live with the unknown, the unexplained. Their spirituality is expressed through play and playfulness; it is embodied in every action that they take. Their spirituality is found in laughter, smiles and giggles as well as in the tears and suffering that is part of what it is to be human. Their vulnerability and dependency are features of their spirituality.

Children's Spirituality is founded on their relationships with themselves, others, the world around them and with God/The Other. Children's attachment to significant adults is important. This is part of normal psychological development for all children. These relationships are explored through play and interactions with others. Intentional acts will signal the desire for play or engagement and these form part of their living spirituality.

Children's ability to be in 'flow', totally absorbed in an activity which holds all their attention is a feature of their spirituality. They are able to live fully in the present moment. This is a feature of their being in the world and could be described as a vocation of 'being.' Children live at the edge of their being and knowing allowing their creativity in play to take them further as they explore their worlds. There is a richness in their being, where the end

product is less important than the process. Children are able to play vicariously, enjoying the experiences of others, thus developing their relationships with other people.

There is the breath-taking 'shift' that occurs when children encounter a significant depth of understanding through their experiences. This seems to happen when they get in touch with a deeper sense of self or others, or the world or God/The Other. This is 'relational consciousness,' a moment of deep connection. This may not be expressed in words; it can also be expressed through silence.

However, the vulnerable nature of children's spirituality puts them at risk in a world that is focused on productivity and materialism. Children are at risk of becoming objects, of being exploited and abused. Their voices are easily missed and ignored if adult needs pre-dominate. Their spiritual voices can be difficult to recognise; therefore, children need theological advocates to enable their voices to be heard.

Children's Spirituality needs nurturing and encouragement to flourish. It needs a safe environment, allowing children to find their own meanings. There needs to be an informality, a sense of adults being alongside rather than leading. There needs to be an attentive adult that allows the silent voices to be heard, in verbal and non-verbal language. For children's spirituality to be recognised, heard and valued by adults, the adults need to be in touch with their own spirituality with the accompanying grace and humility to put children first. When children's spirituality is acknowledged and recognised, it reflects an image of God that is countercultural and confrontational. It challenges views of power and status. Engaging with children's spirituality is demanding, requiring full attention to detail, to verbal and non-verbal language, to the whole of the child's being. It is transformative work.

4.12 Summary of Chapter Four

In this chapter I have explored children's spirituality through a theological perspective, that of *imago Dei*, bringing that into conversation with social science, educational and healthcare contributions. From these explorations I have created a broad description of Children's Spirituality which highlights the complexity of children's spirituality. Paradoxically, I suggest it also highlights the simplicity of children's spirituality. Children's spirituality is about 'being.' There does not seem to be any evidence proposing that the spirituality of children with complex and profound disabilities is different from other children. I suggest it is the same because first and foremost, severely disabled children are children, expressing spirituality in the same way that all children do, through their being, through embodiment and play.

However, I have speculated that non-verbal severely disabled children might use silence in a different way to verbal children. What is important, I propose, is to acknowledge that skilled attention is required to find a way, as Matthews (2013 p.78) suggests, to fathom out how to successfully engage with this group, in order to recognise and support their spirituality.

For the work of chaplains in children's hospice care it is imperative to find ways of hearing severely disabled children's voices and finding their spiritual signatures. Once that is heard, it then may be possible to find what is being revealed by these children as *imago Dei*. As Nye prophetically says: "Phrases like… 'children are made in the image of God' demand much more of us than lip service…they demand action and transformation in real children's often complicated lives" (2009a p.17). It is important not to sentimentalise the study cohort's situation, but, as Eiesland (1994 p.14) suggests, they lived a difficult life ordinarily, even though their disabilities and medical conditions could seem to be overwhelmingly complex. However, it is from the complex realities of their situations that the children's unique spiritual signatures will be formed. Therefore, I suggest the action and transformation Nye demands, reflected in my research questions, involves finding a method of incorporating ideographic children's spiritual signatures, which I maintain are not appropriate to formally assess, within the nomothetical holistic assessment process. It is essential that there are ways to include this significant information to enable severely disabled children's spirituality to be heard and recognised and responded to meaningfully. It is the task of the next chapter to propose methods arising from my methodology, that will contribute to enabling severely disabled, non-verbal children's spiritual voices to be heard.

Chapter 5 Methodology

5.1 Introduction

This chapter explores the underpinning methodology for this project, examining the epistemological basis for the research and the lenses I am bringing to bear to make sense of this epistemology in practice. I detail how my methodology influences the methods selected to carry out the fieldwork component and data analysis for my research. My methodology enables findings to emerge that work towards answering my research questions: What is it that enables severely disabled children's spirituality to be heard and recognised? What enables those practising in a healthcare context to recognise spirituality and so respond to it meaningfully?

5.2 Epistemology – different ways of knowing

In Chapter Three I discussed the predominance of nomothetic knowledge within healthcare. Using nomothetic knowledge to determine scientific truths demands that they are falsifiable, replicable and generalisable. This positivist approach assumes that reality can be known objectively, using quantifiable methods of enquiry. I have argued that spirituality does not fit into this way of knowing, instead a different way of knowing is necessary that understands and appreciates unique, non-replicable and ungeneralisable ideographic knowledge (3.8). My research makes the theological assumption that the children have an innate capacity for spirituality. How I know this and how I know that this information is valid, valuable and true is the epistemological basis for the research. Swinton and Mowatt discuss three kinds of knowing: knowledge of the other, knowledge of phenomena and reflexive knowing (2016 p.32). My research requires knowledge of the other and reflexive knowing.

5.2.1 Knowledge of the other

Knowledge of the other is particularly relevant to my work as it allows the experience of silenced groups to be made explicit and given a public voice. This is a critical epistemological position as I maintain my study group is powerless as their voices are not heard. Their voices can be heard, I suggest, through a co-constructionist approach to knowledge formation which does not assume prior knowledge of the truth. Instead, it allows truth to emerge from the interaction between the researcher, the participants and the research itself. Together, I and the children become "co-creators in the knowledge building process" (Hesse-Biber, 2017 p.7). Central to this approach is the understanding that social reality is continually being created "through the ways we interact with each other" (Mcleod, 2011 p.51). This approach centres, Mcleod proposes, on relationships, with meaning being

constructed using language, rituals, conversations and other artefacts (2011 p.52). The emphasis on relationships is congruent with my theological exploration of *imago Dei* and the significance of relationality (4.2). Through relationality, co-constructive knowledge can be created. However, I note the reliance on language in Mcleod's approach. The children in my study do not use verbal language. I argue that their non-verbal language contributes to creating a social reality. The issue remains that in the past, their language and voices have not been included in the creative process of co-constructing knowledge of the other.

Essential for this dynamic, co-constructive process of creating knowledge of the other is the understanding that the children involved are participants and subjects, not objects of research. It is not appropriate to consider them as co-researchers, but their input through my encounters with them is an essential contribution to the valid knowledge about their spirituality. However, using the children's input requires an interpretive approach that looks for the deeper meanings within the reality. To discern the deeper meanings requires reflexive knowing.

5.2.2 Reflexive knowing

Swinton and Mowatt describe the process of reflexive knowing as the way a researcher "deliberately turns their attention to their own processes of constructing the world" (2016 p.33). They also claim reflexivity is the most crucial dimension within the qualitative research process because it is a way of knowing that accepts it is impossible for the researcher to be distanced from the research. The researcher's knowledge, generated through the research process, needs to be incorporated into the work. In this way, the researcher becomes the "primary tool that is used to access the meanings of the situation being explored" (Swinton and Mowatt, 2016 p.57). This suggests there needs to be epistemological reflexivity reflecting on the assumptions made during the research. Marilys Guillemin and Lynn Gillam summarise the reflexive process as one of "critical reflection both on the kind of knowledge produced from research and how that knowledge is generated," therefore, knowledge is constructed "as a reflexive process" (Guillemin and Gillam, 2004 p.274).

My reflexivity is influenced by my autobiographical history. My occupational therapy training uses specialised observation and assessment skills within a medical context. It uses nomothetic knowledge. My theological knowledge is developed through my personal commitments and study and therefore is better described as ideographic knowledge. I am

exploring an under-researched area which necessitates a heuristic approach. Therefore, I need to be aware that my intuitive judgements in conjunction with my professional and theological knowledge will have a bearing on the methods used and my interpretation of the findings. This is illustrated in my choice of methods as detailed below. As summarised by Swinton and Mowatt, reflexivity "makes explicit the reasons behind particular modes of engagement, the choice of methods…and the impact of the researcher's personal history and pre-suppositions on the situation" (2016 p.58).

To be reflexive demands a high level of self-knowledge and self-awareness. My understanding of my reflexivity has been influenced and developed by other women. Through supervisions with my female supervisors and in exploring Leach's model of theological reflection I discovered *Women's Ways of Knowing* by Mary Field Belenky et al (Belenky, 1986). This research highlights that for women, 'voice' rather that 'sight' acts as a metaphor for women's knowing. They propose that 'sight' metaphors are frequently used within scientific and philosophical reasoning, for example describing something as 'illuminating.' These visual metaphors suggest that distance from an issue is needed, to be able to get a proper view. In contrast, Belenky suggests that 'voice' metaphors require proximity, for "the ear operates by registering nearby subtle change… (it) requires closeness between subject and object…speaking and listening suggest dialogue and interaction" (Belenky, 1986 p.18). This, I realised, is my intuitive way of knowing and has influenced this research from the very beginning in my aspiration to concentrate on hearing these children speak. However, solely paying attention to voice runs the risk of not paying attention to sight metaphors such as the three 'looks' described by Coulter (2002) (4.10). For this research, voice metaphors and sight metaphors are both needed, to enable a fully attentive approach to the different types of evidence.

In summary, my epistemological framework, using co-construction and reflexivity, requires my research to be carried out in conjunction with others, for the resultant truths need to be sought and explored communally. This approach echoes the theological understanding of *imago Dei* explored earlier (4.5). This way of knowing can contribute to the reality of the nature of humanity and the nature of God.

5.3 Applying co-construction and reflexivity to this research

Acknowledging that I cannot be distanced from this research is an important part of the necessary reflexive process. I am emotionally invested in it and it is associated with my previous work in a children's hospice. I was often asked how I managed to work in that

environment, the assumption being that it was very sad and therefore a difficult place to be in. I usually replied that it was not sad, there were times of great intensity when there were very sad moments, but there were also times of great joy, fun and laughter. In other words, being in a children's hospice was like ordinary life, but lived intensively. However, the more profound answer is that I could only do the work because of my personal commitment as a chaplain. This is true wherever I work, be it in the hospice, or in research, and best described by Ruffing's phrase "service mysticism" (2001a p.104). Similarly, to spirituality and play, mysticism is a concept acknowledged to be "very difficult to define" (Sheldrake, 2007 p.39). My understanding of mysticism for this context refers to a prayer life, that engages all the senses, continually trying to deepen a relationship with God, out of which comes action.

This understanding resonates with Sölle, who suggests that "the mystical eye sees God at work: seeing, hearing, acting, even in forms that are utterly secular…A mysticism of wide-open eyes" (2001 p.284). For Sölle, this is especially so within liberation movements, which is an underlying influence throughout my work. Nor does she see mysticism as exclusive, in her opinion, "we are all mystics" (2001 p.15). Sölle's emphasis on sight may seem to contradict my intuitive position that emphasises voice and hearing. However, whilst I acknowledge that is my preference, I need to engage all my senses within this research.

Ruffing proposes that service mysticism leads to social transformation. The social transformation that I am seeking is a wider appreciation of the significance of these children's spirituality. I have identified these children as marginalised and am proposing that it is imperative that their voice is heard for that is where God is to be found. From a theological point of view, if the link between action and mysticism is lost, then the resulting action can enable the unjust situation to continue because of "a lack of analysis about the causes" (Ruffing, 2001a p.115).

The action I am working towards is the co-construction of a deeper understanding of this group of children's spirituality, created between the children and myself. The reflexivity required to achieve this demands contemplation and attention which are significant elements of mysticism. Therefore, to co-construct and be reflexive in this research requires an understanding and practice of contemplation and attention.

5.3.1 Contemplation

Contemplation is deeply rooted within the Christian tradition, focusing on the stilling and silencing of self in order to be able to listen and hear God. Teresa of Avila's approach, described by Rowan Williams as "a matter of the sustained awareness of living within the movement of God's love into creation, through the life and death of Jesus Christ" (1991 p.10). Contemplative prayer is not of the intellect or rational thought. It is prayer as a process of becoming ever closer to God. This process, as described by Teresa of Avila, moves from a state of doing things for God to being where "God does things for you" (Williams, 1991 p.55). Contemplative prayer is one way of developing a relationship with God and, in Clayton's phrase, is "characterized more by being than doing…and responds more from the heart than from the intellect" (2015 p.42).

My understanding of contemplation suggests it requires the ability to stay with and be present to whatever is occurring, be that joyful or distressing. It is listening for God, about God and with God. Contemplation takes practice and repetition. It is a way of praying that is my personal preference, using silence and stillness to become more "attuned to the silent music of the heart" (Clayton, 2015 p.36). Through this practice, it becomes easier to adopt the contemplative stance, as advocated by Clayton, which creates space and time for others (Clayton, 2015 p.37). A contemplative stance involves attentive listening to what is said and not said, paying attention to the non-verbal language. It also involves watchfulness and waiting which requires patience. Saunders, in her description of setting up the first adult hospice in Britain, describes the phrase "watch with me" as the foundation for her hospice, stating that it means "really looking" at the person concerned, with respect, warmth and friendship (Saunders, 2016 pp. 21 - 22).

It is obvious that I am applying a Christian view of contemplation to my research. However, it is worth appreciating that 'contemplation' and 'contemplative practice' are phrases finding resonances within non-religious settings, particularly in American Higher Education. These resonances are of value here, suggesting that the application of contemplation within learning and teaching has implications for using contemplation within research. Olen Gunnlaugson and colleagues propose that "contemplative process and method is well equipped to enhance, deepen and broaden academic thought and praxis" (2014 p.1). They consider introducing contemplative practices into teaching and learning environments enables all concerned to "deepen their awareness of and engagement with self, others and the world" (2014 p.2). It is not certain whether Gunnlaugson et al realise that they are using

phrases associated with spirituality in various contexts. They imply that relationships with self, others and the world are deepened through contemplation. I add that from a Christian perspective, the practice of contemplation deepens the relationship with God. Therefore, including contemplation within the methodology for research into spirituality, in which relationships with God, self, others and the world is central, is valid.

5.3.2 Attention

To develop a contemplative stance requires attention to this research process, to the relationship with oneself, attention to the relationship with the other, and, within my Christian tradition, attention to the relationship with God. As Leach emphasises: "being attentive is not a mindless or a passive business" (2007 p.24). Attention is required in the moment, responding and engaging as necessary. Psychologist Mohamed Khaldi describes attention as "the act of using our senses" (2005 p.63). He suggests that attention begins with the ability to concentrate, which then requires the ability to process what is happening by taking an interest. The information thus received needs care and an appropriate response. As a result of this process of attention, there is respect "for what our senses have heard, seen and tasted, smelled or touched" (Khadli, 2005 p.63). Attention thus described is an active process, which is needed when applied to Leach's Pastoral Theology as Attention and I suggest is the active component needed in conjunction with contemplation.

Pauline Oliveros includes Khaldi's understanding of attention in her development of Deep Listening, her approach to music composition. She defines Deep Listening as "listening in every possible way to everything possible to hear" (2010 p.73). Her approach is relevant to my work as she distinguishes between hearing and listening. "To hear is the physical means that enables perception. To listen is *to give attention* to what is perceived acoustically and psychologically." (*my italics*) (Oliveros, 2010 p.xxii) In my own work, for clarity, I am including the understanding of giving attention to what is heard, the active process of listening, within my use of the word 'hearing.' 'Hearing', in my context, requires observing and noticing subtle changes. It needs proximity to the children to physically hear them. To be able to hear what is being expressed requires repeated listening with all the senses. Listening in this way, as identified by Slee, is not only key to every stage of the research but is also a particularly feminist form of spiritual practice, giving "the most attentive listening to self, other and God we can manage" (2013 p.28). For this research, in which I seek to hear the unheard voices of the children, methods that give attention to all that might be perceived are required.

The methods chosen for my fieldwork with this group of vulnerable children reflect my methodology by incorporating contemplative and attentive structures. This included paying specific attention to ethical procedures which contributed to the careful consideration of the methods used for data collection, analysis and discussion.

5.4 Ethical Issues

"How did you get ethical approval for that?" was a frequent response whenever I described my research. This comment bears out Shannon Phelan and Elizabeth Kinsella's observation that conducting qualitative research with any group of children is considered by many "to be impossible" (2013 p.81), let alone with disabled children.

The appreciation that children have a right to participate is relatively new. It is enshrined in the UN Convention on the Rights of the Child which states that all children have a right to provision, protection and participation (United Nations Assembly, 1989). However, there is a growing tension between the need for protection and the need to participate, as highlighted by Ann Farrell: "These are times of globalised research productivity, on the one hand, and systematic protective surveillance of children in research, on the other" (2005a p.1). Consequently, direct research with children, due to their vulnerability, is seen as high risk and not readily conducted. However, as I hope this project proves, research with children, including those with severe disabilities is possible and is of benefit not only to the children and their families, but also to society. As one of the parents said to me, when I asked why she had agreed to take part, "children like Andrew don't get asked to be involved in research, but I think he should be, just like everyone else, he has so much to tell us" (RJ 9/6/2016).

5.4.1 Procedural Ethics

Marilys Guillemin and Lynn Gillam distinguish between procedural ethics and 'ethics in practice', stating that both are needed to maintain research integrity (Guillemin and Gillam, 2004 p.277). Procedural Ethics are the formal ethical approvals needed to conduct the research. For my work, ethical approval was needed from Anglia Ruskin University (ARU) and from East Anglia's Children's Hospices (EACH).

5.4.1.1 ARU Ethical Approval

Stage Two Ethical Approval was required for this project. This was awarded by Anglia Ruskin FREP from 10th February 2016 for one year, then renewed until October 2019, by which time all the necessary fieldwork visits had been completed (Appendix 1). (At the time of the original ethical approval application I was registered for an MPhil, conducting the fieldwork on confirmation of ethical approval. I was upgraded to PhD status 8/3/17.)

I proposed visiting each child in their own home, with either a parent or carer present. Working this way acknowledged the children's high medical and physical needs and provided the necessary safeguards for their welfare. This is in line with ethical research practice involving children with severe disabilities as discussed by Tina Detheridge, educational researcher. She highlights that "removing pupils, whose understanding of the world is very limited, from their familiar environments can be very distressing." Detheridge also points out that working with these children with unfamiliar people and surroundings potentially results in poor responses, providing an "inadequate basis for drawing conclusions" (2000 p.113). This supported my intention to work co-constructively by being with the children in an environment best suited to them. A further safeguard was provided by my hospice employment, giving the families an assurance of my professional standing and confirmation that I held an enhanced Disclosure and Barring Service Check Certificate (DBS).

It was essential that the children and families knew that their confidentiality would be maintained. For this reason, to protect the children and their families I decided not to disclose any specific medical information about the children. Many of the children's medical conditions were uniquely complex, therefore any disclosed details could have resulted in them being easily identified. Throughout the data analysis I used the term 'medical intervention' to describe any event or occurrence connected with their medical condition.

As part of their confidentiality, I asked the children and families to choose their own special name as their identifier for the research. The names chosen by the children or their parents were: Andrew, Dragonfly, Olaf, Superman, Elsa and Butterfly. It was explained to the children that these would be their names for the project and the names that I would use to write about them. It was re-iterated that only they, their parents and myself would know their project names. This supported my position that the children were participants in the research, not objects of research, to be valued as co-constructors in the findings.

5.4.1.2 Issues concerning Consent

There must be an acknowledgement that informed consent could only be sought from the parents of the children concerned. As Jill Harshaw succinctly puts it: “the kind of data being sought from [the children] requires a level of understanding and capacity for self-expression that cannot be expected” (2016 p.73).

Parents were asked to complete two forms, one for parental consent and the other on behalf of their child (Appendices 2, 3). I experimented with producing the children’s participation information and consent forms in ‘widget’, a pictorial written language frequently used in special education. However, the resulting ‘translation’ was a large document, unlikely to engage the children or hold their attention. Instead I devised a simplified story board (Appendix 4). I decided that I would use this at each visit, to remind the children why I was there and what we might want to do together. I used a picture of myself, the same one that was on my ARU ID badge which I also showed them at the first visit. I had simple pictures of happy or sad faces, a book, bubbles to represent playing and a picture to represent being quiet. The story board was a useful way of reminding the parents why I was there and became part of the opening ritual for each visit. It had limited success with the children. Butterfly used it to make choices and to indicate mood. For Dragonfly, Superman, and Elsa it became something to play with. It made a satisfying rattling sound and could be easily thrown and discarded. Andrew seemed to listen to my description of each picture, but it was not a useful way for him to indicate choice. Olaf declined to look at it, sweeping it off his wheelchair tray.

This illustrates the level of attention needed to ensure that each child’s responses were accepted and respected within their role of being research participants. It also illustrates the difficulty of obtaining informed consent from severely disabled children. As discussed above, it must be acknowledged that this group of children’s understanding of the project could not be determined. Obtaining informed consent from the parents gave me their permission to spend time with their child. However, I did not assume that the child would be willing to engage with me in any way. The underlying principle was that the children always had the right to engage or to disengage and that this could be made obvious by the children. I also appreciated that this would vary throughout the encounters and that I needed to be aware that this could change very quickly. I needed to be working with principles of assent and dissent to enable the research to be child led.

5.4.1.3 Principles of Assent

My experience of working with severely disabled children gave me the insight that the children would be able to give clear signals of assent or dissent. Monica Cuskelly describes the necessity for researchers working with this group of children to be able to "interpret a passing moment of irritation or a desire to withdraw" (2005 p.102). This was proved in the encounters that I had with the children, occurring in a variety of ways and was frequently checked throughout an encounter. The descriptions of how the children used the story board also illustrate assent and dissent signs. For Olaf, he clearly did not assent to using the story board as a means of engaging with me. Dissent or disengaging was shown by other children by falling asleep or looking away if no longer interested. Elsa hid behind a toy for one session, indicating that she did not want to interact with me. Dragonfly pushed herself away from me at the start of one encounter. Assent indicators from the children included smiling when I showed 'thumbs up', making eye contact with me or placing a finger on the story board to choose an activity. All the children were able to show a level of agency about whether they were happy to work with me at any given moment within a session. One advantage of working with severely disabled children is that their assent or dissent is authentic. They do not have the social or cognitive skills to disguise their genuine responses therefore do not respond just to please the researcher. They are not as suggestible as other children may be to authority figures.

5.4.1.4 Risk Assessment

For this project, to accompany the ARU Stage Two Ethical Approval form, I completed a Risk Assessment (Appendix 5). This focused on potential risks to the children and myself as a lone worker. By insisting that the parents or carers would always be present, and by following the Hospice lone working policy, the fieldwork component of the project scored as a low risk activity.

5.4.1.5 EACH Ethical Approval

Ethical Approval was obtained from EACH on 14/1/2016 (Appendix 6). The Nurse Consultant Children's Palliative Care, with lead role for research, was instrumental in supporting the application to the Clinical Governance Committee (Subcommittee of Trustee Board with delegated responsibility for research). It was agreed that I would be very clear with the families involved that this research was independent of the hospice and did not affect their access to hospice services in any way.

I gained permission to use the hospice database to identify possible families to contact. I also agreed to the strictest confidentiality so that only I, my line manager and the Director of Care knew the names of the families taking part. No other staff were informed of the children involved in the project. Staff were aware that I was undertaking the work and were asked to inform me if any of the families concerned brought it up with them. In order to keep the boundaries between my hospice work and research work distinct, contact concerning the research was made via my university email or the dedicated mobile phone. All information collected was kept on my university computer drive. All information regarding the children and families was appropriately and safely stored, as required by the General Data Protection Regulations (Information Commissioner's Office, 2018).

My line manager and the Director of Care acted as my lone worker contacts for the fieldwork visits, in line with the hospice lone worker policy. These two individuals knew the families that I was visiting, but not the children's research names.

5.4.2 Ethics in Practice

However, as many researchers working with children have identified (Guillemin and Gillam, 2004; Farrell, 2005b; Cocks, 2006; Nutbrown, 2011; Groundwater-Smith, 2015) ethical research is more than the completion of the formal ethical procedures. Paying attention to ethics in practice and responding appropriately to "ethically important moments" (Guillemin and Gillam, 2004 p.262) is a way of ensuring rigorous, respectful and responsible research.

Guillemin and Gillam describe reflexivity as "the bridge between procedural and ethics in practice" (2004 p.273). It ensures that the needs of the child remain central to the research and that an ethical approach is maintained throughout every stage of the research process. For this research, this meant I needed to pay careful and continual attention to ethics in practice throughout the fieldwork visits and in the subsequent data analysis and dissemination of the findings. This approach compliments the reflexive methodology of the research.

As identified by researchers, such as Alison Cocks, it is important in research with vulnerable groups that the participants have as clear as possible an understanding of the short-lived nature of the research relationship (Cocks, 2006 p.260). In order to provide the

children and parents with information concerning the number of visits I would be making I used button bags.

Figure 4 Button bags used to count number of visits

I had two little bags, one for the child and one for myself. At the beginning of the first session I counted out six buttons with the children to show them that I would be coming six times. At the end of each session the children or the parents/carers chose a button to go into their bag. I would count how many were left in my bag to show how many more times I would be coming. The parents used the bags to remind the children that I was coming, they were with the children when I arrived at the start of the sessions. At the final session, at the beginning I would show the children the last button in my bag, explaining that this was the last time that I would be coming to see them at home for the project. At the end of every session, the children were thanked and bid 'goodbye.'

As part of ethics in practice, there was the need to be prepared for the "ethically important moments", described by Baker et al as "those difficult, subtle and usually unpredictable situations that arise during research practice" (2016 p.607). An example of this arose with Olaf, who, when choosing his project name was able to indicate that he wanted to be called after a television character. However, to do so would have made him instantly recognisable to hospice staff. In order to protect his confidentiality, his mother and I had to disappoint him. This happened in my first encounter with him. Although it was the ethically responsible reaction at the time, I wonder if this subsequently affected his relationship with me. There were other instances, such as a parent leaving me on my own with their child whilst they attended to something else. I recognised this showed that the parent trusted me with their child, but I also had to instantaneously make the decision that ethically, it was appropriate for this to happen.

In order to keep ethics in practice in mind and to be prepared for ethically important moments as they arose, it was essential that I was reflectively attentive. Discussing issues with my supervisors as they arose as well as writing in my research journal and my contemplative prayer practice enabled me to pay attention to what was being revealed through my own approach. This became a continuous experience of the "infinite mystery…" (Cameron and Duce, 2013 p.23), an ongoing sense of the revelation of God.

5.5 Data Collection

Within the growing corpus of published practical theology research, hermeneutical phenomenology is a common methodological and epistemological approach. The hermeneutic tradition seeks "deep understanding by interpreting the meaning of interactions, actions and objects" (Hesse-Biber, 2017 p.23). Used in conjunction with a phenomenological approach which "attempts to understand the hidden meanings and the essence of an experience together with how participants make sense of these" (Grbich, 2013 p.92), this appeared to be suited to my research. However, the methods used within this approach are usually language based, using interviews with participants to hold in-depth conversations exploring the meaning of different experiences.

Whilst hermeneutical phenomenology is a valid approach to achieve academic rigour, it excludes anyone who does not communicate verbally and therefore the children in my research. Harshaw (2016) tackled this issue in her research considering the spiritual experience of profoundly disabled people. Her solution, working within a church-based context, was to use a theological method that sought to understand God's relationship with profoundly learning disabled rather than trying to understand their spiritual experience of God. Although her research is specifically focused on the spirituality of severely disabled people, her approach is not appropriate for my context. Harshaw researched within a faith-based setting, where theological language and traditions are readily understood. Within healthcare settings, where spirituality is not necessarily linked to faith-based traditions, in order to achieve academic rigour and validity it was necessary to consider alternative methods.

As explored in Chapter Four, children's spirituality is embodied and expressed through their 'ordinary'. The 'ordinary' for children is seen in their play and their relationships with themselves, family and friends within everyday lives. For the research group, the complexity of their medical and physical conditions was part of their 'ordinary'. This was different for each child and could not be systematically measured against a list of potential spiritual

indicators. Due to the variable nature of their disabilities, this group of children could not be considered as homogeneous. I required data collection methods that could capture the children's ideographic experiences.

Amanda Begley, researching views of disabled children in education, points out, "if the research aim is to understand how children feel about themselves, the researcher should gather views directly from the children" (2000 p.99). It was not possible to gather views directly from my study cohort using semi-structured interview techniques. My chosen method was to spend time with the children, paying attention to them, waiting to see what happened, adopting a contemplative stance. These times could not be classified as interviews, therefore I called them encounters. From my professional background, I appreciated that play, in all its different forms, could be a way of inviting the children to engage with me. Play, as previously discussed, (4.7), is an essential component of the ordinary for children. Through play and by being with the children, I hoped to be able to gain an appreciation of their spiritual signatures and of their collective voice concerning the spirituality of severely disabled children.

5.5.1 Selection of participants

My aim was to work with six children. This allowed for a range of disabilities within the PMLD criteria and for enough data to be generated to be able to explore the collective voice of the children as well as seeking to find their personal spiritual voice.

I used an 'opt in' approach by contacting twenty-six families with severely disabled children. Families were asked to contact me directly if they were interested in the project so that I could contact them (Appendix 7). These letters were sent out from the hospice. Eight families made an initial reply, one of these after the deadline, this family became the reserve. The seven families who had given permission for further contact were sent further information and consent forms (Appendices 8, 9).

Six families replied giving signed consent on behalf of their child and for themselves to take part in the project. The families were contacted with an approximate time scale of when they would be visited for the research. Five of the initial six families responded to this second contact. I then contacted the reserve family who were still interested in being involved. The families were visited one at a time, for six consecutive sessions. The visits were conducted from June 2016 to July 2017.

Of the six children who took part, four were girls, two were boys. Their ages ranged from 5 years to 11 years old and the ethnic background of all the children was 'white.'

Based on my professional experience of working with severely disabled children, I planned six consecutive sessions with each child. I was aware that it took time for this group of children to become familiar with someone, getting to know their voice, and to begin to build up a relationship. I also hoped that by visiting each child six times it would be possible to see a range of situations and interactions.

5.5.2 Structure of the sessions

Each visit began by asking the children if they were happy to work with me and for me to be there. Where appropriate I used the story board to reinforce this. Throughout the session I tried to be sensitive and alert to recognising when the children had had enough. In order to be able to see the children and their facial expressions, I sat adjacent to them, making sure that I was either sitting lower than them or at their eye level, so that they could see my face and I could see theirs. This position also enabled me to be aware of their body movements and breathing rates.

I chose to audio-record each encounter to capture what happened each time. This supported my reflexive position of prioritising 'voice'. It also allowed for deeper listening through repeated hearings. I made the ethical decision not to video record the encounters, as I felt this was too intrusive for the children and families. The children required personal care and medical interventions during my time with them. To video record these interventions would have been an invasion of their privacy which I did not feel was justified or appropriate. I also needed to consider practicalities as the location for each encounter varied, therefore setting up video recording would have been difficult and time consuming.

The audio recording method of data collection was successful. It was easy to set up and the audio recorder was discrete and non-intrusive. I ensured that the children and parents knew that the recorder was on. I was able to comment to the children on their behaviours and actions as the recording was taking place, such as: "I can see you are smiling". This also helped me when transcribing the recordings to provide contextual detail. For a couple of children, the recorder became something to play with. For Butterfly, helping me to turn it on and off became part of the ritual of our encounters. I became increasingly aware that the

recordings were of value to the families, it seemed that they had not considered recording their children themselves. The recordings were sent to the families at the end of the project.

The parents or carers would sometimes stay for the whole time, or I was left with the child, with the parent within calling distance. Due to the varying medical complexities of the children this was appropriate and necessary. During the first few sessions with each child, I would check with the parents for any particular signs or symptoms that I needed to pay attention to.

5.5.3 Choosing their project name

The initial session for each child focused on choosing their project name. I used pictures of cartoon characters, animals, flowers, a train, a rainbow etc. With their parent present, I would go through the pictures and note their reaction. Smiles, or reaching for the card indicated that they liked that object, other cards were taken and thrown, or the children looked away. I found that the children made a definite positive response to one of the pictures, ignored most of the others, and made a less definite positive response to some. When the children had chosen or responded to a few of the cards, I would go through the ones selected again. The children selected the same card as first chosen. This worked for four of the children. One child's parent had already chosen their name before the first session and as discussed above; Olaf's name was selected by his parent.

Figure 5 Feely bag available for the children

The second and subsequent encounters were child led. I took a bag of small toys and story books with me which worked with some children and was ignored by others. The key to working with this group of children focused on being with them, giving them my attention and seeing what emerged. I would have resources with me, but it was entirely up to them whether they chose to engage with me or the resources that I

brought. My method was to be with them in their 'ordinary' of that moment, which may have been taken up with a medical intervention, being quiet or playing. I used this method to see if within that 'ordinary' I could gain an understanding of their spirituality, based on the approach Adams et al suggest of "sensitive and quiet observation…in order to appreciate the spiritual moments of the children…" (2008 p.38). My findings from these sensitive, attentive observations are discussed in the following chapters. It is important to note that due to the complexity of their medical conditions, there could be several appropriate interruptions whilst their parents or carers provided the children with their necessary care. This had to take priority during my visit and is evidence of the continual need to pay attention to ethics in practice.

As far as possible, the six sessions were on consecutive weeks, however, due to varying circumstances either for the families or myself, there were occasions when there was a fortnight's gap between the visits.

Table 3 showing number of sessions and length of recording in minutes for each child

	Andrew	**Butterfly**	**Dragonfly**	**Elsa**	**Olaf**	**Superman**
Session 1	27	37	28	52	18	33
Session 2	39	50	30	55	50	42
Session 3	48	Unwell, no session	48	47	49	46
Session 4	7	47	30	60	60	47
Session 5	49	26	41	48	25*	45
Session 6	32	56	40	59	50	25

*recording stopped as toy fell on recorder

In total, 35 sessions were audio recorded and transcribed for later data analysis.

5.5.4 My own research journal

Swinton and Mowatt suggest that keeping a research journal helps support the reliability and reflexivity of the research (2016 p.66). I was aware that I needed to pay attention to my experience of being with the children for these encounters. Recording my feelings, thoughts and impressions in my research journal enabled me to become attentive to my own voice, an important step for Pastoral Theology as Attention (Leach, 2007 p.25).The journal became an essential tool as I realised that the data was more than the transcripts or personal reflections. Writing the journal after every encounter developed my reflexivity. It enabled me to appreciate how the data lived within me through the impressions the children made on me and the feelings that being with the children engendered. The journal contributed to my research data as I explored, analysed and interpreted all that had occurred (Appendix 10).

5.6 Selecting appropriate methods of data analysis

The data collected consisted of the audio recordings, my observations and my research journal. The audio recordings consisted mainly of non-verbal sounds such as grunts, crying, 'raspberries' and giggles, along with times of silence, all of which were significant depending on the context in which they were made. This meant that I needed to find a way of analysing the different vocalisations and absences of sounds in order to try and gain an understanding of what was potentially being expressed.

It is noteworthy that different data analysis methods use phrases such as: 'allow the text (data) to speak', 'be with the text (data)', 'pay attention', 'be open', 'be aware', 'reflect'. These are words that can equally apply to contemplation and attention. My methods selected for data analysis reflect my contemplative and attentive stance.

5.6.1 Using an adapted Content Analysis Approach

Content analysis is used for large volume text-based documents such as business and legal reports. It is also used to analyse multi-media content, looking for the number of times and patterns of word use, and can be combined with thematic analysis (Grbich, 2013 p.189). My transcripts could not be considered large text documents; but adapting this approach to produce a visual linear diagram, showing who was present and when different interventions happened, enabled me to highlight and give attention to the many happenings within an encounter. These included medical and carer interventions, times of silence, times of vocalisation and movement. Working this way provided a visual method of being able to see

patterns and movement within an encounter. This approach helped to illustrate the relationships the children had with different members of their family. The significance of these patterns is discussed further in the next chapter.

Solely using this approach was not enough to capture the full picture of each encounter nor the potential common themes. To identity commonalities, an adaptation of thematic analysis was used to further explore the data.

5.6.2 Using an adaptation of Thematic Analysis

I needed a method that would enable me to highlight important and significant moments. Thematic Analysis, although more commonly used for verbatim transcripts, provided me with a method that could be adapted to do this with non-verbal data. Richard Boyatzis describes thematic analysis as a way of seeing a pattern or something of significance. “It allows a researcher using a qualitative method to more easily communicate his or her observations, findings and interpretation of meaning to others who are using different methods” (1998 p.6). Boyatzis describes Thematic Analysis (TA) as a tool to be used to discover themes within the qualitative information. TA involves finding the “codable moment”, (Boyatzis, 1998 p.1) recognising something important and then seeing if it recurs elsewhere. These ‘codable moments’ become codes that are then grouped into themes. Developing codes involves reading, re-reading and re-reading again the data and needs the researcher to be “open to sensing themes” (Boyatzis, 1998 p.13).

Psychologists Virginia Braun and Victoria Clarke have developed the use of TA further, suggesting that it is a method in its own right: “a flexible and useful research tool, which can potentially provide a rich and detailed, yet complex account of data” (2006 p.5). They suggest that this method provides the basic skills needed for qualitative research, which can then be further developed to be used in other methods (Braun and Clarke, 2006 p.4). Braun and Clarke also suggest that TA can be a particularly useful method when investigating under-researched areas as it can help bring out the rich over-arching themes present in the data (Braun and Clarke, 2006 p.11). Therefore, this method was particularly suited to my study.

Developing codes for the data can be theory driven, taken from prior data or inductive, using the raw data. Inductive thematic analysis was appropriate for this project, using the raw data gathered from the encounters, the parents and my reflections. As already noted, there

appears to be no other prior data captured in this way for my cohort. It demanded reflexivity on my part, putting aside any pre-conceptions and being faithful to the data to allow commonalities to emerge. This combined with the frequent re-listening and re-reading involved, matched the contemplative stance that I adopted. This, I suggest, is a way of being empty-handed, where "real attentiveness to…the other depends upon an evacuation of the ego…" (Jacobs, 2001 p.104). It was where I had to lose myself, as Jacobs suggests, within the object of my contemplation, becoming totally open to and absorbed within the data.

Themes are identified as either 'semantic' or 'latent' (Braun and Clarke, 2006 p.13). Semantic themes focus on what has been said or written. The researcher does not look beyond that and the resulting analysis produced is descriptive. For my data, what was said was in the form of 'para-linguistics', body movements and silences. Therefore, to find the semantic aspect to produce the children's spiritual signatures, I needed to focus on what happened within the encounters considering when movements, sounds and silences occurred. I could not produce themes in the standard TA way; however, I was able to collate codeable moments into groups relevant to each child. Consequently, I refer to 'findings' rather than to themes. In traditional TA, latent themes involve interpretation, looking deeper for the underlying meanings of what has occurred, thereby producing an analysis from interpretative work which is already theorised. My adaptation of this was to use latent analysis of the findings to identify and interpret the collective voice of the children.

"Analysis involves a constant moving back and forward between the entire data set, the coded extracts…and the analysis of data…" (Braun and Clarke, 2006 p.15). There is also the encouragement that there is likely to be a pile of 'miscellaneous' codes. They are of value too, although that code may only appear once, it might be an essential part of the overall analysis. The need to go 'back and forward' over the collected data was essential to search for semantic and latent findings.

5.7 Data Analysis Process

Data used:

- Recordings of each session
- Transcript of each session
- My reflection notes written after each session
- Comments from parents extracted from the recordings and those given to me after recording stopped.

The data analysis process is summarised in the table below:

Table 4 Data Process stages

Stage	Task	Comment
1	Transcription – First Listening	Completed as soon as possible after session.
2	First reading of each transcript	Mind map made of observations Undertaken after all the sessions had taken place
3	Second reading of each transcript	A further, more detailed mind map of observations created
4	Repeated Listening to each recording	Notes taken through listening on observations, transcript not followed
5	Creating Content Analysis charts	To show overall patterns within and between the different encounters
6	Finding codable moments from each transcript	Codable moments put onto 'post it' notes onto large sheets of paper. Each moment given identifier label
7	Grouping of codable moments for each child	Initial list of findings proposed. First Findings map created.
8	Using each child's initial list of findings to create their personal spiritual signature (Ch 6) Reviewing and theming parent comments	Further findings emerging Re-reading all transcripts, mind maps and notes – looking for anything missed. Review parent comments for each child Review/refine findings
9	Reviewing initial Findings map	To show inter-relationships, using data collected in Step 8.
10	Refining Findings map	
11	Findings map	Showing main findings
12	My Reflections	reviewing and analysing my reflections
13	Discussion (Ch 7, 8)	Using Findings maps, personal spiritual signatures of each child, my reflections.

5.7.1 Stage One: Transcription – First Listening

I decided, due to the nature of the recordings, to transcribe the 35 encounters myself. My practice was to listen to and transcribe each session as soon as possible after each recording was made, and before the next session with that child. I was able to recall what had happened and explain various sounds because I was transcribing so soon after the recording. I became aware, through this process, that I had not heard all that had gone on whilst physically present during an encounter.

This method of attentive listening enabled me to appreciate and realise the amount of vocalising that the children were doing. It enabled me to listen more deeply to what had occurred within each encounter. I found I needed to note the pitch and volume of the variety of sounds made. It was through the careful listening to what had gone on within an encounter that I became increasingly aware of the different ways in which the children responded. As a result, my listening skills developed as the fieldwork continued, becoming more skilled at recognising the significance of the variety of sounds and times of silence that each child used.

For all the children I was transcribing paralinguistic components – non-verbal sounds such as grunts, raspberries, giggles, crying, distress sounds. One child had some verbal components along with the paralinguistic. Different behavioural patterns were also noted such as increased animation and vocalisation when excited. I observed that three of the children had self-comforting behavioural patterns that they used during the encounters. Noting the time when a child made a sound or behaved in a particular way was important as it enabled me to detail the duration of silence or vocalisations or behaviours.

Transcribing in this way became part of my contemplative spiritual practice supporting my reflexive process. It was, as Slee describes, “a way of embodied visceral listening” for it enabled me to reflect on my emotional engagement within the encounters (2013 p.29). It was difficult to listen again to Dragonfly when she was very upset and in pain during Encounter Three. It was a delight to listen again to Superman’s laughter and I found myself smiling as the recording played, enjoying the encounter again through the recording. I found that I felt peaceful after listening again to the shared silence in the last encounter with Andrew. The transcription process was a way to give “reverence to our subjects’ [the children’s] lives” (Slee, 2013, p.29). Working through the process of transcribing also improved my fieldwork skills. I can notice a change in the way I worked over the 35

encounters that were recorded and transcribed (Appendix 11: transcription examples). I note that I am able to simply be with the children, rather than being concerned about doing things with them.

Once each encounter was transcribed, I deliberately did not review them until I began the next phase of the data analysis. I needed to leave contemplative space before my next encounter with the transcripts so that I could come to them refreshed, ready to go deeper.

5.7.2 Stage Two and Three: First and second readings

Stage two comprised reading through each transcript. A notes page was created detailing significant points. Stage three repeated this process, the resulting notes page contained greater detail (Appendices 12, 13).

5.7.3 Stage Four: Listening again

This stage involved listening to each recording again, without reference to the transcript. This involved going back and forth within each recording, repeatedly listening for greater depth in my observations. I noted my impressions and thoughts, trying to "listen to everything possible" (Oliveros, 2010 p.73) on the recordings. This produced more detail for each encounter (Appendix 14).

5.7.4 Stage Five: Content Analysis Charts

Using the transcripts and notes of my impressions, I produced linear diagrams to show the content and movement of each encounter. This was an alternative way of showing who was present and when, who was vocalising and when and an indication of what might have been affecting observed behaviours (Appendix 15).

For stages two – five I had worked through each child's sessions in numerical order. I realised that as I was becoming increasingly familiar with the data, I was anticipating what was happening rather than examining each occurrence in detail and looking for greater depth. I decided for stage six I would work in a more random fashion to concentrate more effectively on each separate transcript. This became another important part of the contemplative space that each transcript needed.

5.7.5 Stage Six: Finding codeable moments

Due to the nature of the collected data it was obvious that computer assisted programmes (such as NVIVO) were not appropriate for code identification. I used a manual approach. Each line of script was given an identifying code to be able to pinpoint its exact position in the corresponding transcript. For example, ***D.6.1.2.a*** refers to **D**ragonfly script, Encounter **6**, page **1**, section **2**, line **a.**

Each transcript was analysed for codable moments. The simplest way to do this was to write each codable moment onto a sticky note and stick it onto a large sheet of paper (Appendix 16). This meant that I had a way of beginning to move the data about and look for emerging patterns or findings. I used this process for the parent and carer comments and my own recorded interjections.

5.7.6 Stage Seven: Emerging themes

I decided I needed different sets of findings to be able to collate them for each child's individual signature and for the children's collective voice. Set one collated the findings for each child. Set two collated each child's parent/carer comments. Set three combined all the children's codable moments. Set four combined all the parental codable moments. Set five considered at my interjections within each session and to then combine those with my own journal written after each encounter.

After 'deconstructing' each encounter into different codable moments, I categorised them for each child. This led to an initial list of codeable moments, such as who they responded to, types of sounds made, response to toys. These were not common to all children (Appendix 17). By transferring these categories onto an Excel spreadsheet, I was able to sort and connect the different categories. These were cross referenced with the content analysis sheets and the original transcripts (Appendix 18). Working this way enabled me to see that there were consistent categories, developing into findings shared between all the children.

5.7.7 Stage Eight: Set one - refining the thematic analysis to find the spiritual signatures for each child.

To create the spiritual signatures for each child, I began by writing a brief description of them and their circumstances, with an overview of each session. I re-grouped the initial list of codable moments identified for each child into two main groups, their own world and the wider world (Appendix 19). I then spent time with each child's findings, taking a

contemplative and reflective stance to see what emerged for each child. I wanted to use the findings to show how each child expressed their spirituality. I wrote reflective notes for each child and used these to partially create each child's unique spiritual signature. This involved ethics in practice, as I decided to redact sensitive information. I questioned whether the parents would want to read certain information about their child in ten or twenty-year's time, especially with the possibility their child would no longer be alive. Attention to ethics in practice influenced the way I wrote their signatures. I decided not to use a technique sometimes used within person-centred work that writes statements about an individual in the first person. For this work, I was aware that I could not know for certain what each child would want me to say on their behalf. Ethically, I needed to write in the third person.

5.7.8 Stages Nine – Eleven: refining the thematic maps

Once I had written the spiritual signatures for each child and included the parent comments, I reviewed and refined the finding groups. This resulted in further Findings maps (Appendix 20).

5.7.9 Stage Twelve: My Research Journal

My reflections were written as soon as possible after each encounter and before transcribing the sessions (Appendix 10). My reflections were subjective, capturing my immediate impressions and feelings about the encounters. I recorded what was foremost in my mind following each session, in free writing style. They also capture comments and events that happened either before the recorder was turned on or after it was turned off. I then deliberately did not look at my journal again until I reached Stage Twelve in the data analysis process.

My aim, by not returning to my research journal until this stage, was to try and ensure that my views, feelings and understandings impacted as little as possible on the findings for the children. This was not easy, as I was emotionally invested in the research, therefore using reflexivity helped to ensure that as far as possible I was hearing the children's voices. I approached reviewing my journal in the same way as the children's encounter transcripts. I read each entry through, then repeated the process used with the children's transcripts, making initial notes. I read through a third and fourth time, noting comments about myself and the children. I intentionally left time between each reading to give contemplative space to ponder my reflections. I recognised that each time I worked through the journal entries I was able to extract more information as I became more attentive to the detail. For example,

I noticed that the significance of Andrew's interaction with me in Encounter 6 is not recorded in my reflections, instead I had concentrated on how I felt after spending time with him and his impact on me.

From spending time reading, musing and allowing the text to speak to me, I had observations to add to the spiritual signatures of each child and the combined analysis work. I noticed observations about the family's relationships with the children, the fieldwork process itself and the impact of the fieldwork on the families and on myself (Appendix 21).

My reflections evidence how I developed as a researcher. I notice I stopped being the Occupational Therapist working to get the children engaged through activities. I become noticeably quieter and more relaxed, confident in being contemplative with the children, listening, watching and waiting for whatever emerged. This was an energising, intense and transformative personal experience. Despite the medical complexities they encountered, all the children possessed a vitality and zest for life. It was a joy to be with them.

5.7.10 Issues of triangulation

In the same way that I have identified issues concerning consent with this research group, I recognise that there are issues of triangulation. The purpose of triangulation is to be able to corroborate research findings using different data sources. Vicky Lewis and Mary Kellet acknowledge that when researching severely disabled children "traditional methods of triangulation may not be possible" (2004 p.200). My experience supports this view. As already stated, this is an under researched area, I have not been able to find an independent alternative data source with which to compare my findings nor was it possible to ask the children if I had understood them correctly. The corroborating data sources available were my research journal and feedback from the parents. My research journal along with the detailed analysis of the transcripts and parental comments adds to the co-construction of my findings but it is not an independent or unbiased source. In the same way, the feedback from the parents is also biased. I provided them with their own child's spiritual signature and a summary of the key findings. I received feedback from four of them and their comments were very encouraging:

'I have read through your write up and think it's brilliant. I think it captures Andrew really well and I can really tell that you have understood a lot about him through your sessions together.' (email from Andrew's mother 30/4/2018)

'It's lovely Sue and very interesting. I haven't read it all but I've read some and it gives such a wonderful picture of Dragonfly's communication. It's lovely!' (email from Dragonfly's mother 1/5/2018)

As encouraging and supportive as these comments are, they cannot be considered true triangulation. Harshaw points out the issue with considering this as method of triangulation is the question: "whose words are heard?" (2016 p.71). These answers reflect the parental understanding of their children, which is very valid. I acknowledge that the parents are important advocates and interpreters for their children, but I cannot know that Dragonfly would describe my description of her as lovely.

5.8 Summary of Chapter Five

This chapter has discussed the theological framework that underpins my methodology. The theoretical frameworks underpinning my research and the important ethical issues involved have been identified. I have outlined the data collection methods used and discussed the adapted data analysis methods applied to the data. The findings from the data analysis will be discussed in conjunction with the literature explored in Chapters Two, Three and Four. Chapter Six prioritises the children's voices, detailing their personal spiritual signatures. Chapter Seven relates the findings that have emerged to my first research question. Chapter Eight explores how the findings from the fieldwork can be developed into practice within a healthcare setting.

Chapter 6 Hearing the Children Speak

Having explored the academic and theological voices in Chapters Two, Three and Four, and detailed my methodology and methods in Chapter Five, this chapter priorities the children's voices and what I perceive to have heard each of them speak about their spirituality. I present the children's personal spiritual signatures, created from the detailed observations and findings heard from the children through my encounters with them. These spiritual

signatures support my contention that the children are shouting out their spirituality, what is needed is deep listening that enables their spirituality to be heard. I have used narrative and detailed 'thick' descriptions to present their signatures.

6.1 Introducing the children

I introduce Andrew, Elsa, Superman, Dragonfly, Olaf and Butterfly with a portrait of each of them. This provides the context for each child, detailing family situation, necessary details of their physical abilities and my understanding of their communication. Appreciating how they communicate and how they use their bodies reflects Elaine Champagne's approach, (4.6) which proposes children's spirituality is embodied (2003). Therefore, all their sounds, behaviours, reactions and actions are able to provide an insight into their spirituality.

My observations led me to recognise that happiness, enjoyment, distress, pain, being cross and discomfort were conveyed through sounds by the children. The vocalisations varied in pitch and types of sound – ranging from 'mmm' and 'pfft' sounds, to raspberries, grizzling, loud shrieks and squeals. Higher pitched sounds could indicate happiness or distress. The frequency of the sounds was also an indicator of mood, more frequent sounds seemed to indicate unhappiness or being unsure. Sounds made in a regular way seemed to indicate being happy. As I spent more time with each child, I built up a picture of these meanings, learning their unique language.

All the children used different facial expressions. They all smiled, two of them had an 'eyes wide open' expression that indicated alertness and listening. Body movements such as extending their bodies and stretching out would usually indicate being uncomfortable or distressed. Turning their heads away was usually an indicator of 'no'. It is therefore reasonable to state from these observations the children were communicating a range of emotions, choice, and indications of relationships through their body language and non-verbal vocalisations. This broader understanding of communication enables, I propose, hearing the children speak of their spirituality.

Having first given a portrait of each child, I then give what I perceive to be their spiritual signature. Throughout the encounters, my aim was to follow Hay and Nye's principle of attending to each child's personal style, to see if I could 'hear' their spirituality (Hay and Nye, 2006 p.97 - 98). Providing a detailed description of each child can be described as a 'thick' description as defined by Geertz (1993 p.10). For, as Gaventa points out creating 'A "thick" description…would involve much time, care and attention to the multiple ways that spirituality can be expressed in someone's life…'(2018 p.49). This was required to be able to write each

child's unique spiritual signature. The data used to write their spiritual signatures was from the semantic analysis of the transcripts. The spiritual signatures capture what I was able to observe about their relationships with themselves, others and the world around them (Appendix 22 provides an overview of each child's encounters).

6.2 The Children's Portraits and Spiritual Signatures

6.2.1 Andrew

Figure 6 Picture card used for Andrew

Andrew, six years old, lived with his parents and sibling in an adapted property. He needed support for all his personal care and high-level medical interventions. He was a quiet child; it is not always obvious when he was engaging but he appeared to be aware of what was happening around him. His mother reported that he would go to sleep if he is not interested. He often appeared to have his eyes closed, but this did not necessarily mean that he was asleep. Andrew had visual and hearing impairments. His mother described his world as the area immediately in front of him.

His complex medical conditions dominated the encounters, requiring regular interventions from his mother or carer. Due to the complexity of his physical and medical needs, his movements were not always under his control. His movements could indicate engagement and contentment, they could also be an indicator that medical intervention was required. Intentional movements took considerable energy and effort and were often very small, such as very delicate movements of his fingers.

Andrew interacted with his world through these very small intentional movements. He derived great pleasure from feeling different textures such as a very soft bear. These small movements enabled him to create sounds when he touched the wind chimes. This he would do in silence, concentrating on the sounds that he was creating or the textures that he was feeling. This gave him a way of playing independently. He appeared to enjoy having stories read to him, and to enjoy exploring the props for the stories that I brought with me. It is also interesting to note that the buttons and button bag appeared to have significance for him. He

chose a button at the end of each session by reaching out and touching one. He appeared to enjoy the hunt for the button bag in the last encounter which had been put in a safe place by his sibling.

Andrew indicated choice through sound and by reaching for objects that were near to him. He seemed to remember different toys I brought with me, intentionally reaching for them. He also appeared to remember and recognise me and my voice, smiling as I came near him. He knew and recognised the individual cues that his family gave him to help him know who was with him.

The encounters took place in the family living room. One of his parents or carers was always present, his sibling present for three of the encounters. Andrew preferred to be laying down, he was usually side lying on his specialist day bed. The sessions took place during the week after school. Andrew's name for the project was chosen by his mother before the first visit.

6.2.2 Andrew's spiritual signature

Andrew fully lived in the present moment, whether it was distressing or pleasurable. The present could be totally dominated by his medical needs or focused on engaging with a story, being with a member of his family, being quiet or falling asleep

He expressed his emotions and feelings of that moment in his body. His breathing became slower as he relaxed. When listening and concentrating he would smile, opening his eyes wide. He appeared to accept his body's medical needs which significantly dominated his life and therefore I would suggest he had an accepting relationship with his own self. This is evidenced from the way he appeared to go with his body rather than react against it when medical needs were present.

He vocalised intentionally with a range of very quiet sounds that indicated happiness, contentment or distress when unwell. His vocalisations were easily missed as they were so quiet. He needed people to pay attention to the sounds he made because they were significant. The quiet murmur he made when his mother left the room in Encounter One illustrates this. I speculate that this very quiet murmur indicated his awareness of his mother moving away as well as his uncertainty about being left with someone he did not really know.

He would also vocalise more loudly, especially if excited or interested in something that was happening around him.

Andrew was definitely in relationship with his close family. These relationships had meaning for him, shown by the smiles and vocalisations he made with different members of his family. He developed and sustained relationships with others through touch. He responded positively by smiling and vocalising when his parents or sibling kissed him, touched him and spoke to him. I observed his response to his carers, he vocalised in a quieter, less enthusiastic way, which was subtly different to his response to his immediate family.

Andrew acted intentionally, reaching out to touch people, toys, musical instruments that he wished to engage with. He moved his hand away if he did not want to touch something or engage with someone. He reached out to touch in a very delicate, subtle and gentle way, which could be easily missed. Therefore, when he did reach out and touch it was significant. It was his way of expressing the strength of relationships he had or wished to make, such as the deliberate reaching out to touch his mother in Encounter One.

Andrew's relationship with myself developed over the six encounters. There were examples of 'sound' conversations where I echoed back Andrew's sounds. He grew to recognise my voice and smiled when I greeted him at the beginning of the later sessions. He allowed me to put different objects in his hand for him to explore, we also played 'peek-a-boo' which made him laugh. He also chose to not engage with me, falling asleep if he had had enough. Touch featured in this growing relationship, for example we engaged in a 'finger dance'; he allowed me to gently stroke the back of his hand. This relationship culminated in a very small but significant moment in the final encounter when Andrew intentionally tickled my hand.

Andrew appeared to have an awareness of the world beyond his immediate surroundings. He responded by moving or vocalising when people came into the house. He was aware of his sibling moving around between the living room and kitchen. It was not possible from these encounters to know if he had a relationship with the natural world. Anecdotally, his mother described how he enjoyed being by the sea.

Evidence from the encounters does not indicate whether Andrew experienced any transcendence. However, a noticeable development over the sessions was that both Andrew and I became quieter and increasingly still. In the first encounter, even though I was

not aware of it until I listened to the recording, Andrew was continually making vocalisations. In contrast, during the final encounter, Andrew and I were quiet for the majority of the session. There was a sense of being present to one another. This seemed to confirm the sense of peace that Andrew generated in the people who spent time with him. His mother commented that his teachers noticed how other children actively sought him out to sit next to if they were feeling stressed or upset, becoming calmer being in his presence. His mother remarked 'he is so good to chill out with; he is very calming.' (RJ 21/7/16). This was true for myself; I experienced a very deep sense of peace and calm driving away after one encounter. Andrew's mother described this as Andrew's gift. I propose that this reflects Andrew's spiritual signature, that of a quiet, fully living-in-the-moment, peaceful, gentle spirituality that can be felt and recognised by others.

6.2.3 Butterfly

Figure 7 Picture card chosen by Butterfly

Butterfly, eleven years old, lived with her mother in an adapted property. Butterfly needed help with all her personal care, mainly provided by her mother with some carer support during the week. Butterfly's encounters took place on a Saturday afternoon. She would usually be in her wheelchair or in her comfy chair.

Butterfly was very interested and curious in all that went on around her. She liked the button collecting and having her own button bag. She was very good at making sure that I did not forget to offer her a button at the end of every session. She did this by looking at her button bag which was always in sight for the sessions and then looking at me. She was curious about how the recorder worked so I assisted her to turn the recorder on/off each time.

Butterfly 'talked' with her eyes and her face, engaging everyone with her eyes and smile. She indicated how well she knew someone by the size of her smile, giving the largest smile possible to her mother every time. She was able to make her choices and intentions very clear using facial expressions, eye pointing and finger pointing. She was a very skilful eye pointer and could indicate her choices by looking directly at different things or pictures on the story board. She was also able to move her finger to touch something that she wanted if it

was placed within her limited reach or point to something on the story board. This took considerable energy and effort. Butterfly would look away if not interested. She was often uncomfortable and showed this by extending her back and arms whilst sitting in her wheelchair.

Although she used few sounds and vocalisations, Butterfly was very ‘chatty’ when engaging with people. Her mother acted as her interpreter, explaining the meaning of different vocalisations and facial expressions. Due to her medical condition, it took considerable effort and energy for her to move her arms and hands voluntarily. This made it difficult for her to hold or reach for things. She was fed via a gastrostomy tube; she was able to have ‘tasters’ which were a source of great delight by licking a sweet or tasting something put on her lips. Butterfly chose her project name from a selection of picture cards. She was able to make a very definite choice by placing a finger on the butterfly card.

6.2.4 Butterfly’s spiritual signature

Butterfly’s world was full of significant people, memories, and anticipation. She knew that she was important to people and known by others as evidenced by her excitement at going to a party and meeting people she had not seen for a while. She was aware that she was significant in the world and had a place in the world.

She had a great gift of engaging with people through her very skilful communication methods. Butterfly had a beaming smile, which when combined with opening her eyes wide conveyed excitement, happiness and consent. She occasionally made a quiet ‘argh’ sound which seemed to express surprise or delight. She used a downturned mouth or would grizzle to indicate unhappiness or distress and cried if very upset.

She was able to indicate choices. However, it needed attention on the part of others to be alert to the subtle communication methods she used. It was easy to miss some of her subtle eye pointing. Butterfly used silence as part of her communication. Her silence was interesting. It was through listening to the recordings that I realised that she made very few vocalisations and was silent for the majority of the time. During our encounters it felt as if there was a constant flow of conversation. Out of that silence came shared moments, for example watching television with her, and later both of us sucking a sweet. It was notable that those shared moments came in Encounter Six.

She had a great sense of fun and playfulness. She seemed to take vicarious pleasure in my clumsiness when I dropped things. She would also deliberately knock things off her wheelchair tray. Butterfly enjoyed playing imaginary games with me such as pretending to blow out candles. She was very sure to remind me, using her eye pointing skills that I did not forget to offer her a button at the end of the session. She was also very capable of showing utter disdain at my choice of a song, the look on her face when I suggested singing 'Old MacDonald' was a very clear indication of what she thought. This was part of the growing relationship that she and I had over five Encounters. In the final encounter, when we watched a television programme together, there was a quiet companionship as she responded and interacted with the action in the programme.

Butterfly was curious and inquisitive about the world around her. When the neighbour put his keys through the letterbox it was obvious that Butterfly could not settle until she had them to hold. She wanted to know what was in the bags and boxes that I brought, she was alert and curious about the sounds in the garden. She responded to stories of things that happened in the past such as her mother talking about the butterflies they once kept in the garden. Butterfly enjoyed looking at the pictures of her holiday with me, recognising herself and others in the pictures as her mother recalled the events. She was able to anticipate and imagine events in the future such as the party she was going to. Her world was not just the present but had memories of the past and anticipations of the future.

Butterfly enjoyed stories that used props she could feel and explore. She seemed to really engage with *The Very Hungry Caterpillar* story, (Carle, 1987) her eyes opening wide with delight and wonder, vocalising her enjoyment of discovering the large butterfly toy that emerged from the cocoon bag.

Butterfly had a sense of herself. She recognised herself in the mirror, smiling at her reflection, she would often deliberately look at herself in the mirror, spending time and gazing at herself and what she could see. She recognised when she is being talked about such as her mother naming her mood as grumpy caused her to respond by smiling. Her body helped to convey her mood such as when she was tired or uncomfortable. Her body did not always respond as she wanted it to, it could take very long time for her to achieve small movements. She demonstrated great patience and perseverance with herself as it took considerable physical effort for her to be able to do anything for herself, such as putting out her tongue to suck a sweet, which took her six minutes to achieve. This was hard work

and tiring. It took considerable effort to reach out and touch others. Butterfly did do this in the last session when she reached for and held onto her mother's arm. To me, this indicates that the meaning of such actions is significant.

Her most important and significant relationship was with her mother. Her mother recognised this, acknowledging she was the most important person in Butterfly's life. There was lots of eye contact and smiles with her mother. They both enjoyed a sense of playfulness with each other, such as her mother pretending to catch the sweet Butterfly was holding. Butterfly became distressed and anxious when she was not able to see her mother (Encounter Five). In the other sessions, when her mother was near and within sight, then she was able to engage with me. Her mother reported that Butterfly found times of transition difficult, such as people leaving, or when she had to go to bed.

It is not possible to know whether Butterfly experienced any sense of transcendence herself but being in her company whether she was in despair or in happiness touched me deeply. It was good to be in her company; this perhaps reflects the sense of being in the presence of God (the Other) that she called forth in me.

Butterfly's spirituality was an active spirituality, focused on engaging with people, and engaging with herself, understanding herself and working within her own limitations. Her relationship with her mother was her most significant one. However, she was aware of a world beyond this relationship. I suggest that she knows that she matters to her mother and the world.

It was not always easy for Butterfly. Her distress in Encounter Five illustrated the fragility of her world when it did not make sense or feel secure. That fragility triggered a sense of loss. Her mother was 'lost' for a short time, this was enough for her world to collapse for that moment. That was part of Butterfly's active spirituality, of living in this world. It did not always make sense and that was distressful. However, when it did make sense, her smile lit up the world engaging everyone who encountered that smile. Her mother described Butterfly's ability of engaging people by using her eyes and her smile as her gift.

6.2.5 Dragonfly

Figure 8 Picture card chosen by Dragonfly

Dragonfly, eleven years old, lived with her parents and three siblings in an adapted property. All the sessions occurred at the end of the school day. On her arrival home from school she would be transferred out of her wheelchair into her more comfortable relaxing chair. Dragonfly required specific medicines and her feed pump to be attached shortly after she had got home, these interventions happened during the encounters but did not particularly impact her.

I spent time with Dragonfly in the kitchen area of the family home, which was part of a large open plan area incorporating kitchen, dining and living space. The usual family routines of siblings doing homework, meal preparation and entertaining visitors carried on around us whilst I spent time with Dragonfly. It was a busy, happy and hospitable family environment.

Dragonfly had lots of active movements with her arms and her legs and a large range of sounds, including laughter and blowing 'raspberries.' Dragonfly was usually very happy. She had a specific comfort pattern which she regularly used.

During each session, her mother would come over to spend time with her or see to her medical needs and then move away again to attend to the other siblings or household tasks. There was a sense of constant movement throughout the sessions, part of this family's normal lifestyle. Whenever her mother came near her, Dragonfly would smile and often reach out to touch her mother. She did not appear to be distressed when her mother was not with her. Towards the end of each session, carers were present waiting to provide her personal care.

Dragonfly choose her own name for the project. She selected the dragonfly picture from several cards. The dragonfly card received the largest smile and was the card that she reached out for and wanted to hold.

6.2.6 Dragonfly's spiritual signature

Dragonfly was a very lively and animated person, making lots of movements with her arms and legs and a variety of sounds. She blew raspberries, shrieked with delight, laughed and giggled. She made eye contact when engaging with someone and smiled at them. She sometimes scrunched up her face. She used a distinctive rhythmical behaviour pattern which appeared to be self-comforting. If in pain she cried and became very distressed as at the beginning of Encounter Three. If uncomfortable she grizzled. However, once the source of the pain or discomfort was found and resolved, she immediately became calm and happy. If she was bored or not interested, she completely disengaged, becoming very quiet and unresponsive.

There were several occasions where she would be laughing and giggling for no apparent reason. Her laughter was infectious, making other people laugh too. These occasions could last for some time and seemed to give her great pleasure. It could be said that in these times, she was absorbed in her own world. She also had times of complete stillness.

Dragonfly had a definite relationship with her mother. Her face lit up whenever her mother came near her, becoming animated and making eye contact with her mother, intentionally reaching out to touch her. She explored her mother's face and mouth with her fingers and held her mother's hair. Touching and feeling seemed to be important ways for Dragonfly to connect with her mother. She let her mother play with her lips, moving them to encourage her to make a sound. Dragonfly had a playfulness in her relationships as evidenced by the way she teased her mother and me by intentionally looking past us, rather than directly at us on a couple of occasions.

A relationship between myself and Dragonfly seemed to be growing through the first three encounters. She intentionally reached for and held my hand, although never tried to explore my mouth and face with her fingers. She used my hand to tap objects and allowed me to play 'round and round the garden' on her hand. She made eye contact with me and smiled when I spoke to her. She allowed me to hold her hands and distract her while her mother was attending to her medical needs at the beginning of Encounter Three. However, in Encounters Four, Five and Six she very definitely pushed herself away from me and indicated that she did not want to engage with me. We did have some interaction in those last three encounters such as a tapping conversation or a sound conversation. I was left

with the distinct impression that she did not want to fully engage with me at all. This was her right.

This indicates to me that Dragonfly was able to select who she wished to develop a relationship with. This was also evidenced by observing her reactions to other household members. It was noticeable that she did not react or respond to the carers who were present. It was also noticeable that she mainly reacted to one sibling and not to the other two. She responded to the calls of this sibling by looking in their direction and smiling at them.

Dragonfly played with objects, particularly shaking noisy objects. If she dropped something, she did not look for it, it was as if it no longer existed. She had no interest in the buttons or button bag and appeared to be more interested in people, watching the hustle and bustle around her. Dragonfly enjoyed being outside, laughing at the wind, listening to sounds from the neighbours and street. There were clear indications that Dragonfly had a relationship with herself, others and the world outside. Dragonfly was totally present to the moment and lived that moment fully. It may be a moment of great distress such as at the beginning of Encounter Three or it may be a moment filled with laughter for no apparent cause. It is not possible to say whether those moments of sheer delight for no apparent cause were moments of transcendence. Dragonfly's spirituality was seen through her total engagement in the present moment, and as a visitor observed, someone who got pleasure out of the smallest things. (D.5.4.6)

6.2.7 Elsa

Figure 9 Picture card chosen by Elsa

Elsa, six years old, lived with her parents and siblings and pet cat in an adapted property. Elsa had a large smile and became very excited especially when people she knew were near. Her whole body moved as she laughed and smiled. At home, Elsa enjoyed spending time lying on her back on a large mat in the kitchen/dining area, whilst her parents and

siblings carried on with their routines. She could move herself around her mat if she wanted to. On her mat, she had toys and things that were of interest to her within easy reach. She could swipe programmes on her iPad. She would intentionally reach for things to play with or to discard them. Elsa was visited during the week, after school. She was usually lying on her mat when I arrived.

Elsa had a rhythmical pattern of self-comforting behaviours that occurred during every session. These seemed to relate to when she is anxious or on her own with me, or if she did not want to engage with others. However, when Elsa did engage with anyone and played with them, there was lots of laughter and engagement, smiles and giggles. It was infectious. Her whole self was engaged in being playful.

Elsa was not particularly interested in the buttons or button bag. However, she was very definite about choosing Elsa as her project name, deliberately holding onto the Elsa card from the selection offered to her. Elsa liked going to films; *Frozen*, which features a character called Elsa, was one of her favourites.

6.2.8 Elsa's spiritual signature

One of the most striking features about Elsa was the importance and significance of the relationship with her parents. Usually, whenever her parents came near her or called to her, she would smile and become animated. She responded to the games they initiated with her by getting excited, laughing and giggling. These interactions were playful and fun.

There was a difference in the way she interacted with me, depending on whether one of her parents was present. If her mother was present in the background, Elsa interacted with me through play. For example, Elsa taught me to play a game with her in Encounter Three. This developed into me devising a game with Elsa in the following Encounter. These were times of lots of laughter and giggles and animated movement. She had 'sound' conversations with myself and would watch me getting things out of my bag. She was able to direct me to change programmes for her on her iPad using vocalisations that I responded to by adjusting the iPad which then seemed to calm her. She would intentionally give me things to hold and intentionally push my hand away if she did not want me to give things back to her. There was a real growth in the relationship between us.

However, as soon as her parents left the room, Elsa tended to retreat into her own world. For the first few sessions she became distressed when this happened, then seemed to accept that she was left alone with me. She appeared to know that I was sitting next to her, but no longer wanted to interact with me in the same way or with as much animation.

Over the time of the sessions, Elsa's awareness and interaction with her siblings also grew, she responded more to them, so that by the final session, I recorded a brief 'babble' conversation between Elsa and her siblings.

Elsa communicated using her whole body, this is through a range of sounds, movements and facial expressions. She was able to convey a range of emotions such as distress or frustration when she could not do something or her enjoyment in an activity. She was also aware of her body and was able to touch her tummy or her head when asked to do so by her parents.

Elsa's own world was significant to her. She became totally self-absorbed when in her self-comforting pattern. This could be described as 'flow', nothing distracted her when she was in this way of being, nor did she appear to need or respond to her mother or anyone else. Elsa had significant times of silence, not only when absorbed in her own world, but also when concentrating on a game or when transitioning into a new activity. The silence in Encounter Five had a different feel to it. It was not a shared silence between Elsa and other people. She appeared to deliberately place a large board on herself completely covering her face. It seemed as if she was shutting out the rest of the world. Elsa rarely reached out to touch people. I noted one occasion when she held onto my finger for a few moments in Encounter Four. She seemed to prefer reaching out to different objects. Elsa seemed to fix on an object and would become totally absorbed with them. She remembered things I had brought and would look for them and find them in the feely bag.

From these encounters it was not possible to say if Elsa was aware of the outside world. However, she was aware of things going on within the house, outside of her immediate vision and so seemed to have a sense of a world beyond herself.

Elsa's spirituality focused on her relationships with herself and her parents. If this part of her world was making sense to her, then she was able to expand her world to include other people. This was a world of laughter, play and animation. However, if she was very tired or

distressed, she seemed to need to retreat into her self-comforting patterns. This was a world of silence and repetitive behaviours and a world that did not need anyone else in it. It was as if she moved between two contrasting worlds: the playful, animated, laughing and giggling one which drew other people to her and the silent, concentrated, totally self-absorbed one. I wonder if for Elsa to be 'Elsa' she needed time in both worlds. Elsa's gift of being totally absorbed in the moment whether that is in relationship with herself or with others, sums up her spirituality.

6.2.9 Olaf

Figure 10 Picture card chosen for Olaf by his mother

Olaf, seven years old, lived with his mother and older sibling in an adapted property. Other family members were in the household but not present during the sessions. The encounters were held after school, in either the main living room or Olaf's bedroom. Olaf had very definite tastes in television programmes and strong preferences for certain toys. Olaf had some verbal language; he was able to consistently verbalise 'yeah' meaning 'yes'. Olaf had a sense of humour and would laugh during the sessions. He liked making his toys operate and would bang them to make them work and become frustrated when they did not. The strong relationship with his mother was very clear throughout the sessions. Olaf was also a great singer, the louder he sang the happier he seemed to be. He sang tunefully and recognisably to nursery rhymes and theme tunes for children's programmes. Olaf was able to eat orally, however, the effort required was tiring. He would suddenly 'flop', indicating that he was tired.

Choosing his name for the project was a challenge for him. He was not really interested in the picture cards and did not want to select one. He was sounding out the tune for his favourite television programme which might have been the indication of the name he wanted. To preserve his anonymity his mother suggested 'Olaf'.

6.2.10 Olaf's spiritual signature

Olaf's relationship with his mother was very significant to him. Their relationship was expressed through touch, vocalisations, singing and facial expressions as they interacted

and played together. Sometimes their play involved singing together or singing line by line. Sometimes the play focused on different toys which completely absorbed Olaf. On other occasions play was initiated by his mother, using action songs that involved rocking him or moving him up and down.

I also observed Olaf getting cross with his mother, rejecting all the choices that she offered, ignoring her and becoming very unsettled. However, he always said 'thank you' to her in his way, by making a kissing sound, whenever she got the television or iPad working for him or gave him his supper or interacted with him.

Touch was a key indicator of how he built relationships. I observed him intentionally reaching out to touch the top of his mother's head, her face and hands as well as being cuddled by her. He used touch with his favourite toys, often banging them to make them work or holding them close to his eyes to watch them move. He tried to touch the television screen when his favourite programme was on. He became engrossed and totally absorbed in a television programme or a multi-sensory toy. This could be described as 'flow' as nothing would distract him at these times.

Olaf was able to make choices, often indicated by 'yeah', or by reaching for something or eye pointing at something. He was also able to indicate when he did not want to make a choice. Olaf had a great sense of playfulness and humour. On one occasion he deliberately used a silly voice and found it funny when he broke wind or burped. He also mimicked his mother and me as we sipped tea with an 'ahhh' sipping sound. This playfulness and humour were important ways in which he related to other people. However, although different members of the family were sometimes present for a short while in the sessions, there was hardly any interaction observed between Olaf and his relatives at those times.

Olaf was wary of me at first, and gradually came to accept me being with him. It took all the six encounters for him to begin to accept my presence. I wonder if his unsettledness and constant flitting between objects and demands in the first three sessions were connected to him adjusting to me being present in his world. Perhaps I was perceived as a threat and as someone who was going to make changes. The gradual movement during the sessions from myself being an observer to being able to interact with him illustrates that a relationship was beginning to develop. His mother gradually stepped back, having modelled to him that it

was alright to be with me as she gradually involved me as she played with him. I needed to become silent, in order for him to be able to interact more with me.

He showed his acceptance of me being with him by the way he used singing during the last three sessions. The more he sang, the more relaxed and happier he was. It is notable that he did not sing in the first session but sang frequently in the final sessions. In the final session he was able to sing a song with me, taking turns with each line. He was also able to thank me in his way, without being promoted on one occasion. We also enjoyed a 'tap' conversation through repeating tapping patterns back to each other.

Olaf did seem to have an awareness of the wider world. This could be positive for him, he smiled as his mother talked about a special friend he had at school. A story from his mother showed how he engaged with other people in the wider world as he had interacted with a shop assistant who had complimented him on his beautiful eyes. He had blown her a thank-you kiss, which his mother noticed left the assistant beaming and glowing. He recognised the noises coming from the kitchen meant that his supper was being prepared. But the wider world also worried him as indicated by his distress and grizzles as his mother related the stories of going to a car wash and visiting his consultant. The fact that he was startled at unexpected sounds as well as the tumble drier in the kitchen indicated a level of hyper alertness.

Olaf seemed to need input from several things at once. He often needed a favourite musical toy to hold and bang and have either the television or iPad or phone playing programmes too, on mute. He would then become silent, concentrating and absorbed in the toy or the programme. He learnt about the wider world through watching his favourite television programmes. He initiated a game of hide and seek with his mother and me, copying what was happening in the television programme he was watching. This was played by his mother covering him with a blanket, which he pulled off himself, to our 'surprise'. Olaf asked for a specific television programme in every encounter. This was requested by Olaf singing or sounding out the name of the programme. He often needed this programme on in the background. I wondered if this programme acted as a visual and aural 'comfort blanket' for him.

Olaf used imaginative play such as holding the torch to his ear, imitating the doctor's actions from earlier in the day when the doctor used an ear thermometer on him. This type of play

was a re-working of events of the day and so possibly enabled him to make sense of his experiences.

Olaf was able to identify when something is not right, provoking an ‘oh no’ response from him. This happened when a toy stopped working or when a toy got broken. It also happened when he was listening to a nursery rhyme that included the line ‘I took him by the left leg and threw him down the stairs.’ Olaf seemed worried by this perhaps knowing that this was not an appropriate action for someone to carry out to another.

Olaf’s spirituality focused on key relationships with his mother and in relationship to specific television programmes and toys. They seemed to be essential to help him make sense of the world around him. These relationships seemed to hold him, and therefore if those relationships felt secure, other people, such as I myself, were gradually accepted into his world. If those relationships did not feel secure then he became very unsettled. Olaf’s spirituality was not a silent one. It was expressed in his singing or in grizzles and the throwing of toys. I sensed his spirituality was a restless one, a continual seeking to find a sense of contentment. Within that seeking, Olaf had a sense of what was right and wrong. When he did find moments of contentment, his humour, playfulness and singing were expressions of his spirituality.

6.2.11 Superman

Figure 11 Picture card chosen by Superman

Superman, eleven years old, lived with her parents and three siblings. At the start of the encounters, she and her family were waiting to move into another property that could be adapted for her. It was a busy, welcoming household with many people coming and going. Superman was seen after school; her carers were present to provide personal care towards the end of the encounters.

Superman very definitely chose ‘Superman’ as her project name, she reached for the superman card, held it and smiled. She ignored or turned away from the other cards.

Superman had a wide range of vocalisations and enjoyed blowing raspberries. She was very lively and often moved her whole body seemingly for the joy of moving. She always recognised her parents and got very excited when they came near her. She seemed to enjoy the hustle and bustle of all that was going on around her for the first five encounters, as more and more packing boxes appeared. The encounters took place in the kitchen area, where Superman could see and hear the family around her.

The final encounter was conducted in the new property. This encounter had a very different feel. Superman was very quiet and very still. Instead of an open plan style ground floor, Superman and I were in the new living room and none of the rest of the family were there.

6.2.12 Superman's spiritual signature

Superman's world revolved around her family, she appeared to love watching the hustle and bustle of a busy household. She would look around and gaze at all that was going on, smiling and following people with her eyes. In contrast, it was noticeable in the final session how still and silent she became as there was none of the usual family activity around her in the new property.

The importance of being with her parents was very marked. The moment either of them came near her, her face lit up, she smiled and reached out for them, touching their faces and hair, often with shrieks of delight. She played and interacted with her parents.

Superman could also surprise her mother and myself such as the occasion when she sang a single note which her mother had never heard her do before. There was also one occasion where she was responding to her sibling even though she could not see them, which was the first time that her mother was aware of this happening.

I realised that she quietly accepted me from the first encounter. She used touch to connect to me, frequently reaching for my hand, playing with it or holding it. This evolved over the encounters so that we played together and had 'sound' conversations. Superman would sometimes break out into fits of giggles that had no apparent cause; these would make me laugh too. There was a sense of joy and fun during these moments. In contrast she would suddenly become very still and quiet, seemingly focused on something in her inner world.

It is not possible to know whether those times of giggles or times of silence were moments of transcendence for her. But in those times, she was contented and happy, seemingly at peace with the world around her. Superman's spirituality seemed to be focused on the present moment and responding to that moment, either with giggles, or silence or by interacting with another person.

6.3 Summary of Chapter Six

Through creating the children's spiritual signatures, it was clear that each child had a unique expression of spirituality. This is consistent with Nye's understanding of children's spirituality (Hay and Nye, 2006). Andrew's peace, Butterfly's engagement with others, Elsa's retreat into her inner world, Dragonfly's infectious laughter, Olaf's singing and restlessness and Superman's acceptance of whatever was happening around her suggest to me something of their ideographic expression of their spirituality. These thick descriptions reveal "something of the richness and depth of human experience and of…spirituality", the task of thick descriptions identified by Swinton in email correspondence with Gaventa (2018 p.293).

I acknowledge that these observations are my perceptions of each child's spiritual signature. They are my interpretations of what I have heard, based on detailed observations, deep listening, attention and contemplation. I found it a deepening spiritual experience and a sense of becoming very close to these children. It was difficult to leave them at the end of a session if it meant that they were going to be left alone. I loved them all, just for who they were and the fact that they allowed me to be with them. It was also a very real reciprocal relationship between love and knowledge as described by Jacobs (2001 p.43). I loved the children through getting to know them and I came to know them more fully because I loved them.

From the work involved in creating the spiritual signatures, commonalities have emerged which, I propose, contribute to a broader understanding of this group of children's spirituality. This has implications for recognising and hearing the spiritual voices of these children within settings outside of their family contexts. I explore these findings in the next chapter.

Chapter 7 Analysis of the Findings

7.1 Introduction

This chapter begins by briefly recapping the theological lenses, discussed in detail in Chapter Four, used to explore children's spirituality in relation to my specific cohort of severely disabled non-verbal children. I bring these theological lenses, in conjunction with other multi-disciplinary views, into conversation with the analysed fieldwork data to answer my first research question:

> What is it that enables severely disabled children's spirituality to be heard and recognised?

I have identified from the literature and data analysis that these children's spirituality centres on the interplay and interrelationships of their modes of being. The first three findings I explore in this chapter are:

1. The children's relationship with themselves and their own inner world
2. The children's relationship with their wider world within their family
3. The children's relationship with the external world

These interrelationships are nurtured, maintained, seen and recognised through the children's experience and use of play and silence. These are the next two findings analysed:

4. The children's use and experience of play
5. The children's use and experience of silence

A further finding identified concerns:

6. The impact of the children's physical and medical needs upon their spirituality.

The final findings I identify are:

7. The movements the children make between their inner world, their wider family world, and the external world.
8. The children's relationship with God.

The process followed to identify the findings is outlined in Chapter Five (5.7, Appendix 20 for the findings maps). I explore these findings to establish ways in which these children's spirituality can be recognised through the patterns revealed in the data.

Throughout this chapter I draw on other disciplines previously deliberated (4.4) to support the discussion. However, the primary focus is to consider these children's spirituality and the

subsequent contribution to theological knowledge. These children cannot verbally speak of God, but they embody and express God through their lives that are lived meaningfully, in relationship, with a sense of the sacred, in their "difficult lives lived ordinarily" (Eiesland, 1994).

7.2 The Theological Lenses

The grounding theology behind this work starts from the premise that because God loved us first, we then can love (1 John 4:19). This initial loving by God creates the capacity everyone has for natural knowledge and love of God as identified by Augustine and Aquinas. Hay and Nye's significant finding, named as 'relational consciousness' (4.6), demonstrated all children had an innate desire to be in relationship with other (Hay and Nye, 2006). This connects the emergent field of children's spirituality with the traditional teaching of the church as seen in Augustine and Aquinas (4.2).

In my consideration of *imago Dei,* I have argued that God is relational and desires to be in relationship with humanity. Therefore, the most applicable understanding for my context is to see *imago Dei* as *imago Trinitatis*, for this emphasises relationality and community. This view is especially significant for this cohort of children because of their dependency upon their family community for every aspect of their lives. I am proposing it is the mutual indwelling relationships within family communities that enable the children to relate to self, other, the world and God. These relationships potentially mediate God, thus enabling the children to know God through God, as proposed by Volpe (2013) (4.3).

The literature I have reviewed considering children's spirituality and disability theology has consistently emphasised the value of everyday living as the locus of theological meaning-making (4.5,4.6) and that is how I have approached this data, framing it ideographically as seen in the children's spiritual signatures detailed in Chapter Six.

7.3 Analysis of the findings

It is important to appreciate and note it is not possible to provide verbal quotes from non-verbal children, therefore I have used brief description and narrative to provide the appropriate 'quotations' to support my qualitative data analysis.

7.3.1 Finding 1: The children's relationship with themselves and their own inner world

All the definitions and descriptions of spirituality reviewed in the previous chapters, proposed that a relationship to self is part of spirituality (e.g: Meraviglia, 1999; Cortez, 2010; Selvam, 2013; Puchalski, et al., 2014). This is described by Selvam as "a movement towards the self"

which he sees at work within his religious/spirituality framework (2013 p.142). Five out of the six children demonstrated this relationship with self through their ability and desire to be totally engrossed within their own world. A key feature was that no-one else was needed, no-one else was invited into this world. Their inner world was a happy, contented place to be as expressed through their vocalisations and body language. (I address the issue of distress and suffering in Finding 6 below, as part of the discussion concerning the impact of the children's physical and medical condition.) Their time of being in their inner world matched the description of 'flow' as used by Hay and Nye as an indicator of their Awareness Sensing category (4.6). The children were so absorbed in what they were doing that they appeared to be at one with the activity and themselves.

The exception to this state of being totally absorbed in their inner world was Butterfly. In the encounters I had with her, she did not spend time completely engrossed in her own world. There are several factors that may have influenced this. Butterfly appeared to be very curious, wanting to know what was going on and wanting to be involved in everything. She was very aware of all that was going on around her, alert to all sounds and movements by others, both in and outside her home. In the encounters with her, it is possible that due to her curiosity and engagement with others, she did not need to retreat into her inner world. Another interpretation could be that she needed others around her to be in relationship with herself. I suggest that she did have a strong sense of who she was and of herself. This is evidenced for me by her deliberate use of mirrors observing herself and looking for and at others indirectly. She also recognised when she was being talked about and would react and respond appropriately and accordingly. This to me, was Butterfly's way, during my encounters with her, of showing her relationship with herself. She was very aware of who she was.

The other five children spent varying times in their inner world, as detailed in the table below. However, it is important to appreciate the contextual factors influencing the time spent in their inner world. I highlight this by analysing Olaf, Dragonfly and Elsa's time in their own world in more detail.

Table 5 Showing % of time five of the children spent in their inner world in each encounter

Encounters	1	2	3	4	5	6
Andrew	11%	36%	8%	71%	4%	41%
Dragonfly	53%	60%	46%	42%	87%	70%
Elsa	60%	78%	32%	55%	92%	47%
Olaf	0%	6%	12%	13%	4%	11%
Superman	15%	46%	40%	23%	58%	72%

Olaf spent little time in his own world during my encounters with him. In the first encounter, he was cross with the change to his routine and spent most of the short time I was there protesting. He was not able to become totally absorbed in a self-directed activity. By Encounter Four, when he was able to accept my presence, he could retreat into his own world, possibly because he was aware that I was going to respect it. Olaf's time in his own world was influenced by his physical needs of hunger or being uncomfortable, as well as his need for input from several sensory activities at the same time. When these needs were met, he would spend time being completing absorbed, at one with what he was doing. This fits Hay and Nye's (2006) category of awareness sensing or 'flow'. However, Olaf's ability to do this was very dependent on others being able to recognise and meet his needs so that he could spend time in his own world. It was not easy for him to maintain this without assistance.

In contrast, Dragonfly had a very different way of being in her own world. She would become very animated, very noisy and totally engaged in her movements and spontaneous laughter that had no apparent cause. Her delight at being in her own world was embodied, giving an example of Champagne's embodied spirituality (2003) (4.6). Dragonfly was not reliant on support from others or objects to be able to move into her inner world. As seen in the table above, Dragonfly spent a considerable amount of time in her own world, especially in the last three encounters when she had made it obvious that she did not want to engage with me. Being in her own world was her choice, in preference to engaging with me or others.

The fifth encounter with Elsa when she was completely absorbed in her own world, in silence, concentrating on one specific activity provides a further contrast to the way these children experienced their own world. Elsa choose to ignore everyone else; it was obvious that no-one else was going to be invited into her world at that time. She was absorbed and

engrossed in her own self. One interpretation of this time could be that she was very tired and did not have the energy to engage with anyone else. However, during this encounter Elsa did not even respond to her primary carer which was unusual for her. She appeared to be deliberately shutting out the rest of the world, absorbed in her own inner world. As seen in the table above, Elsa appeared to need time her own world in every session, being in her own world appeared to be restorative for her.

I propose that these examples highlight how individual each child was in showing their relationship with themselves. Simply using the factual (nomothetic) evidence from Table 4 does not give the context in which these children were living their ordinary, complex ideographic lives. These children were not able to verbally express their relationship with themselves. With no verbal language to express fatigue, a sense of being 'fed up' or simply wanting to spend time alone, the children used body language and vocalisations. By paying attention and listening to their body language, their vocalisations and their physical reactions I suggest that for five of the children their inner world was revealed to be a happy and contented place in which they were in relationship with self. For Butterfly, her relationship with herself, as observed through my encounters with her, was seen through her interaction with her primary carer, which was a positive and happy relationship. All the children had a relationship with self, expressed in individual ways. It also needs to be appreciated that the children chose whether to enter their inner worlds, demonstrating that they could freely exercise preference at times.

The fact that none of the children were distressed when in their own worlds is, I propose, an indicator that the children were content within themselves when in this mode of being. The evidence from this research supports Simmons and Watson's (2014) challenge to an educational assumption that considers children with profound and multiple learning disabilities do not have the capacity for a sense of self and therefore are not able to relate to themselves (4.4). For all the children in the study, their relationship with themselves had purpose and therefore they were living meaningfully. I propose too, that the way the children related to themselves provides evidence for Matthews' (2013) suggestion of a vocation of being. Dragonfly, in her spontaneous outburst of giggles was simply 'being' at that moment, just as was Elsa in her total immersion in her own world. That sense of 'being' had meaning and purpose for them.

7.3.2 Finding 2: The children's relationship with their wider world within their family

The desire and capacity to relate to others is a further feature of spirituality that is evident in all the literature I have explored. It is the outward movement towards others and the world to which Selvam refers (2013 p.142). I propose it can also be seen as the 'relational consciousness' identified by Hay and Nye (2006), the "emerging awareness of themselves in relation to others, the world and God" (Nye, 2009a p.80). This parallels the Christian understanding of God being relational who desires to be in relationship with humanity and humanity is called to be in relationship with God, self and others. There is an outward movement indicated in LaCugna's description of God as "person-toward-another" (1991 p.14). As I have argued, (4.5) *imago Dei* for this context needs to be understood in Trinitarian, relational terms. To be made in the image of God, God who is three persons in one, is to be in community. Fiddes (2000) describes these dynamic communal relationships as movements of relationships. Therefore, the way the children move into relationships with others contributes to an appreciation of how they are made in the image of God.

My analysis of the data shows that the children were aware of and related to others. They appeared to be able to make deliberate choices about whom they wished to relate to and whom they wished to ignore. This, I suggest, was not based upon intellect, instead it was a desire to engage or not with another. I propose this demonstrates the children had some awareness of their interdependence upon others. I illustrate my analysis with brief descriptions of significant moments to contextualise and strengthen my interpretation of the fieldwork encounters.

7.3.2.1 With parents:

The most significant relationship with 'other' for all the children was with their primary carers, which in this research, were their parents. All the children responded and reacted positively to their parents the moment their parents came into their immediate space. There were intentional relational acts as identified by Ranwez, (1965) deliberately reaching out and touching their parents, smiling, making eye contact, following their parents' movements with their eyes, becoming animated and responding whenever parents came near. All the children were aware when their parents were in the vicinity. It is possible to see these intentional relational acts solely as part of attachment theory, as previously discussed (4.5). However, I propose there is a further level of relationship happening between the children and their parents that takes this relationship beyond simply attachment.

It was evident that both the parents and children were involved in each other's lives. The interaction between parents and children, through play and through the care given were meaningful for both the parent and the child. For example, Andrew was completely aware when his mother was in the room, even though he could not see her due to his visual impairment. In our first encounter, I captured on the recording the tiny sound he made as his mother left the room for a few moments, and the tiny sound he made as she came back in. His mother had never been able to hear this before. Reciprocally, Andrew's mother described how when she was feeling stressed, she spent time with Andrew and completely calmed down (RJ 21/7/16).

I suggest this can be seen as an example of *perichoresis*, the children and parents mutually dwelling in each other's lives. The high level of dependency and vulnerability of these children due to their medical and physical needs would suggest that their parents have to be dwelling in their children's lives. However, it was equally apparent that the children dwell in their parents' lives as illustrated by the example of Andrew and his mother detailed above. It was also seen in the play and interaction between Superman and her father in Encounter Two (S.2.3). This was fun for both of them. Olaf's gentle reaching out to touch and pat the top of his mother's head could be seen in purely attachment terms, the child connecting with its mother (O.4.32.10). It is the same behaviour pattern that can be observed in babies and toddlers, especially when they are feeding. However, seen as a movement of relationship and of intention, it becomes, in my view, deeper than attachment. This is a movement of relationship which I propose illustrates Cunningham's understanding of what might be meant by dwelling in the lives of others (Cunningham, 1998). These movements of relationship can be seen as mutual indwelling, which in theological terms, is *imago Dei / imago Trinitatis.*

Boff (1988) and Fiddes (2000) suggest that the family can be seen as a symbol of Trinity. It was evident that the children were wholly dependent upon their family community in order to thrive and flourish. It is therefore relevant to consider the children's interactions with siblings.

7.3.2.2 With siblings:

Five of the children had siblings which gave me an opportunity to observe movements of relationship within the family. What was striking was the intentionality of their interactions. Dragonfly deliberately chose to respond to one sibling and appeared to deliberately choose not to engage with her other siblings (D.6.2). This indicates that Dragonfly was able to freely choose who she wanted to interact with and equally importantly with whom she did not want to engage.

In Encounter Four I witnessed a game between Superman and one of her siblings. They were out of sight of one another but could hear each other (S.4.13). Superman responded to sounds her sibling was making, who then responded back, this went on for a few moments. They were aware of one another and responding to each other in a way that their parents had not noticed before. It was apparent that the two children were in relationship with one another, at an initial stage of dwelling in one another's lives through play.

The most noteworthy relationship with siblings was observed between Elsa and her two younger siblings. During the first three encounters Elsa did not seem to respond to her siblings at all, although they were in the same room. This changed so that by the final encounter there was a brief but significant interchange between them, as illustrated in the figure below, using raw data from the Content Analysis sheets.

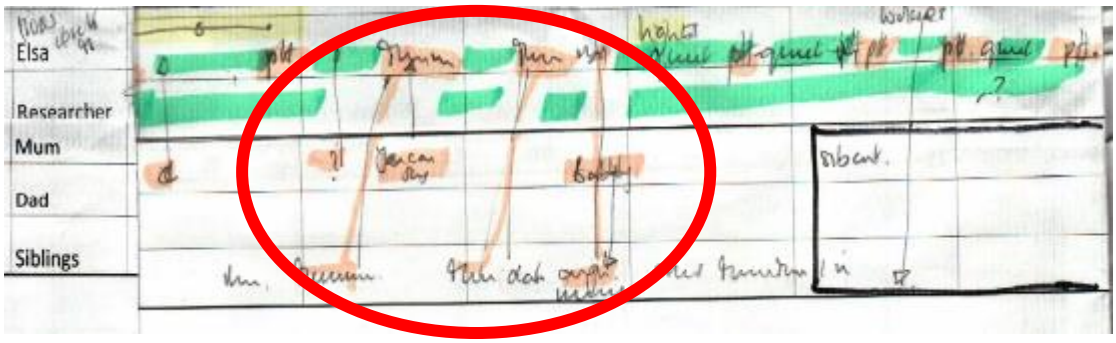


Figure 12 Example from raw data showing interaction between Elsa and siblings in Encounter 6

This was the first time that Elsa's mother had heard such an interchange. It was an example of Elsa's growing awareness of others around her, others within her family and illustrated the beginnings of relationships with others, not just with her primary carers. It is worth noting that Elsa's primary carer, her mother, was present during this interaction. Her mother did not facilitate the interaction, but through being present, it suggests the interaction was enabled to take place.

7.3.2.3 With me:

Having seen how delicately and slowly relationships with siblings within the family were established, it should not be a surprise that it took time for all the children to have the beginnings of a relationship with myself. However, a significant finding has emerged, using evidence from the Content Analysis charts, demonstrating that in order for the children to begin to enter into a relationship with me, it was essential that one of their primary carers was present.

This example from Elsa's Content Analysis chart demonstrates this point:

Figure 13 Example from raw data highlighting Elsa's retreat into her own world when primary carer left the room

In Encounter Three Elsa had engaged me in a game led by her which was very lively and animated. However, as soon as Elsa's mother left the room, (indicated by the red circle in the figure above) Elsa stopped interacting with me and retreated into her own world. I identified that this pattern occurred in every encounter with Elsa. I then noticed that to a greater or lesser extent, this same pattern was evident for all of the children. The literature on attachment theory (4.5) proposes primary carers, as attachment figures, need to be present in order to help babies and very young children feel secure. In turn, this enables them to explore and play, which I maintain facilitates the forming of relationships with others. However, I have not found within the literature reviewed any discussion or suggestion that older children or severely disabled children need the presence of their primary carers in order for them to develop relationships with others, particularly those outside the family. From the evidence of this research this would appear to be needed beyond infancy and into a much later stage of these particular children's lives. I submit that this is an important observation as it has implications for the care of these children. It indicates how dependent they are upon their parents to be able to form relationships with others.

I acknowledge that I am not investigating the developmental stages of disabled children, but it is evident from their behaviours the children were reliant on the physical presence of their parents, which has implications for nurturing their relationships with others as part of their spirituality. I suggest this indicates that the children's dependency upon their primary carer is a core element of their spirituality.

Butterfly's response to me in Encounter Five illustrates the children's dependency upon their primary carer. Although her mother was present in the room, Butterfly could not see her. After being with me for a few minutes, Butterfly's distress at not knowing where her mother was meant that our encounter needed to finish (B.5.6.4). Part of the context for this particular incident was Butterfly's hospital admission due to being very unwell in the previous week. Her world, and possibly her sense of relationship with herself and others, was very fragile at that moment.

This finding illustrates the emotional fragility and vulnerability of these children, which I propose, adds to a deeper understanding of what it means to be totally dependent, vulnerable and reliant on another. The children offer a practical theological outworking of what it means to be vulnerable. It is a shared vulnerability within the community due to the impact of their dependency and vulnerability upon all those around them. Theologically, this demonstrates what a total dependency on God really means. The analogy that could be drawn from this suggests in the same way that Butterfly's world completely collapsed when she lost sight of her mother, so our world collapses when we have lost sight of God. This is an important aspect of living in the present moment, for it includes living with distress as well as joy and laughter.

There were many moments of intentional relational acts made by the children that led to movements of greater relationship with me. I propose these provide examples of a mutual dwelling in each other's lives which I consider to be relational consciousness. One such is the game that Elsa taught me to play. This involved her discarding a torch, which she then with a great big grin and eye contact invited me to retrieve and give back, for her to promptly discard it again. This went on for several minutes, with much laughter from everyone, including her mother who was present. To me, this deepened our relationship because Elsa was coming to know that I respected and recognised her play signals and was prepared to respond to her on her terms. She was also learning that I recognised and respected her dissent signals when she decided to stop playing the game. Therefore, very slowly and gently, a trusting relationship was beginning to form. I suggest this is demonstrated in Encounter Six, where Elsa let me instigate a game to which she responded (E.6.7.7). At the end of this Encounter, although she followed her usual pattern of retreating into her own world as soon as her mother left the room, she intentionally moved out of her inner world to share a brief sound conversation with me (E.6.17.6). This, I suggest, although tiny, was a movement of relationship, a moment of mutual indwelling and a sign of relational consciousness.

A further illustration of a moment of mutual indwelling was with Andrew in my final encounter with him. We were both very quiet, and in the room by ourselves. I had been stroking his hand which he then pulled away, I had left my hand open next to him when, almost without me realising it, he very gently tickled the palm of my hand (A.6.4.1). At that moment, I felt we were deeply connected with one another, there was a mutuality in our relationship that came out of our time of being together. This tiny perichoretic moment was only possible because of the trust and knowledge that had developed between Andrew and me over the six encounters that we shared. It was a moment of relational consciousness.

Through the encounters, the children's ability and desire to choose was also evident. The children chose whether or not they wished to engage with me. Butterfly's and Olaf's disdainful looks at a couple of my suggestions made it very apparent that they were not impressed or willing to engage with whatever it was I was suggesting. Dragonfly's intentional and deliberate pushing herself away from me was a very obvious signal of dissent and statement of not wishing to be in relationship with me at that moment. I was aware that as a healthcare professional, my training demands that I establish a relationship with a patient very quickly and it is very easy to assume that there is a relationship. The children taught me this is a false assumption; they had the capacity to choose with whom they wished to relate. This supports my contention that to a degree, all of the children can be considered as acting persons, with the capacity to be in relationship. The data also suggests that the children were capable of discerning different kinds of relationships, which I now discuss in considering how they responded to external carers.

7.3.2.4 With external carers:

Three of the children had external carers present during the encounters. The children either ignored them or responded to them in a subtly different way in comparison to how they responded to their family. In comparison to the enthusiastic greetings they gave their parents, all the children's responses to the carers, if they chose to respond, were muted and very quiet. The significance of their responses indicates they were able to distinguish between different relationships and chose their significant relationships. This finding highlights the importance of appreciating that a relationship with these children cannot be assumed.

I submit that the evidence from the data demonstrates that these children are in relationship with self and their primary carers. They have growing and developing relationships with their wider family members and with others from the external world. This evidence supports Simmons and Watson's (2014) challenge to education, suggesting that understanding the

children's capacity for relationships has educational implications (4.4). Theologically, appreciating the depth and subtlety of their relationships supports an understanding of *imago Dei* as relational. This also supports Matthews' proposal that PMLD children and adults have a distinct 'vocation of being' (4.4) (Matthews, 2011). Evidence from my research suggests the children I spent time with were acting persons, with limitations. This leads me to question Matthews' description of PMLD people as 'non-acting' persons. The appreciation of profound learning and physically disabled children as 'acting persons' does not seem to be evident within the literature. The children were able make choices about who they wished to relate to, they chose to spend time in their own inner world. Their choices were made within the limitations of their abilities, which did not necessarily use rational thought, or verbal language. However, their communication methods and use of non-verbal language and ways of engagement enabled them to make choices and to act, with limitations, within their own environments. This has important theological implications for it suggests that these children have the capacity for an innate spirituality and a relationship with God which is not dependent upon an intellectual nature. Instead, their capacity for an innate spirituality is dependent upon their relationality with self and others, rather than their intellect. It is their relationality that is constitutive of being made in the image of God.

7.3.3 Finding 3: the children's relationship with the external world

Although the children's wider world is mainly seen in their relationships with their family and family networks, their relationship with the external world, such as education and healthcare, activities and nature, was part of their everyday experiences and therefore influenced their spirituality. This illustrates the outward movement of spirituality identified by Selvam as "the movement towards others and the world" (2013 p.142), reflected in many of the commonly used definitions of spirituality, as discussed in Chapters Two, Three and Four. The encounters that I had with the children provided limited examples of their relationships with the wider world. However, there were anecdotal stories told by the parents that gave a suggestion of the children's relationship with the wider external world.

For some, this could be an anxious relationship, such as Olaf's distress at going through a car wash, (O.5.7.7) and for both Olaf and Butterfly, hospital visits and stays caused anxiety and distress (O.5.7.13; B.4.19). In contrast, Elsa's visit to the cinema (E.3.1.1) and Butterfly's time at the sports club (B.6.6.9) were energising, influencing the subsequent encounters that I had with them, following immediately on from these trips. It was after the cinema outing that Elsa taught me her game. After her sports club session, Butterfly and I played out an imaginary birthday party. Being involved and active in the external world was

a positive experience and therefore, I would suggest, enhances and supports their spirituality. It is worth noting that through technology, such as television and iPads, the children could encounter the external world in a different way, which also influenced them. It was from watching hide and seek played on the TV, that Olaf wanted to play the same game with his mother and myself. This playful activity encouraged and supported his relationship with me at the same time reinforcing the existing relationship with his mother.

Another example is Butterfly's curiosity concerning the keys she heard her neighbour putting through the front door. She could not settle until she was holding them in her hand (B.2.9). These examples indicate to me the awareness that the children had of the external world, and despite the anxiety that it could provoke, the children were in relationship with the world outside of their families to a greater or lesser extent.

The findings discussed so far relate to the children's modes of being. The significance of play and of silence upon their modes of being has also emerged through the data analysis and I now discuss these two findings in more detail.

7.3.4 Finding 4: The children's use and experience of play

The discussion in Chapter Four identifies the importance and significance of play as a spiritual activity and within children's spirituality (4.7). Therefore, it is not surprising that the significance of play emerges within this research.

In the same way that Ammerman (2014) notes that spirituality rises out of everyday experiences, Hay et al (1996) hold this to be the same for children's spirituality. Play is an everyday experience for children. As I have discussed and illustrated above, the relationships the children had were formed through play. Their relationships with themselves when in their inner world often involved playing with a toy or playing through body movements. The relationships with their parents were based on play, my developing relationship with them was based on introducing playful activities. It is worth noting that the one sibling Dragonfly did acknowledge played with her. In the same way, the growing relationship between Elsa and her siblings was seen in a playful sound conversation.

Play is therefore essential in developing relationships with these children. Play is not only a language through which they can express their spirituality, it is a spiritual activity of itself as it is relational. Through play, the movements of relationship that Fiddes (2000) identifies in his understanding of the Trinity can be seen. To add more context to the relational consciousness moment with Andrew, described above, it is important to appreciate it grew out of the previous five encounters in which he and I had played. In this research, play was

the means through which I was able to develop relationships with the children which resulted in moments of mutual indwelling and thus spiritual experiences.

Play was, as Hay and Nye (2006) suggest, the language through which the children could frame and express their spirituality. Through play, the children participated in others' lives: their primary carers, their siblings and others, such as myself, or the shop assistant Olaf encountered (RJ 24/3/17). This participation is, as Cunningham (1998) and Fiddes (2000) point out, Trinitarian. It is, I argue, deeply spiritual and is how these children live a meaningful life.

However, it is important to note that the most meaningful play experiences were the ones that were entirely child led or initiated. The Hide and Seek game initiated by Olaf, (O.6.11) or Elsa teaching me her torch game as described above illustrate this point. It required being attuned to the child, with myself as the adult being empty-handed and contemplative, putting into practice the necessary attentiveness as described by Jacobs, that involved "the evacuation of the ego" (Jacobs, 2001 p.104). Play was on their terms; they had the choice whether they played or not. I suggest working in this way supported their ability to choose to engage in relationship building through play.

I have discussed Graham's finding (2018) concerning the importance of vicarious play with verbal disabled children (4.7.2). There were moments of vicarious play, such as Butterfly enjoying my clumsiness as I dropped or bumped into things (B.4.1). This could be recognised as a moment where she entered into my world. However, vicarious play was not the pre-dominant approach to play for these children. What was more important was to recognise their play signals and their individual play signatures as suggested by Watson and Corke (2015) (4.7.2). It required detailed attention to recognise each child's signaling for play, such as Butterfly's eyes opening wide, Elsa's excited body movements or the tiny finger movements made by Andrew as he wanted to explore a soft toy. This detailed attention required an in-depth understanding of the children's physical condition to know how to position toys to enable the child to play with them. It also required adequate medical knowledge to be able to recognise whether the signal was for play or an indication of the need for medical intervention.

Berryman (2013) has described how children live at the edge of their being and knowing. This is especially so for this cohort of children; they encounter new experiences all the time, over which they have minimal control. Their medical and physical needs bring limitations to their play, but through those limitations, the children are embodying their spirituality,

particularly so within their play through which they chose and develop relationships with themselves and others, and most importantly with their primary carers.

My analysis of the data supports Edgar's statement: "Normal, everyday play is nothing other than a reflection of the relationship that God wants with us" (2017 p.x). Play is a process carried out for its own sake. The consequence, as seen in the evidence from my research discussed so far, is that play nurtures these children's relationships with self and others which in turn become a reflection of God's relationship with each child.

I propose that these children's expressions of spirituality are no different to that of typically developing children. However, it requires the ability, as Matthews suggests (2013), to fathom out how to successfully engage with them in order to recognise their spiritual expressions. This can be achieved through appreciating their play as an expression of spirituality and recognising their play as play.

7.3.5 Finding 5: The children's use and experience of silence

Through the data analysis, I have identified that silence is a feature of these children's spirituality. However, my analysis supports my speculation (4.7.3) that this group of non-verbal children used silence in a variety of ways. Their use of silence does not easily equate with Nye's (2009a) identification of silence as a way of saying something more important than words. It is important to appreciate that vocalising (making sounds) required considerable physical effort and energy for Andrew and Butterfly. Therefore, silence, understood as not making sounds, was their norm. The other four children could all vocalise easily. This needs to be considered when analysing their use of silence.

At first glance, the following table (Table 6) indicates that silence occupied a considerable amount of time for the children in many of the sessions. The assumption could be drawn from this table that the children were not engaged or not communicating in these periods of silence.

Table 6 Showing approximate percentage of silence in each encounter

Encounter	1	2	3	4	5	6
Andrew	0.7%	35%	25%	71%	37%	84%
Butterfly	84%	90%	n/a	67%	52%	90%
Dragonfly	60%	83%	75%	61%	77%	72%
Elsa	71%	87%	61%	81%	52%	42%
Olaf	0%	22%	38%	15%	20%	36%
Superman	45%	35%	62%	57%	51%	92%

However, Table 6 does not show the context or the way the children were silent within each encounter. This highlights the issue of applying purely nomothetic methods to ideographic encounters. Through a detailed, attentive analysis, as shown in Table 7 (see below), a more nuanced appreciation of the children's use of silence is revealed.

I distinguished three subtle different types of silence which I have termed active silence, relational silence and disengagement through silence. Active silence was used to communicate with someone else. It involved concentration and focus on the activities that they were engaged in with another. Active silence was a silence of 'doing', involving activity. This was particularly so for Butterfly. She communicated through her silence and non-vocalisation. It was only by listening to the recorded encounters with her that I realised she hardly made any vocalisations. When with her it felt as if we were in deep conversation throughout the encounter. Her facial expressions and eye contact were so communicative, it did not feel like silence. For Butterfly, when she did vocalise, it was as if she was expressing something that was too deep for her silence, such as her delight at the revelation of the butterfly in the Hungry Caterpillar story (B.2.14.5).

Relational silence was used by the children to engage with another. This was a time of contentment and quiet with each other. The time spent with Andrew in the last encounter is a good example, as was the time spent watching television with Olaf and Butterfly. This was a companionable silence, a silence of 'being', with myself and the child aware of each other, both of us not using words, vocalisations or actions. It might appear to be passive, but I propose this relational silence can also be seen as an intentional relational act, as a way these children expressed relational consciousness. They are not able to use the verbal shift

that Nye noticed in her research that verbal children used to describe a deeper or deepening relationship. (Nye, 2009a) These children appear to use a shift in their relational silence from which they reach out and touch the other, physically and metaphorically. This relational silence of being is therefore not passive, rather it is purposeful activity.

The third category of silence I distinguished was the silence of disengagement. This occurred when the children deliberately turned away from me or ignored me. In this type of silence, the children did not respond or react to others. Dragonfly's complete non-reaction to me reading her a story and Elsa's silence in encounter five illustrate this category. This silence of disengagement appeared to indicate that the child was retreating or in their own inner world, it could also be due to them falling asleep or a signal of dissent.

Table 7 showing approximate percentage of each type of silence used by the children.

Type of Silence	Encounter	1	2	3	4	5	6
Andrew	Active	0%	14%	0%	0%	61%	0%
	Relational	0%	14%	75%	0%	39%	85%
	Disengagement	100%	72%	25%	100%	0%	15%
Butterfly	Active	62%	68%	*	39%	84%	64%
	Relational	31%	19%	*	61%	16%	36%
	Disengagement	7%	13%	*	0%	0%	0%
Dragonfly	Active	100%	92%	48%	52%	16%	0%
	Relational	0%	8%	25%	32%	3%	6%
	Disengagement	0%	0%	27%	16%	81%	94%
Elsa	Active	43%	16%	62%	16%	0%	8%
	Relational	5%	4%	31%	12%	0%	56%
	Disengagement	52%	80%	7%	72%	100%	36%
Olaf	Active	0%	63%	58%	55%	100%	50%
	Relational	0%	37%	42%	45%	0%	27%
	Disengagement	0%	0%	0%	0%	0%	23%
Superman	Active	73%	73%	64%	38%	26%	9%
	Relational	27%	27%	36%	62%	57%	60%
	Disengagement	0%	0%	0%	0%	17%	31%

*denotes Butterfly was unwell for this session.

It can also be seen from this table how the children's use of the different types of silence changed over the time I spent with the children. To illustrate this, I will consider two of the children's use of silence in more detail, Andrew and Olaf.

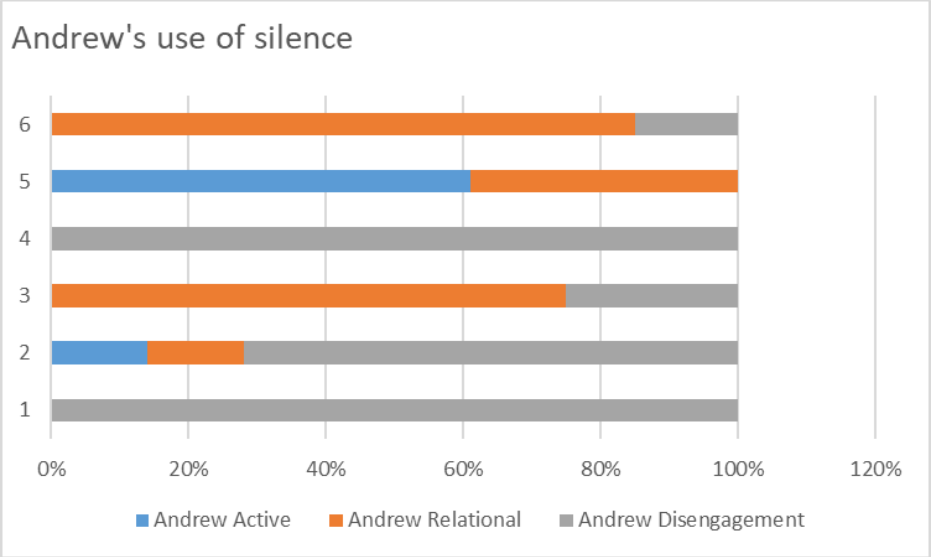


Figure 14 Detailed representation of Andrew's use of silence

The first encounter was significant in that whilst physicially with Andrew, I had perceived him to be silent. Through listening to the recording to transcibe it, I then appreciated that he had been vocalising throughout the session, but I had not heard him. Acknowledging that silence was his norm, his vocalisation throughout this first encounter could be seen as an indication of being unsettled and unsure of what was happening and what I was doing there. It is therefore not surprising that the only silence used was that of disengagement as he fell asleep, signalling to me that it was time for me to end the encounter. This makes the contrast between Encounter One and Encounter Six in Andrew's use of silence as disengagement significant. I interpret this to show that our relationship was growing, with a shift towards relational and active silence, relational silence dominating the final encounter. In that final encounter, we moved from active silence into a deepening relational silence from which Andrew moved back into active silence to tickle my hand, sharing that moment of relational consciousness. For Andrew, active silence was used when he was exploring and engaging with objects with his fingers. His active silence used body movements which communicated his mood and engagement. In his active silence I was aware of his rate and sound of breathing which became increased and slightly louder. There was also a sense of concentrated effort in his actions. His relational silence was shown through his quiet and calm breathing, his whole body becoming still and relaxed, as we were companionably silent together. Each encounter ended in silence, this could be a sign that Andrew was falling asleep, but apart from Encounter Four when he was unwell, the ending of the encounters in silence felt to be relational. The endings with Andrew felt peaceful to me.

In comparison, Olaf was rarely silent during his encounters with me. This could be interpreted as meaning when he was silent, he was conveying something too deep for vocalisations. In his times of silence he used active or relational silence, indicating that for him, silence was a means of engaging with himself or with others.

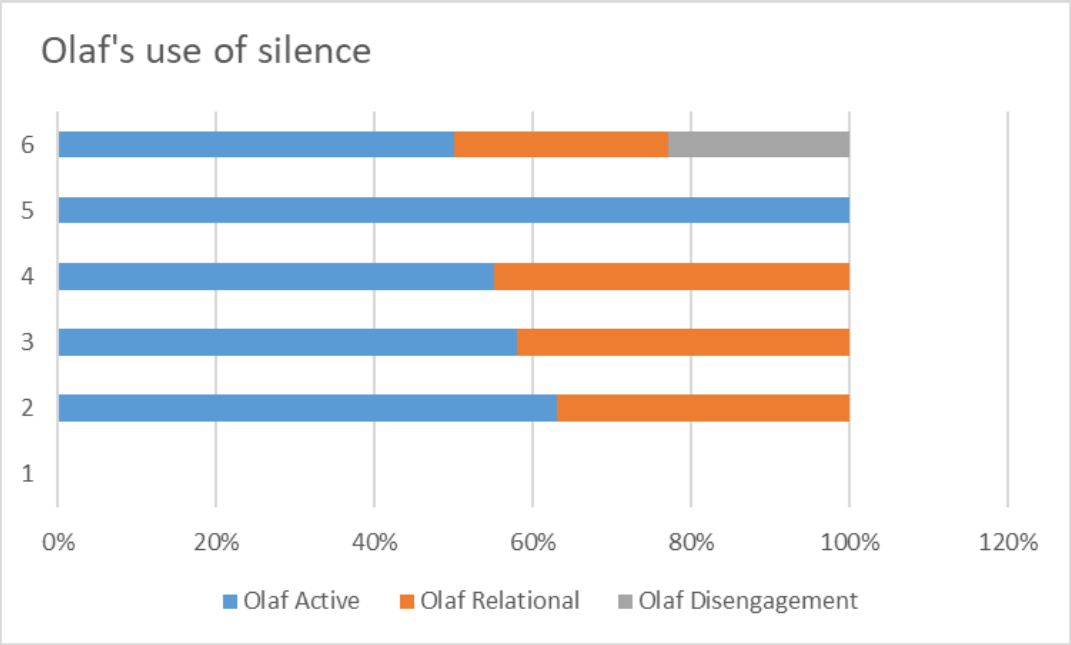


Figure 15 Detailed representation of Olaf's use of silence

Olaf's active silence was observed when he was engaged with his mother or with interactive equipment such as the television. He would listen and watch with great intensity and concentration. He would then copy actions from the television or his mother. In his active silence he appeared to be concentrating and focusing, often vocalising following a time of active silence. This could indicate that he was using the silence to process what was going on. His relational silence occurred when he was sitting in his mother's lap, or the occasions when he was briefly alone with me. This became a time of being, he became increasingly still and more relaxed.

This analysis not only highlights the different use of silence made by each child, it also emphasises the need for periods of time to be spent with each one to gain an understanding of how they used silence and what that might mean for them and their spirituality. The way these children were silent does appear to be different to how typically developing verbal children use silence. These different categories of silence do not appear to be noted in any of the reviewed literature, which indicates this could be an area for further research.

In the same way that play was identified as a language for the children to frame and express their spirituality, I propose silence too becomes a language through which their spirituality can be expressed. The silence of disengagement may well have been a time when the child was falling asleep, but it was equally possible that this silence signalled their movement into their inner world, where they were in relationship with themselves. The active and relational silences were contributing to and strengthening their relationships with themselves and with other people. Their silence was meaningful and part of their movements of relationship with themselves and others.

7.3.6 Finding 6: The impact of the children's medical and physical needs

The literature and discussion explored in Chapters Two and Three explains my view of spirituality as encompassing more than wellbeing. Spirituality includes suffering and distress, as indicated in Jones' (2016) description. Fiddes discusses how God, as Trinity, knows and endures suffering: "the suffering God exists in triune relationships" (2000 p.162). Suffering is part of these children's lives; it is part of their living a difficult life ordinarily as Eiesland summaries living with disability. As such, this mirrors *imago Dei.* Their lives are complex and a mixture of good and difficult times, which affects not only themselves but their families too. As Andrew's mother put it, 'one good moment gets me through all the bad ones' (RJ 30/6/16). In describing the children's relationships with themselves and others, influenced by their use of play and silence, I have concentrated on the good moments. The reality of these children's difficult lives lived ordinarily is that there were 'bad' and difficult moments that are, I suggest, essential to see as integrated into their spirituality.

It has to be acknowledged that due to their physical and medical conditions, the children endured varying degrees of difficulties and distress, over which they had no choice or control. Dragonfly's distress caused by a medical issue with the feeding equipment was out of her control, requiring skilled attention from her mother to resolve the issue. Andrew required medical attention in every encounter, subsequently effecting his energy levels. Olaf's flitting between various activities in the first three encounters highlighted his restlessness and a sense of being unsettled. Butterfly's emotional distress when she was no longer aware of her mother's presence, was, I propose, akin to spiritual distress. At that moment, her most important relationship that gave meaning to her world, her relationship with her primary carer, had become so attenuated that it caused her fragile world to collapse.

No one would wish this distress and suffering on anyone, least of all these children. That suffering and distress does not diminish them in any way, rather it deepens them for this was evidence of the reality of living a difficult life ordinarily. It reflects Berryman's remark already

referred to above concerning children living at the edge of their being and knowing. Importantly, I observed that the children did not appear to hold onto these experiences. Once the distress or pain was resolved, they moved on, and entered into the next moment or experience. It was, in a very real sense, witnessing children living completely within the present moment. This is akin to the form of prayer within the Christian tradition called the Sacrament of the Present Moment (de Caussade, 1981). In essence, this prayer begins from the recognition that God is continually being revealed and is at work in every moment of our lives. Therefore, Christian living is about living each moment, no matter what it contains.

For these children, the present moment may have been taken up with the persistent effort and patience required for six minutes for Butterfly to be able to start sucking a sweet, or Olaf dealing with the frustration of communicating hunger. It may also have been a moment completely taken up with a distressing medical issue or enjoying and laughing at the wind in the garden. From within their physical and medical limitations, all the children demonstrated an ability to live wholly in the present moment, with the uncomfortable, the unknown and the unknowable as well as with the familiar. This, I suggest, provides an example of Sölle's appreciation of mysticism, where she sees everyone as "mystics", (2001) (5.3). Although I do not have the evidence to state that the children have a mystical eye that sees God at work in all things, I suggest that they are mystical in the way they live each moment. In my discussion on mysticism as part of my methodology, (5.3) I proposed that action as service needs to be linked with mysticism in order for both to be effectual. For the children, I suggest this means understanding their action or service is to fully live each moment. This is linked to their innate capacity for spirituality, which is mystical.

These children present a challenge to society's view of perfection. The image they present offers a different understanding of what it might mean to be made in the image and likeness of God. It is not about a physical image, but a living out, in relationship, of the totality of the present moment.

7.3.7 Finding 7: The movements the children made between their inner world, their wider family world, and the external world

Through the process of analysing the data, I noticed a pattern, whereby the children would move into their own inner world, choosing to invite others to interact with them. It was usually through the interaction with their primary carers that the children moved from their inner worlds into their wider worlds and then into engagement with the external world. As far as I can detect, this pattern has not been noted in the available literature.

This movement between their worlds is, I propose, reliant and facilitated by their relationship with their primary carers. This echoes the Trinitarian movements of relationship identified by Fiddes, Cunningham and others. (4.5) I propose these movement patterns between the children's worlds are significant. They emphasise the role and relationship of these children's primary carers, for that is the key relationship enabling the children to move out of their inner world and engage with others. Their physical and medical needs influence and affect this movement. Their play and use of silence, in the three different forms I have identified, also need to be understood as significant features within this movement from their inner to their wider world.

These movements reflect the movements of relationship that Fiddes (and others) propose as an understanding of Trinity. The children live in a family community, they need to do so to thrive and survive, but also to enable them to flourish and live meaningful lives. It could be said that they dwell in the "relational spaces" as described by Fiddes (2000 p.49). Dwelling in these relational spaces therefore can, I argue, be seen as knowing God through God, as Volpe proposes. It is possible that within their inner worlds they encounter God and through that encounter, they bring gifts into their families and the external world; that has been my experience and what I have observed with all of the families. I suggest this is seen in Butterfly's gift of engaging with people through her eyes and smile, Andrew's gift of generating peace and Dragonfly's gift of pleasure in the smallest things. It is also seen in Superman's delight in watching her family, Elsa's ability to totally focus on her inner world, in the moment and Olaf's singing from happiness and his sense of humour. These are signs of God at work, reflections of God's glory. This is God delighting in these children, who most definitely have a vocation of 'being', of being totally themselves.

7.3.8 Finding 8: The children's relationship with God

Within the literature reviewed concerning spirituality there is a consistency amongst writers recognising that a transcendent relationship is part of spirituality. Within Christian terms, this is, as Selvam describes it, "a movement towards the transcendent (God)" (2013 p.142). Working from the premise that God loves us first, therefore we can love, in conjunction with Augustine and Aquinas' position that everyone has a natural knowledge and love of God, I make the assumption that these children are in relationship with God, for God has one with them. The evidence demonstrates that the children are in relationship with self, others and the wider world. Hay and Nye's research (2006) stated that all children had the capacity for spirituality. Therefore, there is every reason to assume that the study cohort of children have that same capacity and so can and do know God.

Whether the children had any experience of transcendence when in their own world or through their relationships with others cannot be categorically known. The children did not have the verbal language to convey an experience of God or Other. However, there are, I claim, indications. I suggest that it is feasible to use the test of "by their fruits you will know them" (Matthew 7:16 NRSV). The 'fruits' I can attest to are as follows: Butterfly and her reaction to the emergence of the butterfly prop (B.2.14.5), as well as Dragonfly's laughter in her garden (D.1.4.3) were responses of awe and wonder, an example of Hay and Nye's category of 'mystery sensing' (2006). Dragonfly's outburst of unexplained and very infectious giggles (D.1.4.10) and Elsa's joy (E.1.7.4.ii) at seeing her father are examples of 'value sensing' as described by Hay and Nye (2006). Andrew's ability to generate peace (RJ 21/7/16) amongst those who spent time with him, as experienced by his mother, myself and his friends at school comes from his mode of being that is truly vocational, as suggested by Matthews (2011). All these examples reflect the fruits of the Holy Spirit, especially of love, joy, peace, patience, faithfulness and gentleness (Gal 5:22 – 23 NRSV) and signify to me God at work in these children.

The witness of their difficult lives lived ordinarily, and their ability to live in the present moment attests to a God of vulnerability and dependency. The richness of their humanity which encompasses suffering, laughter and tears, as well as giggles and blowing raspberries, along with their ability to form relationships and to choose who they wish to relate to, attests to the richness and variety of their relationships, worked out within their limitations, but evidencing some free choice. Their witness goes beyond the disability community. Elaine Graham recognises that Eiesland's work needs to move beyond Disability Theology (Graham, 2009 p.159 - 161). In the same way, I suggest that there is a need for an understanding and appreciation of these children's spirituality to move into the wider Practical Theology field, leading to transformative ways of appreciating how to live in the present moment.

I really enjoyed working with all of the children, no matter what happened in the encounters. I remarked in my research journal: 'I just enjoyed being with Andrew' (14/6/16) 'I come away from Butterfly smiling' (13/5/17). I noted a 'joyful encounter' with Dragonfly, (12/8/16) how 'today was totally amazing' with Elsa (27/10/16). With Olaf, I was excited when I had a spontaneous 'thank-you' kiss sound from him that only happened once (3/1/17). With Superman, I noticed her spontaneous happy reaction to seeing her father as she arrived home from school (24/2/17).

As I noted for Superman: ‘when she fixes her gaze on me there is nowhere else to look’ (RJ 17/3/17). In all the encounters with the children, there really was only one place to look. Personally, I found the encounters to be a deepening spiritual experience and a sense of becoming very close to these children. Through contemplating on and acknowledging the significance of the children’s relationships I became aware of a deeper understanding of *imago Dei,* for these children are most definitely made in the image and likeness of God and are in relationship with Him. They are “imaging a God who is a relational being” (Cortez 2010). They are subjects not objects, in relationship with themselves and others, the wider world and with God.

7.4 Summary of Chapter Seven

I began this chapter by reviewing the theological lenses that have informed this work, using those lenses, in conjunction with resources from other disciplines, to analyse the data. The children’s spiritual signatures, detailed in Chapter Six, gave a semantic analysis of the data collected. This chapter has worked through the data to explore the latent theological and multi-disciplinary themes present.

Through my analysis of the data and the resulting findings, I conclude that this specific cohort of non-verbal and severely disabled children have the same core spirituality as that of all children, a spirituality centred on relationships. My broad description of children’s spirituality (4.11) holds true for this group of children.

A significant finding that has emerged is the need for the children’s primary carers to be present in order to develop relationships with others. It did not necessarily require the primary carers to be interacting with me or their child, but their presence in the same room, particularly for the initial encounters, supported the children to be in relationship with me. (This is different to Family Therapy Interventions where the aim is to work on communication and interactions between all family members.) This finding has theological implications for it reflects the community aspect of ‘person.’ It also has implications for practice for it suggests that for these children to develop relationships with others from the external world, (e.g. healthcare, education) it is most effectively begun in the presence of those with whom they have a significant relationship.

I have also proposed that these children are to be understood as ‘acting persons’, with limitations, as these children were capable of making choices. The children desired to be in relationship with self, others and where possible, with the external world. This is shown by their free choices to not engage with myself or others as well as their intentional relational acts towards others. Therefore, because of their desire to be in relationship I conclude they

have the capacity to be in relationship with God, acknowledging this is immanent and mysterious because they did not have the verbal means to express this. I propose their spirituality is expressed through their play as play and playfulness enabled them to be in and form relationships.

I suggest that their use of silence is another expression of their spirituality. Their silence has subtle variations, which I have identified as active silence, relational silence and silence of disengagement. I consider this to be a potential area for further research. I also conclude from this investigation that to hear and recognise these children's spirituality requires detailed attention and creative ways of engaging with the children to appreciate the embodied expression of their spirituality. My research has been a way of myself, as a chaplain "finding a language that enables patients [these children] …to tell their story..." (Thomas, 2015 p.65). To hear the story for these children requires an understanding of how they live in the present moment, engaged in spirituality all the time.

This investigation has also shown that these children challenge pre-dominantly held societal views of perfection, power and status that prioritise intellect, rational thought and materialism. Through recognising this challenge and by hearing their languages of play and silence, the spirituality of these severely disabled children can be heard and recognised. I acknowledge this is my interpretation of their spiritual expression, which cannot be easily verified directly with them. However, I propose these children image a relational God, where the mutual indwelling and movements of relationship do not rely on rationality, verbal skills or bodily perfection, rather they are based on movements of love and desire.

Chapter 8 Developing Findings into Practice

8.1 Introduction

The task of Chapter Seven was to work towards answering my first research question to enable a different and deeper understanding of these specific children's spiritual reality. I concluded that the study cohort of severely disabled non-verbal children have the same spirituality as those of all children, a spirituality centred on relationships. I summarised my findings as follows:

1. The children's relationship with themselves and their own inner world
2. The children's relationship with their wider world within their family
3. The children's relationship with the external world.
4. The children's use and experience of play
5. The children's use and experience of silence
6. The impact of the children's physical and medical needs upon their spirituality.
7. The movements the children make between their inner world, their wider family world, and the external world.
8. The children's relationship with God and God's relationship with them.

I propose these findings contribute to an understanding of the spirituality of the severely disabled children involved this research. The task of this chapter is to consider how these findings work towards answering my second research question:

> What enables those practising in a healthcare context to recognise spirituality and so respond to it meaningfully?

I acknowledge and appreciate that the data collection, involving delicate, attentive and contemplative work carried out in the relative quiet and familial settings of the children's homes is in stark contrast to the busy, noisy, multifaceted secular environments of society as seen in healthcare. However, I propose the research offers theological insights that can enhance and deepen an understanding of spirituality within a secular healthcare organisation.

Furthermore, as a practical theologian, I perceive I have a duty which I take seriously, as David Tracy emphasises, to speak theology to the academy, the church and to society. (1989 p.5) It is appropriate and necessary to use direct theological language for the academy and the church. However, there needs to be an appropriate way of translating theological language into society, such as healthcare, so that it can be heard "in their own words" (Acts 2:6 NRSV). I suggest that my theological insights can be seen as a form of

practical wisdom, which as Graham suggests can contribute to “a public vocation of active citizenship”. (2013 p.181)

The literature review in Chapters Two, Three and Four, exploring the wider contexts and more specifically the vocational healthcare and educational contexts indicated a need for a broader understanding of spirituality to include a recognition of the multiple ways in which spirituality can be discerned. I have also identified through the literature review that for many practising within healthcare, trying to understand spirituality and provide spiritual care raises concerns and issues. The continual attempts to provide definitions of spirituality has not provided the sought for understanding. I have proposed the focus on spiritual care assessments, as well as the lack of clarity about the role of chaplaincy within an organisation can also hinder understanding and meaningful responses to spirituality.

I propose that the findings identified in Chapter Seven can work towards a broader understanding, thereby contributing to a shift in understanding spirituality. A shift in understanding has the potential to support those practising within healthcare to recognise spirituality in the patients they care for, within themselves and within their working environment. As Swinton and Mowatt (2016) identify, it is through understanding differently that it becomes possible to act differently. By understanding the spirituality of this group of children differently, I suggest that it becomes possible to act differently and therefore respond meaningfully. This presents a challenge, for there needs to be a way of ensuring that the children’s voices are heard and not silenced or lost within the cacophony of a busy setting. I suggest that my research findings could contribute to addressing this need.

My methodology (5.3) proposed seeking a social transformation through this research, brought about by a deeper understanding of the spirituality of the study cohort. The social transformation that could happen as a result of a deeper understanding is that spirituality is fully integrated and incorporated into holistic person-centred care not only for children with severe disabilities, such as those in this study, but for all children within a healthcare context. Spirituality would no longer be something that caused concern or anxiety but was understood to be the foundation for responding meaningfully to all those being cared for and those involved in care.

The discussion in Chapters Two and Three illustrated the increasing complex societal landscape for religion and spirituality. I have proposed religion and spirituality now need to be seen within a multi-dimensional framework that reflects the plural society within which we are situated (2.5.1). There is a growing appreciation as Berger (2015) highlights, that whilst a belief in God can no longer be assumed (Taylor 2007), the way people cope with reality is a

mixture of religious and secular understanding. Therefore, there is a need for supportive ways that enable people to find meaning in their reality. I suggest providing appropriate support within a healthcare context is a key task for chaplaincy work. It also emerges from the literature that Chaplaincy can play a central role in supporting staff and patients when fully integrated into multi-disciplinary teams, thus providing better outcomes.

I see being a chaplain as a working out of Sheldrake's (2014) practical spirituality category. Practical spirituality, understood to be finding God in the everyday and ordinary, is practised by healthcare chaplains, nurses, allied health professionals in a context dominated by scientific knowledge and language. In contrast, the Practical Theology tradition that informs practical spirituality seeks to provide a space where it is possible to "speak truthfully and meaningfully about human realities" (Cameron, et al., 2010). It can be a challenge for a practical theologian working within a secular environment to speak "truthfully and meaningfully", to do so involves talking about God. Within healthcare practice this is not necessarily easily or readily accepted. I suggest part of the difficulty comes from an underlying concern about potential proselytization and a strong sense of the dominating religion/spirituality binary (2.4). As a result, anything to do with religion is categorized as private and therefore not for general discussion. Consequently, a different way of speaking truthfully and meaningfully, needs to be found. I propose my findings may offer alternative ways of speaking theologically within healthcare settings.

From the literature review, there appears to be a consistent agreement that spirituality is an aspect of life that needs to be acknowledged and recognised as relevant within healthcare (3.3). However, as identified by Liefbroer et al (2019), there is continual debate concerning the challenges of integrating and delivering spiritual care within healthcare, reflecting the complex, plural and spiritually diverse wider context. As they state: "…there is no single way to deal with these challenges" (2019, p.256). As discussed in Chapter Three, there is an expectation within the NHS for a generalist approach whereby everyone can deliver spiritual care, however, incorporated into that is an appreciation for a specialist chaplaincy team. As I have also discussed, with the professionalisation of chaplaincy teams, there has been an increased focus on creating standardised spiritual care assessments and definitions reflecting the need for chaplaincy to fit into the scientific healthcare context (3.3.1). Liefbroer et al's research recommends that healthcare organisations need to determine their view and understanding of spiritual care because that affects its delivery. If spiritual care is purely functional in that it offers supportive visits and practices it then fits into a task-orientated environment. The risk, if adopting a functional approach, is the 'ministry of presence', a feature of chaplaincy work that supports the understanding of being there for or with

someone, can become lost. If spirituality is seen as a meaning making system then a different, experiential approach, incorporating an understanding of being present, is needed, which does not fit so easily into task driven practice.

My findings indicate that for the children who took part in my research, a functional approach was not appropriate, nor were standardised assessments or definitions. Using a functional approach, based on formal assessment methods would not have enabled the detailed and rich descriptions of spirituality seen in these children as given in Chapter Six. The insights I have found concerning the spirituality of the study cohort have of necessity been expressed in ideographic language. These insights, I propose, can significantly contribute to the provision of holistic care. However, the challenge is to find appropriate ways for these insights to be incorporated.

From a Practical Theology stance, the challenge is to "articulate a theology of practical relevance" (Swift, 2014 p.150). One way of demonstrating the practical relevance of my insights would be to provide detailed concrete examples of how incorporate my insights into practice. However, my concern, as explored in the literature review (3.3.5) is that concrete examples can be easily turned into detailed checklists, reflecting a nomothetic and positivist approach, which then become a list of tasks. Checklists are important for the physical, social and psychological domains, they ensure that the appropriate attention is paid to the necessary measurable details required in those areas. What I am proposing is that a different type of attending is required for spirituality. It is an attention to the ideographic, the unique experiential expressions of spirituality that are not measurable but are essential to be recognised if holistic care is to be provided. It is by paying attention to the meaning behind an action or silence that relational spirituality may be revealed. This type of attention requires contemplation, which of itself will be ideographic. Therefore, I am not providing specific concrete examples of how to incorporate my insights into praxis. Instead, I am describing three proposals that offer ways of paying attention differently to key areas within healthcare praxis. Attending differently supports understanding differently, understanding differently enables acting differently. Acting differently, through paying attention to the ideographic nature of spirituality, can enable those practicing in a healthcare context to recognise and so respond meaningfully to spirituality.

The first proposal I explore is how the relational understanding of person, that I discerned through theological reasoning, has the potential to provide a different understanding of holistic person-centred planning and care. Findings One, Two, Three, Seven and Eight focus on relationships. I have explored the relationship that the children have with themselves,

with their primary carers in particular and the relationships that they have with others shown through movements of relationship and mutual indwelling. I have also proposed how their relationship with God can be viewed. These movements of relationship are the core of their spirituality. As I have explored in Chapter Four, these relational movements reflect a relational God, the Trinitarian God, the God of Three Persons. I have argued that understanding the concept of *imago Dei* in these terms contributes to seeing how children with severe and complex disabilities are made in the image of God and are to be considered 'acting' persons. I propose that paying attention to the children's relational spirituality contributes to person-centred care.

The second proposal I explore is an understanding of prophetic spirituality. I suggest the way the children live, as identified in Finding Six, can be seen as prophetic. I will also consider the prophetic nature of chaplaincy work within healthcare. I briefly explore how healthcare settings such as a children's hospice can potentially be seen as prophetic through the way care is delivered.

The third proposal I explore is a deeper understanding of hospitality. The hospitality already evident within many healthcare settings can be seen as practical spirituality. I propose understanding the significance of hospitality in a very broad sense, is a meaningful way of embodying and embedding spirituality within an organisation and can be seen as prophetic spirituality. This proposal does not come directly from the findings identified in Chapter Seven, it arises out of my reflections on the experience of conducting the fieldwork in the children's homes, the overall process of conducting the research and my experience of working within a children's hospice. There is not sufficient room to explore the rich theological tradition of hospitality in depth for this proposal, which could be an area for further research. However, the existing practices of hospitality within healthcare practice understood differently could enable spirituality to be more easily recognised.

I suggest these three proposals act as the bridge to enable the movement of the research findings from the children's homes into healthcare practice and potentially beyond into wider societal situations that surround the children, their families and all staff involved in their care. Through exploring 'person', prophecy and hospitality in this way, I suggest an alternative perspective to the purely functionalist approach to chaplaincy and care can be considered, enabling all to find a way of speaking their spiritual truths within a secular healthcare environment.

8.2 A relational understanding of 'person' and its application to person-centred planning

Through my theological explorations, discussed in Chapter Four, I have proposed being made in the image of God is to be made in the relational image of God. I have also linked the understanding of 'person' to that of relationships in community. The understanding of a relational image of God and of person seen in relationship with others as part of community is supported by the findings emerging from the data analysis, in particular Findings One, Two, Three, Seven and Eight. These focus on the relationships that the children had with themselves and their inner world, the relationships that they had with the wider world of their families and with the external world. These also considered the movements between their worlds and what could be said about the children's relationship with God and God's relationship with them. The children were in relationship with themselves and others through the strong and influential bonds of their family community. I recognise that all the children in the research were part of loving families. For these children, being part of their family community enabled them to flourish and build relationships of love and desire.

The understanding of person in this light is in contrast to that currently seen in the wider world. I have discussed in Chapter Four how within theological terms the word 'person' refers to community and relationships. However, as Cunningham (1998) has identified, contemporary society's understanding of 'person' considers this word to refer to the individual. Bender's (2010) research highlights the high importance placed by contemporary society on the individual and individualistic experience (2.2, 2.3). It is also evident from the literature review that spirituality is now considered to develop from an individual's experience (Zinnbauer, et al., 1997; Bender, 2010; Woodhead and Catto, 2012). There appears to be an emphasis as described by Taylor, on "self-sufficient humanism". (2007, p.18) The children are individuals with their own experiences, but they, in the same way as everyone else, are not and never will be self-sufficient. In order to live and love, thrive and survive, these children are totally reliant on their relationships with others for those experiences to happen. Therefore, seeing the spirituality of these children in terms of relationality, rather than from their individual experiences, enables their spirituality to be fully recognised.

The children's personal spiritual signatures, detailed in Chapter Six, reflect the contemporary definitions of spirituality as being concerned with ways of relating. All the proposed definitions of spirituality, discussed in Chapters Two and Three, despite the focus on individuality, emphasise relationships (e.g. O Murchú 2015; Meravigilia, 1999; Puchalski et al, 2014). However, these contemporary definitions are presented as a list and do not reflect the inter- and intra- connections between different relationships. My research highlighted the

dependency the children had on their relationships for all their support. The children gave a witness to the movements of relationship and participation as described by Fiddes (2000) and Cunningham (1998) and the understanding of family as described by Boff (1988) as a reflection of the Trinity (4.5). They needed those significant relationships to be in place. They lived in the image of God as 'person-toward-other (LaCugna, 1991). Finding Seven of the research considered the movements of relationship. I identify this to be significant as it highlights the importance of the children's relationship with their primary carers. It was this relationship that drew the children in the study out of their inner worlds, moving them into the wider contexts, thus enabling them to move toward others. I have illustrated the significance of this relationship in the examples given in Chapter Seven, the most striking example being that of Elsa, who needed the presence of her primary carer in order to be able to relate to me (7.2.7).

I have also identified in Finding Two the reciprocal relationship between the children and their parents. There is an implication that in the same way their parents enabled the children to move between their worlds, the children enabled their parents to move between worlds too. I noted in my research journal (22/1/16) how Andrew's mother was able to move into her inner world and become calm through being with Andrew. Understanding this reciprocal relationship is a potential area for further theological study as it suggests that relationships explored in this way may expand a relational understanding of 'person' as community.

I explored in Chapter Four the debate stemming from Aquinas that deems an acting person to be someone who has rationality, autonomy and self-awareness. There is, as I have discussed, ongoing debate highlighted by Matthews (2013) and Romero (2012) as to whether or not severely disabled children and adults are to be considered 'non-acting' persons. (4.3) I propose that the evidence from my research highlighting the deep and significant relationships the children had with themselves and others contributes to the discussion, demonstrating that the children were 'acting' persons. I also suggest that the finding concerning the study cohort's use of silence contributes to a relational understanding of what it means to be a person. The children's silence, seen as active and relational, was a way of 'fathoming out', to use Matthew's (2013) phrase, a way of successfully engaging with the children. Therefore, by appreciating their silence as engagement, the children are not 'non-acting' persons, they can be considered to be 'acting persons'.

These reasonings summarise the theological insights of a relational understanding of person that I have explored through this research. These insights need to be offered to a secular healthcare environment in a sensitive and appropriate way. I propose that offering an

understanding person in terms of ‘relationships’, rather than in terms of the individual, is a way of presenting these insights in a manner that could resonate with current healthcare practice. This can be introduced, I suggest, by working with the focus in healthcare on holistic care and person-centred planning. By introducing a different understanding of ‘person’ that focuses on relationships and community, in conjunction with an understanding of ‘person-centred planning’, a potentially different and richer understanding of spirituality can be discovered.

I have discussed how the holistic approach to care appears to focus primarily on the physical, psychological and social domains (3.2.2). I have suggested this is because these domains are handled by nomothetic understanding. The assessment process for person-centred planning tends to focus on factual information concerning the individual patient, recognising the importance of their family tree, which involves listing the different relations connected to a child. Through discussion with family members, usually from parents for non-verbal children, information is gathered concerning what is important for and to each individual as well as highlighting what is considered to be important aspects about that individual’s personality.

In contrast, the evidence from my research highlights that it is the importance of the different relationships, in particular with their primary carer, rather than the number of relations that a child has, that is significant. How these significant relationships are expressed and recognised need to be recorded as part of person-centred planning. What has emerged from my research is that the key to understanding spirituality for the study cohort was to recognise how their significant relationships were expressed. The excitement Superman showed on unexpectedly seeing her father when she came home from school, (S.2.3.11, S.2.5.8) in contrast to her total ignoring of an older sibling illustrates this point (S.4.2.11). Through being able to observe, attend to and recognise the significance and movements of relationality, the children’s significant relationships became evident. In turn, the focus moves away from the child as an individual, instead they are seen as a person with desires and differing values.

Within the study group the primary carer relationship was the most significant. I acknowledge that this cannot be assumed to be necessarily so for every child. My findings demonstrated that the presence of primary carers for the children in the research was necessary in order to facilitate relationships with others. I suggest both these points need to be taken into consideration and understood when caring for children within any healthcare setting. I propose that further research is required, which is beyond the scope of this current project, to understand the implications of what happens to these children when they are in new and

unfamiliar surroundings. Consideration needs to be given to the impact this places on the children when their most significant relationship, which enables them to relate to others, is not present. The evidence from the fieldwork, particularly seen in Elsa, Butterfly and Olaf, implies that the absence or lack of awareness of their primary carers' presence caused the children spiritual distress. It also indicates that the children retreated into their own worlds and therefore were not able to form and develop relationships with others around them. As evidenced from the research, it took time and the presence of their primary carers for these children to begin to form a relationship with myself. Applying this to practice within health settings suggests that for this group of children, there needs to be very slow, gentle and careful introductions to new environments, involving the presence of whoever holds the most significant relationship to be with them, to enable them to begin to form relationships with others. In the research this was the primary carer relationship, with other children the significant relationship may be with a sibling or grandparent or someone else.

It is also important to note that the six children in the study were able to choose with whom they desired to relate. Forming a relationship with each child could not be assumed. Through paying attention to whom the children did relate to and to whom they choose not to relate to, by noticing how the movement of relationships were expressed, a relational understanding of the child began to emerge. I propose it is this relational understanding of the child which provides the spiritual dimension of person-centred planning and which needs to be included in holistic care assessments.

Introducing a relational understanding into person-centred planning has implications for practice. In my fieldwork research, as highlighted in my methodology (5.5) I appreciated that I could not conduct formal interviews or use standardised assessments. I called my time with the children 'encounters.' Through these encounters, in which, following the children's lead, we spent time being together, through play or in active or relational silence, I was gaining knowledge about their spirituality. I sought to have no pre-conceived assumptions about what might emerge. My knowledge grew out of the constant reflection and reflexivity necessary to keep attuned to these children.

Being in touch with my own spirituality supported my approach, enabling me to become aware and to recognise the children's spirituality. My emphasis was not to assess or evaluate the children's spirituality, rather it involved paying attention to the children, then contemplating all that I had seen and heard. The research process has for me been of itself a spiritual practice. It has been, as Slee identifies, "a practice of research (which) both arises out of and feeds back into women's own ethical and spiritual lives" (2013 p.25). The

spiritual practice of the research parallels the 'being with' approach identified in Llewellyn's research (2015) and I suggest moves 'being with' to a different level. 'Being' in this way is Clayton's (2015) contemplative stance, which he suggests is essential to provide spiritual care, requiring the ability to be present and empty handed.

My approach also reflects the first way of 'looking' as described by Coulter (2002), discussed in Chapter Four. Spending time being with the children enabled me to become aware of the first 'look', to begin to discover who was this child, who did they know and love, what was important to them. Coulter's 'first look' approach is reflected in the portraits of the children, described in Chapter Six. As the encounters progressed the 'second' look became apparent, in the way that the children and I began to relate to each other, which, I suggest, is reflected in the personal spiritual signatures detailed in Chapter Six. I have described in Chapter Seven moments where I identified the presence of Coulter's third look.

I acknowledge that working with a child who is non-verbal to gain an understanding of them as 'person' in the theological sense, takes practice so that the necessary skills of paying attention and listening can develop. As I discovered and noted in my research journal (9/6/16) working this way was not an easy process. It required of me a discipline and understanding to be able to move from 'doing' things with the children to recognising 'being' was all that was required to become their story hearer. It was, as I discovered, easy to be distracted and not present to the children, especially if I allowed my attention to wander. Andrew's mother brought my attention back to him by moving to kneel next to him when I had become distracted by his sibling (A.3.11.21). In a simple, yet very powerful way, she reminded me of why I was there and to whom I needed to be giving attention.

I accept that to work through using attention and contemplation, with an understanding of the importance of 'being' rather than 'doing' will not necessarily come easily within a healthcare context which, often out of necessity, prioritises action. It takes time and an ability to be with the children rather than 'doing' to the children. It requires attention and contemplation to become aware of the fleeting moments that communicate so much. It then requires further attention and contemplation to reflect on what is being communicated through those fleeting moments that are so easily missed. However, through this process, as my research has shown, it is possible to identify their significant relationships. It is through these relationships that the children are supported and enabled to move into relationships with others. In turn, these relationships which I propose, are an expression of their spirituality, influence their physical, social and psychological domains. The anecdotal incidents discussed in Chapter Seven referring to Butterfly and her participation in the sports club (B.6.6.9) or Olaf and his

encounter with the shop assistant (RJ 24/3/17) highlight this point. They were with their primary carers, which enabled them to engage socially with others. I propose that these ways of working, focusing on being rather than doing and on building relationships can be applied within healthcare settings and enables the spiritual domain to be recognised. However, to do so requires appropriate support, for this approach is counter to the current healthcare focus.

The current focus within healthcare acknowledges the importance of spirituality and spiritual care. However, research has concentrated on trying to define spirituality and provide training and competencies for spiritual care. There is also a focus on creating assessments to assess what, in my view, is impossible to assess. The research acknowledges that all involved in providing care, especially nurses, are in a position to provide spiritual care, with the expectation that everyone will engage with spirituality and spiritual care provision (e.g. (Narayanasamy, 2001; McSherry, 2001; McSherry, 2006; Carson and Koenig, 2008; Clarke, 2013; Timmins and Caldeira, 2017). It is equally acknowledged and recognised that in order for anyone to be able to provide spiritual care it is essential that they are in touch with their own spirituality first (E.g. Coulter, 2002; McSherry, 2006). To be in touch with spirituality, I suggest, initially entails a recognition of spirituality as relational. This recognition I propose is essential for staff to then not only be in touch with their own spirituality but also to recognise spirituality in others.

To support staff to understand 'person' as relational, to then have a different understanding of spirituality requires, I suggest, opportunities for staff to consider their own relationality. My experience suggests that within a healthcare setting, staff expect and want to have good relationships with those they are caring for and their work colleagues. I acknowledge that these professional relationships are not and cannot be the same as familial relationships, but they are relationships that contribute to an understanding of person. I stress that I am not advocating a psychotherapeutic approach for that would not be appropriate. However, taking a contemplative approach, which is similar to Škof's ethical approach which requires being attentive to one self, to then be in a position to be attentive to others (Škof, 2016), allows staff to recognise and value their own relationships as part of their own spirituality. It also enables them to appreciate that they have choice with whom they desire to relate to, thereby enabling the staff to pay attention to themselves in the same way that I am advocating they pay attention to the children's relationships.

I suggest that enabling staff to understand 'person' in a relational sense can be appropriately supported through Chaplaincy teams, where, as previously discussed, the priority can be on

hearing the ideographic story. I suggest that by paying attention to relationships and the way in which relationships are expressed enables everyone to become a story hearer (3.8). In turn, it becomes possible to describe ideographic expressions of spirituality that contribute to holistic care planning. As a result, a more meaningful understanding of person-centred care can be formed as the spiritual domain is purposefully included.

8.3 An understanding of prophetic spirituality

In Leach's (2007) model of theological reflection, the final voice that she proposes to be heard as an outcome of the reflective work is that of the mission of the church. As an outcome of this research I propose there are three areas of mission that can be identified: the mission of the children, the mission of chaplaincy within healthcare and the mission of healthcare practice itself. I suggest that the idea of mission is best expressed by exploring an understanding of prophetic spirituality, that aspect of spirituality that seeks to address social justice issues. I propose understanding prophetic spirituality within the children, chaplaincy and healthcare can contribute to the ongoing conversation about spirituality and its role within healthcare settings, thus leading to acting differently with meaningful responses by all involved in providing care.

8.3.1 The prophetic nature of the children

I suggest that for staff to be able to respond meaningfully requires an understanding of how the study cohort lived meaningfully. The data analysis contributing to Finding Six: the impact of the children's physical and medical needs on their spirituality, highlighted that the children did so by living a difficult life ordinarily, in relationship with themselves, others, and, within my understanding, with God. Their lives were lived in the present moment, whatever that moment may have held, be it times of suffering or pleasure. I suggest it is in the way these children and their families live their difficult lives ordinarily that gives them their prophetic nature.

Nye has highlighted that it is "a genuine feature of [children's] spirituality to speak out, to be prophetic, to articulate (not necessarily through words alone) the need for a change or to offer a new way of seeing things" (Nye, 2009b p.72). I propose these children do offer a new way of 'seeing things' and highlight the need for change. I suggest that the children are 'forth tellers', those prophets, as described by M. Daffern (2017 p.364) who challenge social justice through critically speaking out. These children speak out using non-verbal language, expressed through the way they live. Their prophetic voice is heard in their ability and desire to live relationally and meaningfully with themselves and others, with complex medical and

physical issues ordinarily, living each moment to the full. Living relationally, for these children, is “a process of reaching out” (Nye, 2018 p.151). However, I must emphasise that I do not see the children as fodder for ‘inspirational porn’. Stella Young, in a TED talk describes how as a young disabled teacher, she finds that students expect her to give an inspirational talk about living as a disabled person (Young, 2014). She makes the point that is not her job, her job is to teach, it is her teaching she desires to be inspirational, not her disability. In the same way, the children and their families would not want to be seen as special or to be pitied or a source of so-called inspiration. They are, just as all children and families are, very ordinary, dealing with incredibly complex issues in a matter of fact way.

The prophetic challenge the children in the research presented was an alternative view of perfection and the reality of what it means to live in total dependence and vulnerability. Their dependency and vulnerability contrasted sharply with the understanding of perfection that the World Council of Churches conference (2005) identified as the predominant worldview of what it means to live in the image of God. Yet, I argue, these children live in the image of God *because* of their total vulnerability and dependency. Living in this manner is, as Hauerwas (1986) declares, their prophetic voice.

The children challenged a materialistic world that prioritises possessions, wealth and intellect, for they did not appear to value those attributes at all. A visitor watching Dragonfly playing with a wrapper commented: “She gets so much pleasure out of the smallest things” (D.5.4.6). I suggest Dragonfly’s pleasure in the simplest of things influenced those around her and shifted their priorities too. This challenges contemporary society which emphasises individual achievement and accumulation of individual possessions. This group of children did not “love… the things in the world…– the desire of the flesh, the desire of the eyes, the pride in riches” (1 John 2:16 NRSV). These meant nothing to these children and had no value for them. Their priority was their relationships, especially those with themselves and their primary carer, and therefore, I propose, they were living out “the love of the Father” (1 John 2:15 NRSV). The children portrayed a different way of living, which, I argue, enhances a Christian understanding of *imago Dei*. The children showed, through their relationships, a glimpse of what it means to live perichoretically where there is a mutual indwelling and participation in one another’s lives, as discussed by Cunningham (1998) and Fiddes (2000). Their relationship with their significant carers was one of attunement, it was a dynamic, reciprocal relationship, as I have discussed above in my reflections on a relational understanding of ‘person’.

I suggest their witness is not only prophetic within Christian circles but applies to wider society. Although this will not necessarily be understood in Christian terms, within a non-religious setting, it can be recognised as being something unique in the way these children inclusively live within their families. Swinton has identified that the ongoing social inclusion debate is politically framed to ensure that the rights of all people with disabilities are protected. This is important and essential, but as Swinton also points out, legislation does not ensure those with disabilities truly belong and are loved within society (Swinton, 2016 pp.92 -93). The children and their families involved in this research present a prophetic vision of how society could become an inclusive welcoming place where everyone belongs, and everyone is loved as they are.

I have previously identified how spirituality can be seen to focus on positive emotions and a sense of wellbeing. A further aspect of the prophetic spirituality shown by these children was their way of living with suffering. Within the literature, (4.3), there is a false presumption that these children suffer too much. As I have discussed, suffering is part of ordinary human life, it is not exclusive to disability, nor is it appropriate to equate disability with suffering. I propose that the way the children experienced and lived through and with suffering is another aspect of their prophetic nature. Andrew was the frailest child of the study group, needing many medical interventions. It was noticeable how as soon as the medical issue was resolved he appeared to move fully into the next moment. I noticed none of the children seemed to hold onto past suffering, they moved into the next moment, whatever that next moment might be. It is living, as Berryman (2013) suggests, always at the edge of their being and knowing.

I submit that the prophetic nature of these children is important to recognise and incorporate into person-centred planning by capturing comments that acknowledge how other people value and appreciate the child concerned. This recognition values them as important and significant members of the wider community, acknowledging that what they have to say is relevant to the wider world in which they live. This was demonstrated by Andrew's teachers and friends at school who recognised and valued his gift of being peaceful and who were consequently drawn to simply be with him (RJ 21/7/16). Butterfly's beaming smile that drew people to engage with her was also prophetic, emphasising a different way of engaging with people without the need to use words (B.6.15.4; B.6.15.6). The children's prophetic nature challenges others to consider what is really important and teaches others to live differently. Understanding how the children's prophetic natures illustrate the meaningfulness of their lives contributes to enabling meaningful and appropriate responses to spirituality from staff.

I propose this understanding can contribute to seeing the children as acting persons, who, through their interactions and relationships, have a valuable contribution to make to the lives of others.

To recognise the prophetic spirituality of these children demands the ability to pay attention and to listen to their language of relationships expressed through their movements of relationship and indwelling in others' lives, seen in their play, silence, laughter and distress. This is evidenced in Findings Four and Five. (7.3.4; 7.3.5.) Through hearing the children's languages of play and silence, their spirituality is not silent or silenced. However, I acknowledge that support is required by all staff to be able to hear in this way. I propose that chaplaincy teams are able to provide this support as part of chaplaincy's prophetic nature.

8.3.2 The prophetic nature of chaplaincy work

In my conclusion to Chapter Seven, I recognised how this research had supported me, as a chaplain, to find a language that enabled me to understand and practice listening to this group of children in order to hear their spiritual stories. The language required of me to be able to carry out the work was based on contemplation and attention, reminiscent of Oliveros' (2010) methods of deep listening. My research has illustrated that the essential element of a contemplative stance enabled me to learn to be with the children. I propose that working in a contemplative way is a prophetic element of chaplaincy. Chaplaincy is in a position to model a contemplative stance which, on the surface, can appear to be in opposition to the competency framework for chaplains the professionalisation agenda has instituted. However, modelling a way of being that can be encompassed within a world that prioritises action is the challenge for the prophetic role of chaplaincy. Chaplaincy can show how contemplation and attention work as part of an active process through which it is possible to know a person.

One approach identified in the literature that encompasses the contemplative attitude is that of being a 'story hearer'. Puchalski (2015) and Swinton (2015) name being a story hearer as a key task of chaplaincy. Although this role is not exclusive to chaplaincy (3.8), I propose chaplains will hear the story differently, which has a valuable contribution to add to the way stories are heard by others in the multi-disciplinary team. The stories to be heard are those of the children, their families and the staff, for as the NHS guidelines state, the role of chaplaincy is for all involved within a healthcare setting. Through the hospitality of listening, hearing a story from a chaplaincy point of view which considers the religious/spiritual framework and prioritises ideographic language, the stories of those who are often unheard

can become heard. Chaplaincy, I suggest, has a role to ensure that the variety of ways the stories are heard by the different members of a care team are incorporated, thus a more holistic story for each person becomes told. This, I suggest, is another aspect of the prophetic nature of chaplaincy, for it contributes to recognising that everyone's story is of importance. However, I acknowledge that to be able to use the language of attention and contemplation in this way in practice, within a busy, potentially noisy, action focused healthcare environment requires support and reflexivity. I propose that the required support and reflexivity to enable all carers involved to be story hearers can be provided by chaplaincy teams.

I propose too, that chaplaincy's prophetic role requires sharing what has been heard with the wider context, thus fulfilling Tracy's (1989) recommendation for theologians to speak to all publics. I have discussed Swinton's (2016) proposal for theological advocates for this group of children (4.1). Pattison's (2001) point concerning the need for chaplaincy teams to incorporate religious affiliated members with a theological background is of relevance here. These severely disabled children need others to voice their prophetic calling. However, as explored throughout this research, my contention is that the children's prophetic voices are silenced and not heard due to their language not being recognised. I propose theological advocacy is part of faith-based chaplaincy work, enabling the theological prophetic role of the children, speaking truths about God to be meaningfully conveyed to the wider world of academia, church and society. Appreciating the role of theological advocates in this way is a working out of Leach's (2007) appreciation of the mission aspect of theological reflection. My research has worked towards being a theological advocate for this cohort of children.

8.3.3 The potential for prophetic healthcare settings

In Chapter Three I briefly explored the trajectory of developments that as Risse (1999) identified, has resulted in the current high tech, functional approach within healthcare contexts. This trajectory, as Bradshaw (1996) proposed, has resulted in the loss of a sense of vocation, instead values are inspired by science. The resulting functional approach has meant, as many identify (e.g. (McKenzie, 2002; Kelly, 2012; Clarke, 2013), the professional artistry of healing, which appreciates the integral connections between the spiritual, physical, social and psychological needs of each person, has become lost.

Due to the limits of this research, where my primary focus has of necessity been on the children, I have not explored a theological understanding of the professional artistry within nursing and healthcare chaplaincy in any depth. This is an area for further research. However, I suggest that healthcare settings, such as children's hospices have the potential

to become prophetic settings through embracing a deeper understanding of person, as outlined above, and through an understanding of the prophetic nature of spirituality as seen in those cared for and those who are working within healthcare environments. I propose embracing these aspects could enable the connection between spiritual and physical needs, as seen in the healthcare models of antiquity, to be re-established and thus by incorporating those needs with physical, social and psychological issues, enable true holistic care to be delivered.

However, in order to achieve this, I propose that there needs to be a deeper understanding of hospitality, the third proposal which I will now explore, which I suggest is necessary to enable staff within a healthcare setting to recognise and respond meaningfully to spirituality.

8.4 A deeper understanding of hospitality

My appreciation of the need for a different understanding of hospitality arises from my reflections on the process and experiences of this research project, including carrying out the fieldwork and the data analysis, as well as my experience of working within a children's hospice. Through those experiences I encountered genuine practical hospitality. I emphasise that I am not criticising the generous hospitality evident within the children's hospice and the children's homes. Rather, this is an invitation to deepen an understanding of hospitality and to recognise its theological significance and the contributions hospitality makes towards providing spiritual care.

In this section, I consider different aspects of practical hospitality and its influence on spirituality. I then introduce the idea of Ricoeur's 'linguistic hospitality' and consider how this can be applied within healthcare settings. I conclude this section by considering what helps to create hospitable environments. I propose that these three aspects of hospitality contribute to enabling the recognition of spirituality and meaningful responses for all in healthcare practice.

8.4.1 Practical hospitality

During the fieldwork, every time I visited one of the children, I was made to feel really welcome by their parents. Through offers of cups of tea or tasters of food and ensuring I had a comfortable place to sit, all the parents welcomed me into their homes. Their hospitality went further in that once I and the children were settled, they allowed me to spend time with their children. I had a sense that although a gentle eye was kept on me, all the parents trusted me to be there. It was through this hospitality that I was able to get so much out of being with their children, as I have detailed in Chapters Six and Seven.

The resulting data not only supports Detheridge's (2000) recommendation that research studies with this very vulnerable group need to be carried out within environments that are well known to the children, it also highlights the importance of hospitality. The parental hospitality enabled me to create, as Fiddes (2000 p.49) terms it, the "relational space" with the children and their families. In this relational space, I learnt to dwell with them through listening and being present. This relational space enabled me to appreciate the richness of their being. Through the process of working with the children and the subsequent data analysis, I realised they welcomed me into their homes not through words, but through the use of active silence inviting me to play, and the relational silence in which we enjoyed being in each other's company. Their play and silences were part of their language of spirituality, identified in Findings Five and Six, needing attention to be able to discern what was being expressed.

In return, through my dwelling with them, the children were able to welcome me. It was a reciprocal process for in the same way that I was received into the children's homes and lives, something of their lives was received into mine. It was important to remember that the children could choose with whom they wished to relate, as demonstrated by Dragonfly when she pushed herself away from me (D.5.6.i and D.6.1.3) and Olaf when he ignored me. (O.1.2.4.) I needed to be the respectful visitor who realised there were times when I had outstayed my welcome, allowing the children to be in their own world, recognising and accepting that for that moment, I was not welcome there. As well as recognising the language of welcome, I needed to pay attention to the language of farewell. By paying attention to and recognising the different languages being used, the appropriate way of being could be enacted.

Through my experience of working in a children's hospice I appreciated how everyone involved was able to offer practical hospitality. This ranged from the warm greeting by the volunteer receptionist, to the cooked meals created by the catering team, the awareness of everyone to cultural issues, and the cups of tea and skilled nursing provided by the care teams. These were the ordinary, everyday experiences, recognised within the literature as reflecting spirituality (e.g: Clarke, 2013; Ammerman, 2014; Lepherd, 2015; Stephenson, Sheehan and Shahrour, 2017). Practical hospitality given in this way is a working out of Hefti and Esperandio's (2016) recognition of the importance of accompanying people on their journey by being present, with appropriate words when necessary and "humble acts of caring" (2016, p.32). I propose all staff need to be supported to recognise that practical hospitality, shown in the ways described above, is providing profound and attentive spiritual

care. Recognising practical hospitality as spiritual care could potentially minimise the anxiety identified in the literature about how to respond to spiritual care needs.

The practical hospitality demonstrated in the hospice setting was no different to the hospitality shown to me by the families when I entered their homes. In the same way that the parents' hospitality enabled me to create relational spaces with their children, the hospitality within a children's hospice has the potential to create relational spaces with the children and their families which will support and nurture spirituality and spiritual care. Through an attitude of hospitality, the risk that Swift (2014) identified of spirituality being seen as an additional nursing task becomes mitigated. I also suggest this is a way for all involved to reconnect with a sense of vocation and community, as identified by Bradshaw (1996) and Saunders (2016), which is fundamental to providing care within a hospice setting. Hospitality, as a practical task, can enable spirituality to be incorporated into the essence of the organisation. I propose that through the practice of hospitality, the children's hospice was in a position to maintain a balance between the essential high tech scientific professional needs of modern healthcare and being a place of mercy and refuge. (Risse, 1999). The practice of hospitality contributed to ensuring that the demands of the machines and systems did not take precedence over the demands and desires of those being cared for.

It was noticeable how within a children's hospice setting, staff went out of their way to welcome those, who within wider contexts, are seen as different. Children, such as those in the study cohort, were placed at the centre of the care provided. Within the secular environment of a children's hospice, these children were valued in a way that prioritised them as unique and worthwhile.

The hospice gave a practical demonstration of welcoming the different one, the stranger, which can be seen as a worked-out example of practical and prophetic spirituality. There is a theological parallel here, which, although it would not be the understanding of the hospice, is worth briefly reflecting upon. Welcoming the stranger or the different person is a practice rooted within the Old Testament tradition, for God is welcomed through this hospitality. In the New Testament, Christ frequently makes those on the edge of society such as children and those who were ill and disabled the centre of his focus: "Whoever receives one such child in my name receives me…" (Matthew 18:5 RSV). Christ turned the prevailing attitude towards those marginalised upside-down, welcoming them into the centre, for these were the ones that had the Kingdom of God revealed to them. The hospice example illustrates the way a secular environment can challenge and deepen a theological understanding of hospitality. As a practical theologian, I can appreciate this as a possible way of presenting Sölle's

understanding of mysticism, appreciating that God can be seen at work “even in forms that are utterly secular” (Sölle, 2001 p.84) However, I appreciate that this is not the understanding of the secular setting. The challenge, therefore, for a faith-based chaplain working in a secular healthcare setting, is to find a way of holding both theological and secular understandings together, recognising that the theological reading of the secular is “a legitimate sphere for God’s self-revelation and salvific grace.” (Graham, 2013 p.103) In the same way, I suggest that a secular reading of the theological can enable a deeper understanding and appreciation of the significance of practical hospitality.

Chaplaincy, I propose, is able to support staff towards this deeper appreciation of hospitality, through reflecting with staff how an understanding of practical hospitality moves into and supports spiritual care. It is a practical way of identifying the interrelationships between tasks as identified by Kelly, (2012) and supports Clarke’s (2013) understanding that good compassionate nursing is spiritual care. I propose that chaplaincy is best placed to do provide this support as chaplaincy stands apart from the nomothetically dominated provision of clinical care. Chaplaincy, with its priority on ideographic ways of understanding, can provide the contemplative space to reflect upon practice in a different way. In so doing, chaplaincy can support the necessary self-awareness required of all those involved, to be in touch with their own spirituality, to then be able to respond appropriately and meaningfully in encounters with those being cared for.

The relationship between practical hospitality and spiritual care can be metaphorically seen as a movement, showing the interconnection between the two, highlighting how hospitality embodies spiritual care and spiritual care embodies hospitality. I suggest that this movement is reminiscent of the movements of relationship I identified as taking place between the children and their primary carers, identified in Finding Seven. Whilst it is essential that professional boundaries are maintained within a healthcare setting to ensure the appropriate safeguarding of vulnerable children and families, the relationship movements that will occur between the staff, children and families need to be recognised. I propose that in order to recognise relationship movements, an appreciation of the different languages at play is required, which I summarise as a need for linguistic hospitality.

8.4.2 ‘Linguistic hospitality’

The term “linguistic hospitality” was coined by Ricoeur and described as: “the pleasure of receiving the foreign word at home, in one’s own welcoming home” (Ricoeur, 2004 p.10). Ricoeur was considering the challenges involved in translating from one language to another

recognising that in this process, interpretation also takes place. I propose his appreciation of welcoming the foreign word reflects the attitude of mutual indwelling as seen in *perichoresis.* It is also seen in the way I was welcomed into the children's homes and I metaphorically welcomed them into mine, as described above. Moreover, as I have worked through this research project, I have become aware of the many different languages involved. In this section I consider how the attitude of linguistic hospitality is required to appreciate and welcome religious and spiritual language, nomothetic and ideographic language and the languages used by the children. Welcoming the different languages involved contributes to recognising and understanding spirituality.

In Chapter Two, I explored how although the concepts of religion and spirituality have become polarised, religious and spiritual languages overlap. My solution to the religion/spirituality binary was to adapt Selvam's (2013) multi-dimensional, inclusive pluralistic religious/spirituality framework to create a more fluid model. My model (2.5.1) moves away from a binary that implies people are either religious or spiritual. The proposed framework acknowledges the dynamics involved, suggesting that throughout a lifetime, people's position within the framework will change. Enabling staff to appreciate the dynamics of the framework not only potentially provides them with an understanding of their own spiritual journey but also enables them to respond meaningfully to the children and families they meet.

The literature, borne out by my experiences in the fieldwork, supports the notion that spirituality is found in everyday life. What is encountered through everyday experiences may lead to an increase or lessening of religious practice and spirituality. The important point to note is that the movements of engagement in religion and/or spirituality are dynamic, highlighting the ongoing search for fulfilment and flourishing as identified by Taylor (2007). By welcoming and recognising that spirituality and religion are interrelated, the languages of both can be used to help find meaning and understanding within encountered experiences. I suggest this is a hospitable way to treat religion and spirituality, for it welcomes and accepts where people are at any one time and allows for change.

Through this hospitable approach I suggest it becomes possible to live with the 'fuzziness' of spirituality, as described by Zinnbauer, (1997), and to accept that this cannot become 'unfuzzy'. This approach accepts that definitions can contribute towards an understanding of spirituality however, relying solely on definitions is not helpful. I propose it is more appropriate to recognise and describe what is real for people, and as Murphy (2017) points out, to recognise this might be different to where theologians and academics think people

should be. As is shown through my research, reality is fuzzy, it is not clear cut. The religious influences upon the children and families were not explored or discussed in the fieldwork, although it arose incidentally with one parent who mentioned praying. For the children themselves, it would appear that their innate spirituality was their starting point, nurtured through their relationships within themselves and their families.

I propose understanding the dynamic element of my religious/spirituality framework (2.5.1), allows for movements of relationship between the different dimensions of spirituality. I refer here to the inward dimension towards self, the outward dimension towards others and the transcendent dimension which in Christian terms is towards God. By hospitably accepting everyone has a place somewhere within the religious/spirituality framework, it is possible to move away from trying to place everyone into a fixed position. Relating this to my fieldwork, it would have been easy to assume that Elsa did not have an outward relationship towards her younger siblings. However, through the process of the visits, I was able to observe the gentle and slow movements of engagement and relationship that were beginning to emerge. I hypothesise these movements were potentially nurturing her capacity for spirituality through her expanding relationships with others.

I suggest that within healthcare settings the language of relationship, as seen within religious and spiritual terms, needs to be welcomed. The language of spirituality is ideographic. I have posited that within healthcare nomothetic language dominates, with its emphasis on definitions and scientific reasoning. I have also suggested that there is, therefore, a subsequent risk of ideographic language and its emphasis on the uniqueness of an experience becoming silenced. I argue it is very difficult for spirituality to be fully incorporated into holistic person-centred planning when nomothetic knowledge and understanding is prioritised.

In carrying out this research, ideographic language, concentrating on the unique response and experience of each child and creating their spiritual signatures has dominated. However, it became very evident that I needed to be aware and use nomothetic language and knowledge too. Due their complex medical and physical conditions, it became apparent to me that it was essential to include a nomothetic ‘knowledge of other’ about these children. It was essential that I was able to distinguish between flickers of movement that could have been an invitation to play, signs of enjoyment or were signs of seizure activity requiring immediate attention. Both ways of knowing were needed in equal measure. For example, Butterfly and Andrew would both show a ‘sad face’, their smile turned down, eyes downcast, looking unhappy. I discovered this could either be an indication of unhappiness (e.g.

B4.18.4, B5.6.11) or an indication that personal care was needed (B.6.12.4; A.5.1.6). It needed skilled attention and detailed knowledge of their child from their carers to be able to read these facial expressions accurately.

Conducting this research has highlighted, for me, the need for both languages and their respective ways of knowing. This became evident as I developed my methodology and data analysis methods. As I was working on my methodology of attention and contemplation, I became aware that I was in danger of becoming trapped into a binary way of working of my own making. Belenky's (1986) research supported my focus on hearing, suggesting this was an ideographic way of working. Her research indicated that visual ways of working were scientific and therefore more nomothetic in their approach. I realised I was in danger of discounting the visual information. I recognised I also needed to pay attention to my visual observations of the children in order to make sense of what I was hearing. It was apparent that the visual data was as important as the aural. Within the data analysis process, I have needed nomothetic means of analysing and interpreting the data displayed in the content analysis sheets and the tables used in Chapter Seven. These visual, quantifiable, scientific approaches have been necessary to explore the ideographic experiences of the children. Using these methods enabled me to uncover the significant finding that these children needed the presence of their primary carers to begin to develop relationships with myself. Seeing the data expressed in a nomothetic form enabled me to begin to interpret the ideographic experiences of the children captured on the audio recordings. Working with the recognition of the importance of both ideographic and nomothetic knowledge within this research has been an experience of linguistic hospitality, ensuring that the foreign words have been welcomed.

My reflexivity, supported by the underpinning theological reflection throughout this work, based on Leach's Pastoral Theology as Attention, (2007) has required what Michael Paterson describes as the contemplative spiritual discipline of "looking, looking and looking again, until what is seen provokes wonder, insight and response in the beholder." (2019 p.13) It has also involved hearing, hearing and hearing again, as well as listening to all that there is to hear. Seeing hospitality as a spiritual undertaking has necessitated a contemplative approach, using, as Catherine Sexton proposes, "Holy Listening."(2019 p.44). The work has involved welcoming in equal measure nomothetic and ideographic knowledge. I have needed to see the data in order to hear as much as possible and to hear the data in order to be able to support what was seen. I needed to see to hear and to hear to see.

An appreciation of equally attending to both types of language and knowing needs to be translated into the healthcare environment. It requires, I propose, implementing Ricoeur's understanding of linguistic hospitality. I suggest that there are many "foreign words" when considering how to move the findings from this research into a healthcare setting. This is where an attitude of hospitality is needed by all to receive the 'foreign words' into each other's welcoming work environments. There is a need to let go of what Swinton names as the "positivistic desire for certainty" (2001, p.13) to be able to receive the fuzzy language of spirituality, as well as appreciating the need for accurate medical details. In this way, it is possible to understand that recognising and recording the moments of deeper relationality with a child are as important as the noting of significant medical details such of body temperature, nutritional intake and medication. I propose that encouraging staff to appreciate the equal importance of ideographic and nomothetic language will support them to recognise spirituality in the hospitality they provide.

The languages of religion and spirituality, of nomothetic and ideographic languages are organisational and academic languages. The native languages of the children, although fitting into the ideographic category, also needed to be welcomed in a way that recognised what was being communicated. For this research, I needed to welcome and to learn their 'foreign word' such as blowing raspberries, laughter, high- and low-pitched vocalisations, animated movements, silence and play into my 'home.' I needed ears and eyes to be wide open and not presume that I already knew what was being communicated. I had to learn that Elsa's high-pitched vocalisation was one of distress (E.2.6.7, E.3.12.12.), whereas Andrew's vocalisation at the same pitch denoted interest and excitement (A.2.4.18, A.2.5.39). Listening again and again to the recordings, using Oliveros' (2010) principles of deep listening and Sölle's (2001) wide-open eyes, enabled me to begin to know what the children were communicating.

This unconventional language is easily silenced and not heard, but, as my research shows, it is essential to hear if the spirituality of these children is to be given the recognition that it deserves. Theirs is a different language of spirituality that once recognised needs to be appreciated and welcomed. Once welcomed, it needs to be learned to enable the alternative ways these children communicate their spirituality to become evident. I propose that learning their language takes time, patience, attention and contemplation. There needs to be time for the "sensitive and quiet observation" as recommended by Adams et al (2008 p.38). Through this attentive observation each child's playfulness signature, their assent and dissent signals and their different uses of silences as well as noting who they do and do not

relate to, as I have discussed in Chapter Seven, can become known. This is essential for their unique spiritual signature to be recognised to then be incorporated into their holistic, person-centred care plan.

I am reminded that when Saunders set up St Christopher's Hospice, (Bradshaw, 1996) she identified silence was one of the necessary factors required for the supportive environment she wished to create. Listening attentively to others requires silence on the part of the listener and is reminiscent of the deep listening approach advocated by Oliveros (2010). Moreover, as my research has uncovered, this group of children also use silence as a way of communicating (7.3.6). To be able to listen to this silence of communication requires the listener to be able to sit with the silence and not to fill it with noise. This involves the emptying of self that I identified in my methodology (5.7.2) and I propose is a significant part of offering hospitality.

Implementing Ricoeur's notion of "linguistic hospitality" within a healthcare context has the potential to achieve an equal valuing of ideographic and nomothetic language. I propose that Chaplaincy is in a unique position to support this implementation. Although chaplaincy pre-dominantly uses ideographic language, it needs to be equally conversant and familiar with nomothetic language, as I have highlighted from this research. In a conference paper presented at the British and Irish Practical Theology Association (BIAPT) (Price, 2019), I suggested that, by receiving both languages, chaplaincy is able to offer a Pentecost moment, where "each one heard them speaking in the native language of each" (Acts 2:6 NRSV). Through finding a way of speaking theologically in the native languages of children and of their carers and healthcare professionals, such as applying the relational understanding of person to person-centred planning, there is a possibility of opening up a conversation that enables all involved to find ways of expressing their truths meaningfully. In so doing, all are encouraged to recognise their own and others' spirituality. To be able to do this appropriately and professionally, requires, I propose, a deeper understanding of hospitality within the whole organisation.

8.4.3 Creating hospitable healthcare environments

I have identified that practical hospitality is an important feature of healthcare settings such as a children's hospice. I have also demonstrated that spiritual care can be supported and given through practical hospitality as well as contributing to creating the relational spaces needed for spirituality to be recognised. It is therefore relevant to consider the characteristics needed to create a hospitable healthcare environment where practical and linguistic hospitality can be encouraged.

It is worth noting that studies within the hospitality industry have identified how creating a "listening environment" promotes better customer services and supports the wellbeing of staff working in this sector (Brownell, 1994). Judi Brownell identifies that "Values like integrity, co-operation, trustworthiness, and *caring* may be realised most fully within the context of listening environments" (Brownell, 1994 p.7) (My italics). These same values are also integral to providing person-centred holistic care within healthcare practice.

To enable and support staff to offer hospitality in this way, I suggest that healthcare organisations need to be hospitable towards themselves and all their members. I suggest hospitable organisations can be created through the implementation of Škof's proposal of being attentive to oneself, to then be in a position to be attentive to others. As Škof demonstrates, genuine attentive care is required for the "deepest and most sincere hospitality" to be offered (Škof, 2016 p.908). This reflects Brownell's proposal that listening environments are an essential part of hospitality. Brownell points out listening environments can only be really effective if the staff within an organisation are listened to themselves (1994, p.3). If someone has the space in which to tell their story and for that story to be held, then they in turn can hear and hold another's story.

It is essential, therefore, to recognise that to be a hospitable organisation requires a listening and attentive environment that can hear and value the different languages and stories that are being told. A "hospitality of listening" as described by Karen MacKendrick, in which it is necessary to "listen to what we see" (MacKendrick, 2011 p.104) is a way for an organisation to value both nomothetic and ideographic languages and to recognise the variety of languages used by those being cared for.

Incorporating a spirituality of hospitality into an organisation may well answer some of the issues Bregman (2014) identified, as discussed in Chapter Two, arising from the organisational focus on spirituality as it has moved into mainstream, non-religious environments. I have stressed in this research I see the core of spirituality to be about relationships. These are relationships that encourage what Taylor (2007) describes as 'fullness' and that enable people to flourish. Hilary Cottam, in her work considering alternative ways of providing welfare services, proposes that there is a need to move from systems "that manage us to one[s] that encourages us to flourish" (2019 p.241). I suggest organisations that encourage their staff to flourish by promoting a listening environment and healthy enabling relationships are organisations that demonstrate a deeper understanding of hospitality, which in turn, reflects a spiritual dimension.

Creating listening environments and seeing care relationally rather than separated out into different components supports practitioners to naturally provide spiritual care because good care is spiritual (Clarke, 2013). Working this way has the potential to negate the need for completing a spiritual care competency. Instead, by providing good care, that is attentive to people's needs and values, which can be appropriately assessed through a competency framework, staff can be encouraged to value the good care they give and recognise it as spiritual care. I have demonstrated throughout this research that complicated definitions and assessments are not helpful nor appropriate for the study cohort. Instead, I suggest staff need to be supported to understand and put into practice qualities of being present to the moment, being attentive and contemplative, being self-aware and reflective and being able to recognise the relationality of the situation. In this way, it becomes possible to recognise the interrelationships between the tasks that need to be carried out and the holistic nature of the children's lives. The 2Q-SAM proposed by Ross and McSherry (2018), as discussed in Chapter Three, is easily carried out throughout a care shift because what is important to the child and what needs to be done for them becomes evident through practicing hospitality in this way.

Chaplaincy, through the creation of relational spaces, can provide the opportunities for opening up conversations where all can talk from their own meaning making systems. Therefore, it is important that chaplains and chaplaincy teams reflect the plural society in which we live. In so doing, this models the reality as expressed within my version of the religious/spirituality framework. By modelling this framework in the way chaplaincy is set up, it becomes a hospitable space where all can find their place and where it is recognised that there are movements of relationship which will be reflected in each person's spirituality. Within such a space it becomes possible for reflection and reflexivity, which, as is consistently highlighted and I agree with, is essential to be able to recognise spirituality and therefore respond meaningfully. Using chaplaincy to develop such an approach, as promoted by NHS Scotland through using Value Based Reflective Practice (NHS Education for Scotland, 2017) also helps to clarify, as identified by Galek et al (2007) and Todd (2015), the ambiguity surrounding the role of chaplaincy.

I propose through the integration of chaplaincy into the multi-disciplinary care team, as proposed by Hefti and Esperando (2016), not only are the dots between the different specialisms joined (Todd 2015), but also the necessary listening environment can be supported. The literature explored in Chapter Three highlighted the lack of inter-disciplinary working. I have discussed how each professional body has established its own definition of

spirituality and devised its own assessments and approaches. This is counter-productive for it not only creates the risk of 'silo' working, where there is little communication between the professions, it also means that a shared understanding of spirituality and the spiritual care needed is lost. I suggest creating a hospitable listening environment will enable all involved practitioners to be aware of their own spirituality and of the spirituality of all those encountered.

I suggest this deeper understanding of hospitality contributes to enabling these children's spiritual voices to be recognised and so responded to meaningfully. Hospitality, in practical and metaphorical ways creates an environment where the quietest sound or the tiniest gesture is recognised as communicating something important, allowing these children's spiritual voices to be heard.

8.5 Summary of Chapter Eight

This chapter has been an exploration considering how the findings from my qualitative work, can be developed within healthcare settings. This has been with the aim of answering my second research question:

> What enables those practising in a healthcare context to recognise spirituality and so respond to it meaningfully?

Throughout this chapter, I have considered how healthcare practitioners can recognise spirituality and I have clarified what a meaningful response might be. I propose that my considerations work towards meeting the acknowledged challenge of providing spiritual care within a healthcare context, as identified within the research literature (Narayanasamy, 2001; McSherry, 2006; Clarke, 2013; Lepherd, 2015; Liefbroer, Ganzevoort and Olsman, 2019). Liefbroer et al also appreciated that attention needs to be given to how a caregiver's own spirituality can influence the spiritual care provided. My theological reasonings have developed my understanding of the spirituality seen and heard in these children. I see their spirituality as relational, reflecting the image of God through their movements of relationship. In turn, my understanding of the relational nature of their spirituality has led me to reflect on person, prophecy and hospitality. I have suggested in this chapter that through a different and deeper understanding of these concepts it becomes possible to bring the findings of my research into a healthcare context, supporting the recognition and meaningful response to spirituality by those practising in these settings.

I have proposed applying a relational understanding of person to person-centred planning. Person-centred care is a dominant theme within healthcare environments. I have argued for

the need for the theological understanding of person as community and relational to influence the approach to person-centred work. My reasoning is that by using a relational understanding of person, the significance of the children's relationships, as evidenced in my research, can become the starting point for recognising their spirituality. My research has shown that the spirituality of the children in this study, expressed through their relationships, influences every other aspect of their lives, supporting my contention that holistic care needs to start from the spirituality domain.

I have also argued that a relational understanding of person can support all staff involved to connect with and explore their own spirituality. I suggest it is a way of enabling staff to move from a focus on 'doing' and allowing themselves to 'be'. This reflective and reflexive work is essential for all concerned to enable the recognition of spirituality in others. From this recognition, it is possible for all to become the story hearers of Children's Spirituality.

I have suggested that understanding prophecy as seen in the children, within the work of chaplaincy and an organisation, contributes to the recognition of spirituality. I appreciate that by using prophecy in association with spirituality, I am deliberately using religious language which I hope can be hospitably received in a secular context. My religious language is not used in an evangelistic sense, rather it is to highlight the significance and value to what I propose the children bear witness. As I have discussed, I consider the prophetic nature of the children to be shown in the way they live. They offer an alternative way of living, one that prioritises and values relationships, rather than prioritising material wealth and possessions. It is seen in their pleasure at the simplest things, such as Dragonfly's enjoyment of playing with plastic packaging. Their alternative way of living can be summed up as living in the moment, not ignoring or excluding suffering. As I have discussed, suffering was present, the children appeared to be able to live through their suffering to then move on into living the next moment. The witness of their complex lives, lived ordinarily, is prophetic.

Their witness and prophetic nature, I have suggested, deserves to be heard and listened to beyond the confines of their families. I propose that these children's prophetic voices are called to speak to the academy, the church and society. In order to do this, I see the need for theological advocates, whose role it is to speak on behalf of the children, delivering their prophetic message into the wider world. Chaplaincy can play an important supporting part in enabling this to happen. It is where chaplaincy has its own prophetic role to play, ensuring that the voices of those not heard are sought out, listened to and welcomed.

I have also proposed that chaplaincy is prophetic through the way it can model a contemplative stance and prioritise ideographic knowledge, such as the prophetic

contribution of the children, bringing that into conversation with nomothetic understanding to enable a more holistic appreciation of each person. I have suggested too, that chaplaincy's appreciation of the different languages being used, as well as an appreciation of the complex landscape of religion and spirituality in today's society, can support everyone to hear and talk about spirituality "in their own words". (Acts 2:6 NRSV) I have put forward the suggestion that healthcare settings themselves have the potential to be prophetic by understanding person differently. This would enable the spiritual domain to be equally valued with the physical, psychological and social domains, to deliver authentic, holistic person-centred care.

I have suggested that these alternative perspectives of person and prophecy need to be hospitably received within a healthcare context. I have identified three aspects of hospitality that I propose contribute to recognising spirituality, namely, practical hospitality, linguistic hospitality and creating hospitable environments. Practical hospitality is practical spirituality at work, providing compassionate, loving, attentive care and is, I suggest, a meaningful response to spirituality. Listening and appreciating the different languages within an organisation requires Ricoeur's linguistic hospitality. As I have shown, it is essential to equally value the nomothetic and ideographic languages as these are reflected in all aspects of person-centered care. It is also essential to recognise and listen to the children's language of spirituality expressed through their relationships, their play and their silence. All staff need support to be able to appreciate and develop this deeper understanding of hospitality. I have then explored the idea of hospitable organisations, which encourage listening environments and systems that promote flourishing as a further means of supporting the recognition of and response to spirituality.

This chapter has proposed that a different and deeper understanding of person, prophecy and hospitality can support the recognition of these children's unheard spirituality in a healthcare setting. I have suggested that chaplaincy is in a unique position to provide the appropriate support. Chaplaincy brings a different perspective, through a prioritisation of the ideographic nature of spirituality and through being able to provide the necessary reflective and relational space to enable spirituality to be recognised and thus improve the care given.

I propose that the recognition of spirituality is a meaningful response in itself, however, through all staff becoming story hearers, a deeper, more meaningful response can be made by all concerned. For once their story is heard, these children's spirituality brings about change in their hearers. In turn, this moves out into the much larger worlds of healthcare,

education and society, challenging all to live ordinarily, prioritising relationships, living each and every moment.

Chapter 9 Conclusion

I have striven in this research to undertake the practical theology task of making “audible those voices that are usually unheard” (Cameron and Duce 2013 p.38). Nye, Champagne and Hyde are amongst researchers identifying that generally, all children’s voices are unheard. My contention from the outset has been that severely disabled children’s spiritual voices are particularly silenced due to a lack of recognition of how their spirituality is expressed and communicated.

My explorations for this research drew on a wide range of disciplines. I have drawn on the social sciences to consider literature from the sociological and psychological study of religion and spirituality, revealing the continuing search for definitions for spirituality and religion. As I investigated how spirituality and religion were understood within society and within healthcare in particular, I concluded that the continual search for definitions was unhelpful and inconclusive. I also noted that whilst wider society is coming to accept religion and spirituality within the same framework, healthcare contexts appear to see religion and spirituality as binary. Seeking to develop a response to the healthcare approach, I turned to child development studies, childhood studies and disabled children’s studies, as a multidisciplinary exploration of the comparatively new field of Children’s Spirituality, from which I argued that spirituality is better described than defined.

Building from this, my literature review considered features of practical theology, disability theology, and an exploration of the central Christian doctrine of *imago Dei* to explore how severely disabled children and their spirituality can be understood theologically and to find theological means to recognise and support their spirituality. I also drew on my professional training as a children’s occupational therapist and my experience of working as a chaplain in a children’s hospice. These initial explorations highlighted the dearth of research into the spirituality of severely disabled, non-verbal children, which I propose, maintains the silencing of these children due to the lack of knowledge enabling their spiritual voices to be heard.

I proposed that these children’s spirituality needs to be attended to so that their spirituality can be recognised and responded to meaningfully, not only in healthcare settings but within wider contexts too. I maintain that they have something important to share, they too contribute to the “unparalleled ‘kind of knowing’” that Nye (2018 p.140) advocates is present within children’s spirituality.

As a Practical Theologian, I am searching for the infinite mystery of God in the ordinary. When I began my research, my ordinary was working within a children’s hospice where I was increasingly aware of the uncertainty and confusion about spirituality in general and

particularly with the children. This, to me, was a silencing of the children. Having recognised the lack of research in this area, combined with my experience of working within a children's hospice, my research questions were designed to explore ways in which severely disabled children's spirituality could be supported within healthcare practice:

> What is it that enables severely disabled children's spirituality to be heard and recognised?
>
> What enables those practising in a healthcare context to recognise spirituality and respond to it meaningfully?

The practice of ongoing theological reflection was essential in working towards answering my research questions. I used Leach's Pastoral Theology as Attention (2007) throughout the research process, combining my theological reflections with the academic research, the field work, the data analysis and the continual revision required in writing, revealing, I propose, the different ways the study cohort of severely disabled children expressed their spirituality. I suggest my findings contribute to the knowledge base for Children's Spirituality and to a relational understanding of humanity being made in the image of God. My findings offer secular healthcare settings alternative ways to enable a meaningful recognition and response to spirituality for this cohort through a relational understanding of person, prophecy and hospitality.

To offer a final explanation for these key conceptual and practical outcomes, I want to briefly reconstruct the route this thesis has taken in establishing their necessity. I began my research by considering the complexities involved within western contemporary society's understanding of religion and spirituality. Chapter Two explored the historical and social science explanations for society's changing understanding of the concepts of religion and spirituality, revealing confusion and uncertainty. There are many ways people now identify themselves as 'religious' or 'spiritual but not religious', or both. I described the resulting confusion as a complex landscape, (2.2, 2.4), that is difficult to navigate. The complexity, I proposed, arises from the shift within society, identified by Taylor, (2007), where five hundred years ago the belief in God might have been universally assumed, to the position now where belief in God is one option among many. The complexity necessitates multi-cultural, multi-faith and non-faith influences to be incorporated into an understanding of religion and spirituality.

Spirituality, as a concept, has also shifted, going from being solely associated with religious institutions to either individualistic approaches to spirituality as identified by Bender (2010)

and Zinnbauer et al (1997) (2.2), or wider, often vague, organisational contexts (2.3) such as finance, leisure and healthcare, who endeavour to embrace a spiritual dimension to their work. I suggested that, as a result, a myriad of definitions have arisen, (2.3), with minimal consensus as to what is meant by spirituality. All the definitions I encountered in the psychology or sociology of religion and spirituality (e.g. Zinnbauer et al 1997, Sheldrake 2007) emphasised relationships as a common theme.

Religion has become defined as limited to institutional practice, resulting in a simplistic understanding that sees religion and spirituality as a binary. The resulting binary, I have argued, is not helpful, nor does it reflect the reality of contemporary society (2.4). The literature suggests that spirituality and religion both play a role in contemporary western 'post secular' society (2.4) (Habermas, 2006; Watson, 2017). The continuing search for definitions, I proposed, is not helpful, rather, it is more useful to describe spirituality. I therefore embarked on my project conscious that I was not seeking a definition, rather a richer and deeper understanding and description of spirituality which might arise from my research. This approach may have much to offer other research into spirituality in other contexts.

I illustrated the complex landscape of spirituality and religion through my adaptation (2.5.1) of Selvam's inclusive pluralistic religious/spiritual framework (Selvam, 2013), which I proposed, contributes to the ongoing discussion concerning religiosity and spirituality. My adaptation acknowledged the influence of lifetime experiences upon people affecting their identity within religious and spiritual practices. I suggested my spirituality/religiosity framework is a potential tool providing a dynamic understanding of spirituality and religion and a descriptive language for people to use, leading to a way of recognising and describing these concepts within different contexts. I proposed that the complex societal landscape, established in Chapter Two, contributes to the silencing of the children's spiritual voices due to the ongoing confusion concerning spirituality and religion. This continued to underline the importance of my research topic.

In Chapter Three, I explored how healthcare practice reflects the complex landscape of religion and spirituality described in Chapter Two. I proposed that the challenges for recognising spirituality within healthcare, evidenced in the literature, arise from the dominance of nomothetic language that priorities definitions, assessments and outcomes (3.2.2, 3.3.5, 3.4). Healthcare aims to provide holistic care, considering physical, psychological, social and spiritual domains. I proposed that physical, psychological and social domains can be nomothetically understood and assessed whereas spirituality is

ideographic. Consequently, it is left struggling to be heard. I also perceived from the literature healthcare organisations continue to view religion and spirituality as a binary (3.3.1).

The literature reviewing healthcare chaplaincy revealed the delicate task chaplains face to hold fast to the ideographic nature of spirituality. It highlighted the difficulties of integrating chaplaincy into multi-disciplinary, nomothetically-focused medical teams. As a consequence, I identified that chaplaincy teams are providing evidence to validate their roles within a nomothetic framework by creating definitions of spirituality and standarised assessments (3.3.1), causing tension as chaplaincy work is ideographically focused. I also noted the considerable work by researchers within nursing to provide definitions of spirituality, standardised assessments, and competency training packages (3.3.4, 3.3.5, .3.3.6). All definitions reviewed emphasised the importance of relationships reflecting the theological literature explored (4.5). However, the literature review also revealed the anxiety and lack of understanding about spirituality within healthcare (3.3.6). Despite the expectation everyone involved in healthcare is able to provide spiritual care, and be aware of their own spirituality, spiritual care and spirituality remains an uncomfortable area. The nursing literature suggests possible solutions, such as Clarke's (2013) understanding that all good compassionate nursing care is spiritual care (3.3.5) or Ross and McSherry's Two Questions Spirituality Assessment Measure (2018) (3.4). However, there is limited evidence demonstrating the successful implementation of these approaches. I proposed that the anxiety and lack of understanding about spirituality contributes to its silencing because staff do not have the confidence or language to articulate spiritual matters.

My own profession, Occupational Therapy, supports my stance that spirituality is far better described than defined (3.3.7). My conclusion at the end of Chapter Three is that spirituality requires descriptors, not definitions (3.7), as descriptors can enable the on-going story to be heard, (3.8), recognising and valuing the variety of ways that spirituality is expressed and experienced. I also concluded that chaplaincy needs to be fully integrated into multi-disciplinary teams to work alongside the other professions and support the repeatedly identified need for self-awareness of each person's own spirituality. I proposed that healthcare organisations need to shift from seeing religion and spirituality as a binary to being able to see both concepts within the same framework as suggested by my spirituality/religiosity matrix (2.5.1).

Chapter Four considered where children's spirituality fitted into the increasingly complex entangled landscape emerging from the work in Chapters Two and Three. I began by

drawing on theological resources considering what it means for all to be made in the image and likeness of God. My research into the literature proposed that one way of handling the issues of *imago Dei* from a disability viewpoint was to move from an understanding that prioritises rational thought, autonomy and self-awareness (4.2), to considering an understanding of the image of God in Trinitarian terms (Cunningham, 1998; Fiddes, 2000, Moltmann, 2009). I argued that by prioritising relationality as seen in the Trinity and reflected in families and communities, the severely disabled children in the study are brought into an inclusive understanding of person and of being made in the image of God (4.5). I proposed the children could come to know God through God, (Volpe, 2013) through the relationships that they had with themselves, their families and others (4.5).

I brought this theological reasoning into conversation with Children's Spirituality research. The work of Ranwez (1965), Hay and Nye (1996), Champagne (2003), amongst others, highlighted the significance of relationships within children's spirituality, resonating with my view of a relational understanding of *imago Dei.* My explorations highlighted the importance of embodiment, play and silence in children's expressions of spirituality, leading me to consider how these might be seen within my study cohort. This highlighted the paucity of research about play, embodiment and silence with severely disabled children. Research from education (Watson, 2015) highlighted the need for the careful observation of severely disabled children's playfulness signature. Hay and Nye (1996) proposed that all children had a personal spiritual signature, leading me to speculate that this would apply to my study cohort; however, how this and the expression of relational consciousness could be seen needed careful consideration. Considering the study cohort's significant dependence upon medical support, I looked for specialist research to consider how severely disabled children's spirituality is understood within healthcare practice (4.10). This revealed limited studies focusing on assessing verbal ill children's spirituality (Nash et al, 2015; Bull, 2016). However, there appeared to be no evidence of research for my specific cohort. Research by Coulter (2002) with severely disabled adults not only confirmed my contention that spirituality is better described than defined, but also proposed a way of looking by paying attention to the person concerned. Research by Llewellyn, (2015) highlighted the importance of simply 'being' with people.

From the wide-ranging literature review, it was apparent that relationships were significant in understanding spirituality. I posited that the children formed and developed relationships through play, therefore play itself was an expression of spirituality. Spirituality is embodied by the children therefore how they interact with themselves and others also shows their

relationality. I speculated that the study cohort would use silence differently to typically developing children.

I concluded this chapter with a detailed description of children's spirituality, bringing together the various aspects explored, concurring too with Nye's view, that children's spirituality is better described than defined (2018a). The review of the literature, although limited concerning severely disabled children's spirituality, demonstrated that the theological understanding of relationality as the image of God, had something to offer the secular definitions of spirituality that highlighted the importance of relationships. There were also suggestions that by paying attention to play, embodiment and silence as well as relationships could be a way of finding answers to my two research questions. However, what was needed was a sensitive methodology and methods that would enable me to investigate the children's spirituality through fieldwork.

Chapter Five detailed my methodology. I found, similarly to Clare Radford's marginal research (Radford, 2017), my methodology and subsequent methods needed to challenge the usual theological methodologies in order to convey this group of severely disabled children's expressions of spirituality. My methodology can be summarised as using the theological practice of paying attention to and then contemplating all that was seen and heard. It required a deliberate stance of being empty-handed (5.6.2), in order to be able to receive from the children, the literature and the data. My methods reflect a contemplative and attentive stance, focusing on what it was like to simply be with the children. This influenced the fieldwork which comprised visiting six children for a maximum of six sessions, aurally recording the encounters and spending time with them paying attention to their play, silence and relationships. The resulting transcripts were used for data analysis.

My data analysis required having the confidence to adapt standard content analysis and thematic analysis methods (5.6.1, 5.6.2). This was essential to enable the children to be heard. I sought to find patterns and evidence of significant findings for each child's personal spiritual signature and potential answers to my research questions. Through this creative approach, I realised I needed to use nomothetic knowledge and language to explore ideographic research in detail. However, the nomothetic understanding was not sufficient by itself, it was essential to include ideographic descriptions and narrative to convey the full picture.

I argue that severely disabled children can be enabled to participate in research, and this project offers both evidence and a fruitful example for others. I acknowledge that there are issues of establishing triangulation (5.7.10). However, by paying detailed attention to

essential ethical approvals and the overriding principle of the ethical practice of attention, it is possible and worthwhile to carry out research with this study cohort. Future research might deepen and refine this approach. I emphasise that it is essential to have a clear understanding of expressions of assent and dissent, as well as a baseline understanding of expressions of content and discontent. Taking this approach, and adapting traditional theological research methodologies and methods has, I propose, a contribution to make towards research in under-researched areas with marginalised subjects.

Chapter Six gave a portrait of each child and what I perceived to be each child's personal spiritual signature. These were gained from semantic analysis of the transcripts and from my research journal reflections. I proposed these children's spirituality can be heard, using my methodological approach of attention and contemplation. I conclude, in the same way the literature review indicated (Hay and Nye, 2006; Champagne, 2003; Nye, 2009, 2018), that the study cohort expressed their spirituality as all children do, through their relationships, through embodiment, in their play and in their silences. I experienced moments of relational consciousness, expressed through intentional relational acts that deepened my relationship with and understanding of the spirituality of these severely disabled children.

Chapter Seven worked towards answering my first research question: What is it that enables severely disabled children's spirituality to be heard and recognised. This involved using the data, adapted data analysis, my research journal and the insights developed in Chapter Six, bringing these resources into conversation with the literature explored in Chapters Two, Three and Four. The detailed latent analysis resulted in eight findings that considered the children's relationship with themselves, their primary carers, others and with God. My findings gave answers to my first research question demonstrating that these children's spirituality is seen in their embodied relationality, expressed through their play and silence. The findings concurred with Nye's contention that play is a spiritual language used by children to express their spirituality. The study cohort's use of silence was different to that of typically developing children (4.7.3). I also noted the impact of their physical and medical conditions and the movement the children made between their inner world and the worlds around them.

I proposed these findings answered my first research question and contribute new understandings concerning the recognition of severely disabled non-verbal children's spirituality. I identified significant findings which I have not found elsewhere that may be unique to this group. I named these as the need for the child's most significant relationship to be present to enable the child to begin to develop relationships with others; the use of

three different types of silence, identified as active, relational and disengagement; and the ability of the children to live in the present moment, no matter what that moment contained.

The significance of the need for the presence of the child's primary relationship enabling them to relate to others, not only has practice implications, but is also indicates an area for further research to test the validity of this finding. I was unable to find any specific research discussing attachment theories in relation to severely disabled, non-verbal children. This finding may also highlight a particular relationality aspect of their spirituality, indicating the importance of the relationship with a significant other to enable other relationships to be nurtured. This finding supported the emphasis on relationality identified in the definitions of spirituality discussed in the literature review. However, it also illustrated the need for spirituality to be described to enable the full import of the characteristics of the children's relationality to be recognised. I proposed further theological reflection is needed to explore how this finding relates to the Trinitarian understanding of *imago Dei* explored in Chapter 4. This finding could be seen as a reflection of the Christian understanding of dependency on God and God's relationship with humanity, enabling humanity to relate to others.

My analysis of the children's use of silence as active, relational and disengagement gave an important insight into appreciating their way of expressing relationships, a core feature of their spirituality. I proposed further research is needed to explore if silence is used in this way by other non-verbal severely disabled children, such as those on the autistic spectrum and for other non-verbal people such as those with dementia, potentially giving insights into their spirituality.

The findings focusing on the children's relationships with themselves, others and with God builds on the literature discussed in Chapter Four (4.5). I proposed the evidence from my research supports the contention that children's spirituality is better described than defined. I suggested this could be achieved through attentive observation and then contemplation of all that is seen and heard. I proposed that through theological contemplative reflection it is possible to follow Volpe's (2013) reasoning that these children will know God through God (4.3). God is relational and known through relationships. The children, as evidenced through the data analysis, were in relationships that they experienced as meaningful and therefore, I concluded that these children have the capacity to know God through their relationality with themselves and others.

I accept that my sensed experiences of relational consciousness could say more about my own spirituality than that of the children. However, I maintain that in common with all children, as evidenced through the theological reasoning in Chapter Four, this group of

children's innate capacity for spirituality as embodied in their relationships, expressed in their play and silences was evident. I could not establish whether or not the children were conscious of their spirituality, it is probably not possible to do so. However, as Nye has speculated, this is perhaps not necessary (2018 p.142). What is necessary, and what I propose contributes to the ongoing research into children's spirituality, is the simple recognition that this group of children were spiritual. However, the complexity of recognising their spirituality through their way of being, needs to be acknowledged. The children lived relationally, with themselves, their families and with God, living a difficult life, ordinarily, living meaningfully in the moment, no matter what that moment contained. Understanding and recognising severely disabled children's spirituality in this way provides an indicative way of describing their spirituality.

Chapter Eight discussed developing the findings into practice from a practical theology stance, working to answer my second research question: What is it that enables those practising in a healthcare context to recognise spirituality and so respond to it meaningfully. The detailed data analysis, my research journal and ongoing reflective practice in conjunction with reflections from the literature review enabled me to formulate three proposals. These are practical theology offerings potentially supporting a secular understanding of spirituality in a healthcare setting. I proposed that a relational understanding of person, of prophecy and of hospitality articulates a "theology of practical relevance" (Swift, 2014). My proposals build on and enhance existing research and practice that recognises the importance of person-centred planning (3.2.2), the need for awareness of one's own spirituality (3.3), the need for fully integrating chaplaincy into healthcare teams (3.5), along with recognising the spiritual care that is already present (3.5). My proposals offer ways of paying attention to and interpreting what is noticed, heard and experienced to support the recognition of spirituality within healthcare.

My first proposal: understanding 'person' to mean relationships and community (8.2), enables holistic person-centred care to be enhanced, enriched and made whole, for the spirituality domain becomes central to care. My second proposal considering the prophetic nature of the children gives witness to the significance of their difficult lives lived ordinarily. By seeing healthcare as prophetic, staff may be encouraged to recognise their own spirituality, seen in the care they give and in the relationships that they have with the children.

Although chaplaincy was not my research focus, the importance of chaplaincy within healthcare has been a personal outcome of the work and is key for the outworking of my

proposals. I propose that the evidence from the literature demonstrates that staff need considerable support to be able to recognise and respond meaningfully to the ideographic nature of spirituality, their own and those they care for. I advocate chaplaincy teams play an essential prophetic role in providing this support. Consideration needs to be given to settings without chaplaincy support where all are expected to provide spiritual care. This indicates a need for further research, to explore, as Liefbroer et al (2019) identify, the impact of the caregiver's spirituality on their understanding and recognition of spirituality and to investigate the support needed for staff to deliver spiritual care.

My third proposal is to understand hospitality as a meaningful response to spirituality. This includes the practical hospitality of caring (8.7.1), the need for linguistic hospitality (8.7.2) in appreciating the different languages at work and the need for hospitable, listening organisations (8.7.3). I concluded that these three theological offerings are potentially transformative ways of enabling these children's spiritual voices to be heard, recognised and responded to meaningfully within healthcare practice.

9.1 A Grain of Sand…

My thesis has been that the spirituality of severely disabled children is silenced. The severely disabled children in my research were not silent about their spirituality, but I needed eyes and ears to hear and see it. The children were shouting out a spirituality that centres on relationality. It is this spirituality that I propose needs to be heard and understood in far wider contexts. In Christian terms I propose that their spirituality is a reflection of what it means to be created in the image of God. In secular terms, I suggest these children's spirituality demonstrates a way of living relationally, particularly seen in their emphasis of living each moment.

In Chapter One, I likened the existing knowledge about the spirituality of severely disabled non-verbal children to be comparable to a grain of sand. The metaphor of a grain of sand is powerful in many ways. Grains of sand can be an irritant, no matter how often one tries to brush them away they persistently stay stuck to surfaces, making things uncomfortable. Severely disabled children can also make others feel uncomfortable, through their difference, their dependency and vulnerability. They challenge through their being, particularly within western contemporary society's emphasis on individualistic achievement and perfection. I suggest society needs to feel and accept this uncomfortableness because it challenges society to welcome difference, which I have argued is essential for meaningful relationships (4.4).

Looking at a grain of sand under a microscope reveals its true beauty and uniqueness. This thesis is an attempt to pay detailed attention to these children to reveal their beautiful, unique and particular expressions of spirituality. Moreover, my detailed study of these six severely disabled children has sought to respond to Kellet's concern that "the further a child's voice strays from the articulate, performative ideal that is prized in adult forums, the fainter it becomes" (2009 p.242). I have worked to place these children's voices in the centre of an understanding of religion and spirituality within wider contexts where complexity has meant their voices are especially hard to discern.

I began this research by moving through the various social layers that surround the children as outlined in Chapters Two, Three and Four, identifying what is known and unknown about severely disabled children's spirituality. My fieldwork, within the subsequent descriptions of each child's spiritual signature and the detailed data analysis, began to reveal the unique ideographic nature of these severely disabled children's spirituality. Now, at the end of this research, I propose that the starting point for the search for knowledge about spirituality, which is, I suggest, a "pearl of great price" (Matthew 13: 46 NRSV), needs to begin with the spiritual grain of sand as represented by the voices of this tiny group of children. Their 'being spiritual', which involves living a difficult life ordinarily and meaningfully, in relationship with themselves, others and God, living each moment, is, I suggest, at the centre of all spirituality. Their spirituality can inform and influence the understanding of spirituality in other contexts that surround them. For it takes a grain of sand to make a pearl.

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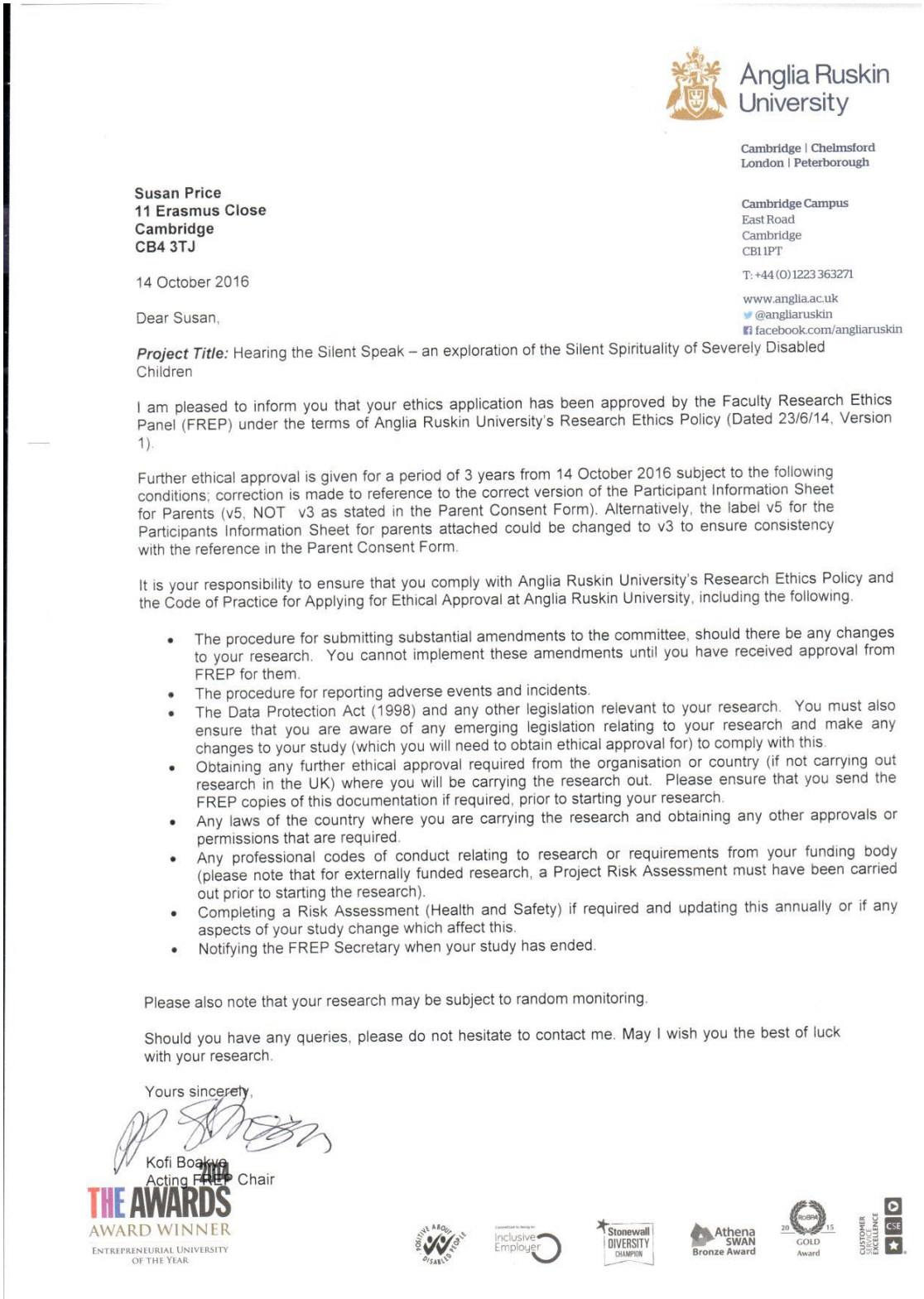
Appendices

Appendix 1: Anglia Ruskin University Ethical Approval



Anglia Ruskin University

Cambridge | Chelmsford
London | Peterborough

Cambridge Campus
East Road
Cambridge
CB1 1PT

T: +44 (0) 1223 363271

www.anglia.ac.uk
@angliaruskin
facebook.com/angliaruskin

Susan Price
11 Erasmus Close
Cambridge
CB4 3TJ

14 October 2016

Dear Susan,

Project Title: Hearing the Silent Speak – an exploration of the Silent Spirituality of Severely Disabled Children

I am pleased to inform you that your ethics application has been approved by the Faculty Research Ethics Panel (FREP) under the terms of Anglia Ruskin University's Research Ethics Policy (Dated 23/6/14, Version 1).

Further ethical approval is given for a period of 3 years from 14 October 2016 subject to the following conditions; correction is made to reference to the correct version of the Participant Information Sheet for Parents (v5, NOT v3 as stated in the Parent Consent Form). Alternatively, the label v5 for the Participants Information Sheet for parents attached could be changed to v3 to ensure consistency with the reference in the Parent Consent Form.

It is your responsibility to ensure that you comply with Anglia Ruskin University's Research Ethics Policy and the Code of Practice for Applying for Ethical Approval at Anglia Ruskin University, including the following.

- The procedure for submitting substantial amendments to the committee, should there be any changes to your research. You cannot implement these amendments until you have received approval from FREP for them.
- The procedure for reporting adverse events and incidents.
- The Data Protection Act (1998) and any other legislation relevant to your research. You must also ensure that you are aware of any emerging legislation relating to your research and make any changes to your study (which you will need to obtain ethical approval for) to comply with this.
- Obtaining any further ethical approval required from the organisation or country (if not carrying out research in the UK) where you will be carrying the research out. Please ensure that you send the FREP copies of this documentation if required, prior to starting your research.
- Any laws of the country where you are carrying the research and obtaining any other approvals or permissions that are required.
- Any professional codes of conduct relating to research or requirements from your funding body (please note that for externally funded research, a Project Risk Assessment must have been carried out prior to starting the research).
- Completing a Risk Assessment (Health and Safety) if required and updating this annually or if any aspects of your study change which affect this.
- Notifying the FREP Secretary when your study has ended.

Please also note that your research may be subject to random monitoring.

Should you have any queries, please do not hesitate to contact me. May I wish you the best of luck with your research.

Yours sincerely,

Kofi Boakye
Acting FREP Chair

THE AWARDS AWARD WINNER
ENTREPRENEURIAL UNIVERSITY OF THE YEAR

Positive About Disabled People · Inclusive Employer · Stonewall Diversity Champion · Athena SWAN Bronze Award · RoSPA 2015 Gold Award · Customer Service Excellence

Appendix 2: Participant Consent Form – for Parents

PARTICIPANT CONSENT FORM (Version 3: 7/4/16)

NAME OF PARTICIPANT'S Parent/Carer:…….

Hearing the Silent Speak – an exploration of the Silent Spirituality of Severely Disabled Children.

Main investigator and contact details: Sue Price.
Email for research project: susan.price@pgr.anglia.ac.uk

1. I agree that my child ……..can take part in the above research. I have read the Participant Information Sheet (version 5 18/4/16) for the study. I agree that I can also take part in the above research as ……..parent/carer.
I understand what my role will be in this research, and all my questions have been answered to my satisfaction.

2. I understand that I and my child are free to withdraw from the research at any time, without giving a reason.

3. I am free to ask any questions at any time before and during the study.

4 I understand what will happen to the data collected from me for the research.

5. I have been provided with a copy of this form and the Participant Information Sheet.

6. I understand that quotes from me will be used in the dissemination of the research.

7. I understand that the interview will be recorded.

Data Protection: I agree to the University[3] processing personal data which I have supplied. I agree to the processing of such data for any purposes connected with the Research Project as outlined to me*

Name of participant (print)……..Signed……..….Date……

PARTICIPANTS MUST BE GIVEN A COPY OF THIS FORM TO KEEP

ADD DATE AND VERSION NUMBER OF CONSENT FORM.

I WISH TO WITHDRAW FROM THIS STUDY.

If you wish to withdraw from the research, please speak to the researcher or email them at susan.price@student.anglia.ac.uk stating the title of the research. You do not have to give a reason for why you would like to withdraw. Please let the researcher know whether you are/are not happy for them to use any data from you collected to date in the write up and dissemination of the research.

[3] "The University" includes Anglia Ruskin University and its Associate Colleges.

Appendix 3: Child Consent Form

PARTICIPANT CONSENT FORM – for Children taking part. (version 4: 7/4/16)

NAME OF CHILD:

Hearing the Silent Speak –
an exploration into the Silent Spirituality of severely disabled children.

Main investigator and contact details: Sue Price susan.price@student.anglia.ac.uk

1. I agree to take part in this project. Mum and Dad have read the information sheet with me. They are happy for me to be involved with this project. I am happy to work with Sue. I have been given the information sheet about the project version 4 7/4/16.

2. I understand that I don't have to take part. I understand that I can stop at any time. I don't have to give a reason.

3. I understand what will happen to the information collected from me for this project.

4. I have been given with a copy of this form and the Information Sheet.

5. I understand that things I say might be used when the project is written.

6. I understand that the interview will be recorded

Data Protection: I agree to the University[4] processing personal data which I have supplied. I agree to the processing of such data for any purposes connected with the Research Project as outlined to me*

Name of participant (print)……..Signed……..….Date……

Signed on behalf of child by parent.

PARTICIPANTS MUST BE GIVEN A COPY OF THIS FORM TO KEEP

ADD DATE AND VERSION NUMBER OF CONSENT FORM.

I WISH TO WITHDRAW FROM THIS STUDY.

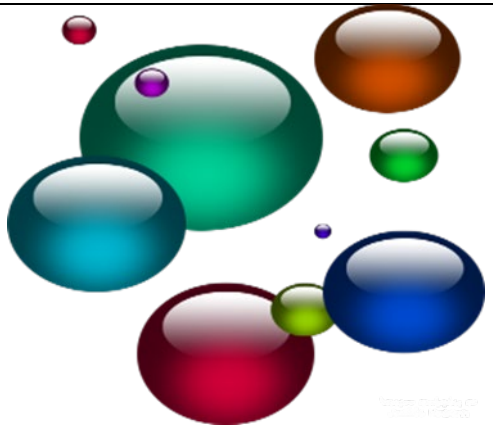
If you wish to withdraw from the research, please speak to the researcher or email them at susan.price@student.anglia.ac.uk stating the title of the research.

You do not have to give a reason for why you would like to withdraw.

Please let the researcher know whether you are/are not happy for them to use any data from you collected to date in the write up and dissemination of the research.

[4] "The University" includes Anglia Ruskin University and its Associate Colleges.

Appendix 4: Story Board

Appendix 5: Anglia Ruskin University Risk Assessment

Risk Assessment Form (AR1)

Subject of assessment (May be an activity, hazard or relate to an individual) If chemical and / or biological hazards exist then a COSHH form must be completed **http://my.anglia.ac.uk/sites/risk/default.aspx** **Home visits carried out as part of MPhil Research Project**	**RA conducted by.** **Sue Price MPhil student**	**Date.** **8/12/15**	**RA ref. no.**
List the risk/s involved or describe the hazard and potential injury/illness **1. Lone Working including travel to home of participants.** **2. Home environment of participants not appropriate/conducive to research session** **3. Participants becoming unwell during session**			

List the current control measures in place. Please check the RM website for help and advice available at;

http://my.anglia.ac.uk/sites/risk/default.aspx

1. **Researcher to have mobile phone charged and available at all times. Researcher to operate buddy system in that work base is notified when researcher is on site and when researcher has left site and is now safely at home. Researcher's car to be in good working condition, appropriate insurance up to date. If severe adverse weather conditions prevail, home visit to be cancelled.**
2. **Gatekeepers for research project to consider home environment when selecting participants. If, on arrival at home of participant, situation appears to be unsafe in any way, researcher to leave home visit.**
3. **Parents/carers of participants to be available throughout the session within the home environment. Researcher to be informed of any medical signs that need to be noted at the start of each session by the parents/carers. Parents/carers to cancel session if they feel participants are not well enough to take part.**
4. **Researcher's professional qualification (Occupational Therapist) and experience working with this specific group of subjects.**

Current risk level. **Low** **(See risk matrix)** **(Delete as appropriate)**						
List the actions required to reduce the risk, include reference to any written safety procedures. Please check the RM website for help and advice available at; http://my.anglia.ac.uk/sites/risk/default.aspx					**Date actioned**	**Actioned by**
Revised risk level. **High / Medium / Low** **(See risk matrix)** **(Delete as appropriate)**						
RA verified by (Usually Dean/Head of support unit/Line manager)						**Date.**
Risk assessment issued to the following;						**Date.**
Risk assessment review date. **(Usually annually)**						
Risk assessment reviewed by.						

Appendix 6: Ethical Approval from East Anglia Children's Hospices

EACH Milton Children's Hospice, Church Lane, Milton,
Cambridge CB24 6AB

each
East Anglia's Children's Hospices

To: Anglia Ruskin University
Bishop Hall Lane
Chelmsford
Essex
CM1 1SQ

14th January 2016

Dear Sue

This is to confirm that I give permission for you to carry out research at our organisation for the purposes of your Masters Degree at Anglia Ruskin University.

I understand that by giving this permission I am granting you the use and ownership of data collected.

I understand that you will write up the results for your degree.

I understand that you may disseminate findings at Anglia Ruskin University and elsewhere, including publication.

I give permission for our organisation to be named in dissemination, provided that the organisation is satisfied with how it is portrayed in the final thesis.

I do wish to see a summary of the findings prior to dissemination. I understand that participants will be informed of this.

Yours sincerely,

Dr Linda Maynard
RGN RSCN CANP IP/SP BSc MSc PhD
Consultant Nurse Children's Palliative Care

Appendix 7: Initial Letter to Families

c/o Margaret Beaufort Institute of Theology,
12 Grange Road,
Cambridge, CB3 9DU

Dear Parents/Guardians,

I am a research student, studying for a Master's Degree with Anglia Ruskin University. I also work with severely disabled children in a palliative care setting. I am conducting a research project and am writing to ask for your help.

I am very aware that many of the children I work with use facial expressions, sounds, movements to communicate rather than words. I feel that it is really important that people ask and listen to children who communicate in this way, especially when trying to learn about their spirituality. I am using the word 'spirituality' to mean what it is that gives them their 'spark', their own specialness and what gives meaning to their lives. My research project is called 'Hearing the Silent Speak – exploring the Silent Spirituality of Severely Disabled Children.'

As far as I can tell, no-one else has done this sort of research with this group of children before, so this is, I hope, an exciting opportunity to take part in new research that could influence how people work with this group of children.

I would like to interview six children as part of this project. My plan is to arrange six sessions for each child and spend time with them. I will be recording each session and writing it up. You will be able to have written copies of the sessions with your child when the work is completed.

This research project is being overseen by Anglia Ruskin University, they have given me ethical approval for the project. EACH fully supports the project too. It is important to emphasise that whether or not you take part in this project, it will not affect your relationship with EACH in anyway at all.

If you would like to know more and are interested in being involved I would love to hear from you. I enclose the participant information sheet that gives more details about the project. I need your permission to contact you in person and so I would be grateful if you could either email me at susan.price@student.anglia.ac.uk or complete the attached form and return it to me in the enclosed envelope. This is important to ensure your confidentiality. I would be grateful if you could contact me by 13th May 2016.

Yours faithfully,

Sue Price

MPhil Student with Anglia Ruskin University, Cambridge.

Consent form giving permission for contact details to be given to Sue Price, Research Student, Anglia Ruskin University.

I am interested in knowing more about the Research Project being carried out by Sue Price.

I give my permission for Sue Price to contact me in person.

My Name:_____

My Child's Name:_____

Address:_____

_____

Telephone number:_____

Email:_____

Many thanks, I look forward to being in touch.

Appendix 8: Participant Information Sheet – for Parents

PARTICIPANT INFORMATION SHEET GUIDANCE - for Parents/Carers

Section A: The Research Project

1. **Hearing the Silent Speak – an exploration into the Silent Spirituality of Severely Disabled Children.**
2. **Brief summary of research.**
   I am carrying out research with a group of severely disabled children to investigate their spirituality. I am using the word 'spirituality' to mean what it is that gives them their 'spark', their own specialness, what gives them meaning in their lives.
3. **Purpose of the study**
   This study is part of a Master's degree in Theology that I am doing with the Margaret Beaufort Institute of Theology. The degree will be awarded by Anglia Ruskin University.
4. **Name of your Supervisor**
   My supervisor is Dr Amy Daughton, Margaret Beaufort Institute of Theology. She can be contacted on ald36@cam.ac.uk. 01223 741040
5. **Why have I been asked to participate?**
   I am wanting to work with severely disabled children who are known to East Anglia Children's Hospice. EACH know that I am wanting to do this research and have given me permission to seek parent's/ carer's consent to work with children from EACH. Your child is within the research criteria – that of a severely disabled child.
6. **How many people will be asked to participate?** Six children are being recruited for this study.
7. **What are the likely benefits of taking part?**
   The main benefit of this study will be to help organisations such as EACH and other interested groups understand the spirituality of severely disabled children better. I hope that the children will enjoy the sessions (see Section B) with myself and that they will benefit from that.

8. **Can I refuse to take part?**

Definitely – there is no obligation to take part at all. You and the children concerned can refuse to take part at any stage of the project. Choosing not to participate in this project will not affect your relationship with EACH in any way at all. EACH will not keep a record of who has been contacted about this project.

9. **Has the study got ethical approval?**

Ethical Approval has been granted on: 10/2/16 Anglia Ruskin University. This is approved for one year and will be renewed in February 2017.

10. **Has the organisation where you are carrying out the research given permission?**

I gained permission from EACH dated 14/1/16.

Dr Linda Maynard, EACH Nurse Consultant can confirm this and would be happy to hear from you if you have any queries or concerns about the project. She can be contacted on 01223 815115 email: linda.maynard@each.org.uk.

11. **What will happen to the results of the study?**

The research will be written up for my Master's Degree. It is also hoped that the findings of the study will be presented to EACH. The findings could also be published at a conference or in a journal to inform other people about the work.

12. **Contact for further information**

Email for further information: susan.price@pgr.anglia.ac.uk

Section B: Your Participation in the Research Project

1. **What will I be asked to do?**

I would like to come and spend six sessions with your child in your home – getting to know them during that time to see if I can recognise their 'spirituality'. In those sessions, I would like to spend time playing with them, storytelling, being with them in the quiet. The sessions will be about building up a relationship with them. You are an important part of your child's life. It will be very important for you to stay at home for the session, so that I can work with you to build up my relationship with your child. It may be appropriate for you to be with me for the first sessions, it may also be appropriate for you to be nearby whilst I work with your child. This will be something that we will discuss at the start of each session, to ensure that you and your child are happy for me to be there and that you are both happy for me to work with your child.

2. **Will my participation in the study be kept confidential?**

Your participation in the study will be kept confidential – I will be taking notes and recording the sessions. I will be talking about the results from the sessions with my main supervisor and with a small group of people who will be helping me to analyse the results.

To help keep the work as anonymous as possible, so that no-one can identify you or your child in the study, I would like your child to choose a special name for themselves that is only known to you, your child and myself. We can do this together at the first session or you might like to do this beforehand. This is the name that, with your and your child's permission, I will use in my discussions with my supervisor and those people who are helping me analyse the results. It will also be the name that I use in the report.

Every attempt will be made to ensure anonymity, but I recognise that I cannot guarantee this. I will be giving a brief description of each child, but I will not be including any specific medical details about your child's condition that could be used to identify them. I will be describing the children in general terms, giving their age and gender. You will be able to see the description of your child and amend it as necessary.

There may be times when you tell me something about your child, or your child has a particular reaction to one of the activities that we engage in. I would like to be able to quote these times. I will make sure that you know that I would like to do this and will ask for your written permission to do so.

I will be using a recording device during the sessions. This will be kept locked away in between sessions. I will be transcribing the information from it after the sessions so that I then have a script of what happened during our sessions. At the end of the project, I will provide you and your child with a copy of the transcripts of the sessions that your child spent with me.

3. **Are there any possible disadvantages or risks to taking part?**

Your agreement to participate in this study does not affect your legal rights, nor does it affect your access to EACH services.

There are no risks that I can anticipate for this study. The study is planned to be 6 sessions in your home that will need you and your child to be there. The aim is for the sessions to be enjoyable for all concerned.

4. **Whether I can withdraw at any time, and how**.

You and your child can withdraw from this study at any time. You do not have to give me a reason. You can let me know in person or by email that you and your child no longer wish to take part in the study.

The information I have gathered up to that point would still be useful for my study and I would ask your permission to use it. However, you do not have to give me permission to do so.

You and your child can withdraw from the study at any point until I begin the writing up stage of the project. This is likely to be September 2017.

I will not be formally interviewing you as the parent/carer of your child, you do not need to tell me anything about your child and the sessions we engage in, but if you do, any information provided will be treated confidentially.

5. **Whether there are any special precautions you must take before, during or after taking part in the study.**

If, during the course of the sessions I have with your child, anything is disclosed that indicates you or your child is at risk, I will need to take the appropriate action and inform the appropriate authorities.

6. **What will happen to any information collected from you?**

All the information I collect from you and your child during our sessions, both recorded and written, will be collected and held for the duration of the project. The information will be kept on password protected computers and laptops. Your personal information and the data will be kept separately. At the end of the project (September 2018) the transcripts of your individual sessions will be given to you and your child. The raw data will be destroyed unless it is identified as being necessary for further study. If this is the case, you will be informed and your permission asked for this information to be continued to be held securely.

A summary of research findings will be available at the end of the whole project. This can also be sent to you with the transcripts of your sessions if you would be interested.

7. **Contact details for complaints.**

If you have any complaints about this study, please contact myself in the first instance: susan.price@pgr.anglia.ac.uk

You are welcome to contact my supervisor, Dr Amy Daughton on: ald36@cam.ac.uk

You can also make a complaint using the Anglia Ruskin University's complaints procedure.

Email address: complaints@anglia.ac.uk

Postal address: Office of the Secretary and Clerk, Anglia Ruskin University, Bishop Hall Lane, Chelmsford, Essex, CM1 1SQ.

Students from Associate Colleges need to check what their procedures for complaints are and provide details to participants.

PARTICIPANTS SHOULD BE GIVEN A COPY OF THIS TO KEEP, TOGETHER WITH A COPY OF THE CONSENT FORM.

Appendix 9: Children's Information Sheet

Section A: The Research Project

Information sheet for the children.

Hello, my name is Sue Price. You may have seen me at Milton Hospice, and I might have worked with you there.

I am now carrying out a special project. It is called a Master's Degree. I am studying with Anglia Ruskin University. Dr Amy Daughton will be checking my work to make sure that I am doing everything properly.

I would like to ask you to help me. I would like to work with you to find out about the special things that make you 'you', the things that are important to you, the things that give meaning to you.

I am asking six children to take part in this study.

I hope that this work will help other people to know how to best work with you and other children like you, especially when you want to tell us about the things that are important to you and the things that mean the most to you.

You do not have to work with me – if you don't want to, you can stop at any time. You can show me in whatever way you like – you might turn your head away, you might close your

eyes and go to sleep – whatever you do that is fine by me. Your mum and dad will also make sure that you are happy to work with me. You can stop working with me at any time.

I have to get special permission to carry out this work. I have got permission from Anglia Ruskin University and from EACH.

When I have finished finding out from all the children in the study what is important to them, I am going to write about it. It will be used for my Master's Degree and will be used to tell people about how we can work with children who don't use words to tell us about how they feel and think.

Mum or Dad can contact me at any time to ask about more information about this study. You can also ask for more information too. The best contact for me is by email: susan.price@student.anglia.ac.uk

Section B: Your Participation in the Research Project

8. **What will I be asked to do?**

I would like to come and see you at home 6 times. Mum or Dad will be there too. Sometimes, if you are happy to do so, you and I will work together without Mum or Dad being in the room.

I will make sure that Mum or Dad are always nearby so that if you don't feel well or want to stop I can let them know immediately.

When I come to see you, I will bring things for us to play with. We might have stories to listen to, we could listen to music. You might want to be quiet with me. What we do will depend on what you want to do. I want to learn from you about the things that are important to you.

I will stay for up to an hour, you can stop working with me at any time when I am with you. You may only want to work with me for ten minutes. That is ok.

Will my participation in the study be kept confidential?

It will be important that our sessions are confidential. This means that what we do in our sessions is known to you, mum and dad and me only.

When I write about our sessions I will make sure as far as possible no one knows who I am writing about.

To help me do this, please can you choose a special name that is just yours for this project. We can choose this together or you can choose it with mum and dad. By using your special

name only you, your mum/dad and myself will know who you really are. In the project, other people will only know you by your special name. No one will be able to find out who you are from the project. I will use your special name when I am talking about the project with the people who are going to help me understand the things I find out.

Sometimes you might make a sound or look at me in a special way. I would like to tell people about that and I need your permission to do so.

I will be recording our sessions on a tape recorder. Then I will write about them. When my project is over, I will give you a copy of the notes I have made for you to keep.

9. **Are there any possible disadvantages or risks to taking part?**

If you get bored or upset, I will stop our sessions immediately. I do not want to do anything that will make you unhappy. If you need a break in our session, or you want mum or dad to be with you, I will make sure that happens.

Can I stop being part of the project at anytime?

You can stop at any time. You can stop before a session, during a session, or after a session. Mum or Dad can let me know and we can stop immediately.

If you have already worked me with me but then want to stop I will ask you and your mum and dad if I can use the notes about our sessions that I have made. If you don't want me to, I won't.

10. **Are there any special things that you must do before, during or after taking part in the project?**

If, during our sessions, I feel that you are not well or not safe, I will tell the best person to make sure that you are safely looked after.

11. **What will happen to any information that is gathered from you?**

Any information that I gather will be kept safe and locked away. At the end of the project, I will give you and your mum and dad a copy of your notes and a copy of the things that I have found out.

Contact details for complaints.

If you or your parents have a complaint about the project, you can contact me on: susan.price@student.anglia.ac.uk

Or my supervisor, Dr Amy Daughton ald36@cam.ac.uk.

You can also complain to Anglia Ruskin University.

Email address: complaints@anglia.ac.uk

Postal address: Office of the Secretary and Clerk, Anglia Ruskin University, Bishop Hall Lane, Chelmsford, Essex, CM1 1SQ.

PARTICIPANTS SHOULD BE GIVEN A COPY OF THIS TO KEEP,

TOGETHER WITH A COPY OF THE CONSENT FORM.

Appendix 10: Extract from My Research Journal

Butterfly – notes after each session

First Session 22/4/18

Butterfly lives with her mother, and she talks with her eyes! This is one instance were videoing would/could have been useful but never mind there was plenty going on. When I arrived, her mum was just putting her in her standing frame as she hoped this would be a distraction for her whilst I was there. Butterfly seemed to recognise me from the hospice and one of the best words I can think to describe her reactions to me is that of curiosity – she was curious to see me, curious about the recorder, curious about the buttons, about the bag, about the story board.

I emphasised several times that she was in charge and that she could stop working with me whenever she liked. She looks directly at you and/or opens her mouth wide for yes, she looks away or down for no. She will look sad – mouth turned down and will also break into a huge smile. She seems to have a continuum for smiles – very small – shy nervous, getting a bit bigger when she likes something/someone, and very broad when very happy/pleased to see someone be doing something. She also has a sense of humour – her mum had forgotten to tighten her knee straps whilst she was in the standing frame so she was slowly sliding down, and she definitely found that funny when her mum realised and then needed to sort it out.

Mood changes can be very quick, and mum reports are affected by tiredness. She can look shocked/surprised by different things too. Is startled by sudden movement the unfamiliar.

dependance de choix.

Butterfly tends to hold her arms out to the side, but if they are positioned correctly for her, she can use her fingers to point and with assistance can hold onto things.

She seemed to get the idea of the buttons, really liked the bag and held onto it for a long time at the start of the session. She definitely chose her button by finger pointing at the end of the session and with assistance put it in her bag.

1

Appendix 11: Transcription Examples

B.1.1

Transcript Session one Butterfly: Test: 40 secs Main Recording 37.51

Present: Butterfly, Researcher and Mum, in their kitchen/diner space, backdoor open onto garden, light airy room, birdsong in background. Space designed around Butterfly's needs.

Once settled in her standing frame, M offered B a choice of drink, orange or summer berries – definite choice made by B looking at orange, echoed and confirmed by M.

At start of session, before recording, R showed B her ARU student badge.

On showing B the recorder she startled, closed eyes with rapid blink movements, M needing to reassure her and to confirm it was a recorder, R then made sure she saw it and saw how it worked. For Test recording, R held B's finger to enable her to press the button to set it working. B definitely curious about how it worked and what it did.

Test 40 secs R	See that made a beep, you pressed it and it made a beep and it is now recording my voice. And if you make any sounds or if you want too	B in standing frame, R standing to side of her, M sitting down on other side. B breathing in background, watching, concentrating on recorder
M	Can B talk, can you say something? Ah ha, hha haaa	M holds her hand as if holding a microphone in front of B, B gives a big smile looking directly at M
R	Laughs So shall I show you so you can hear what we've been recording?	B smiles at M, then looks at R

1

1		*Recorder turned off and above played back to B. B listened to it, and smiled. R checked with her if she was happy to continue recording. B looked at R, taken as 'yes' confirmed by M. R asked B to turn it on with her, R assisted by holding B's finger to push on button.*	
2	Main Recording R	a b c d e f g	So that's now recording, ok. So I am going to risk it and place it down here, so it is recording here so it should pick up all that we are talking about and all that we do. *Pause – R holds thumb up to check with B – looks at it, taken as affirmation.* So what we are going to do, if it is alright with you, I am going to come, one, two, three, four, five, Oh they are going to slide down B, six times. I am going to come 1,2,3,4,5, 6 times. Every time I come you can choose a button, so you know how many times I've come and how many more times I have got to do. If that is ok with you? There is a bit of a smile with that one. So you will have your bag,
			i B's breathing in background – concentration, looking at recorder ii R gets buttons out of bag and counts them out onto B's tray. Tray is on an angle and buttons slide down. B watches buttons and smiles. iii R gives B's bag to her which she reaches out to hold.
3	M		You can hold it, good girl.

2nd Session Transcript – Superman 31.35, + 10

Mum, Dad, siblings and friend, twin, carers x2 – all in open plan living area. Working with Superman at end of kitchen area, her looking down the room but not sure how far she can see.

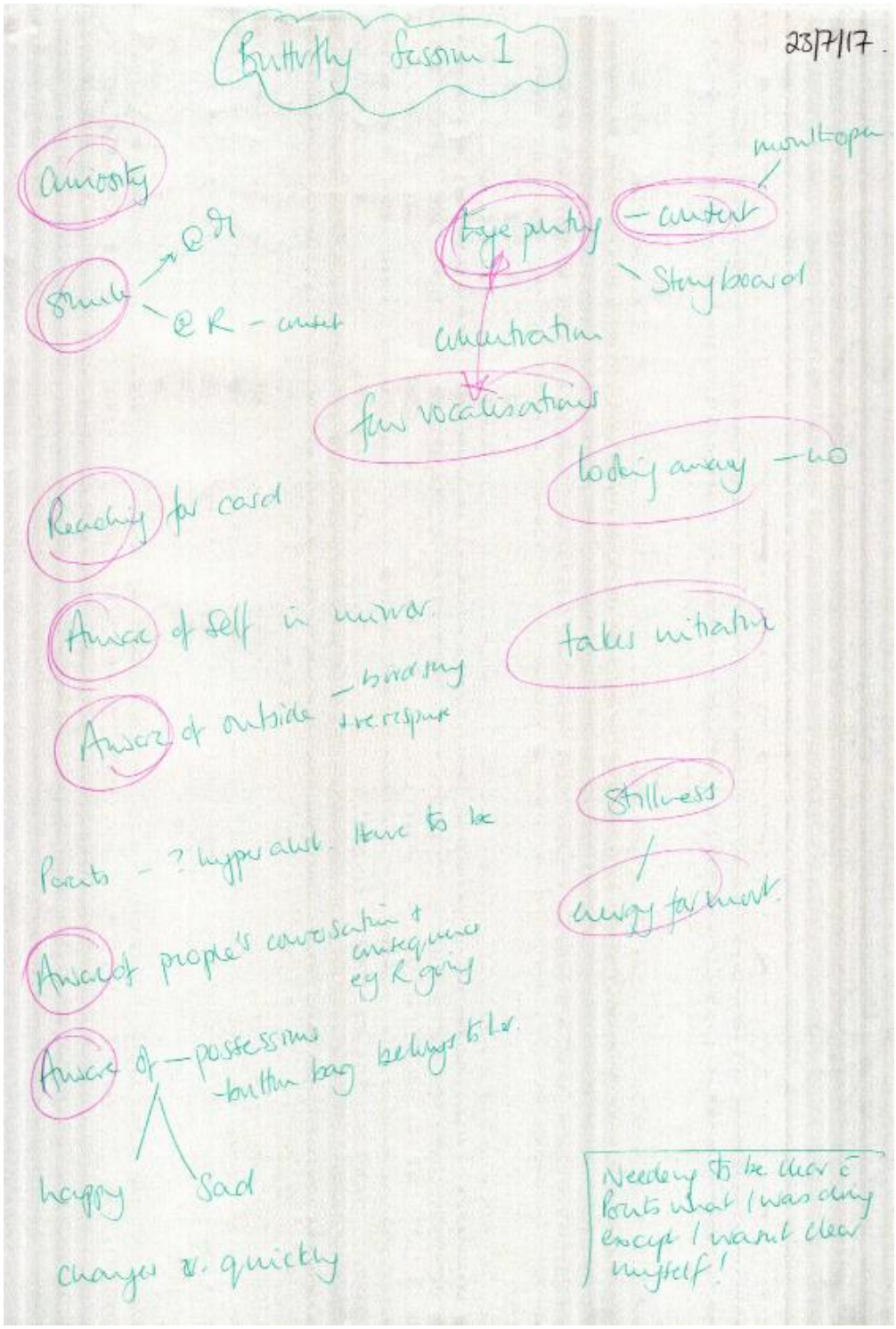
Nb her recognition of Dad and of Mum as she came into the room – perhaps wasn't expecting to see Dad. Smiles, eyes 'lit up'

Something has happened with the recording – seem to have 5 separate sections.

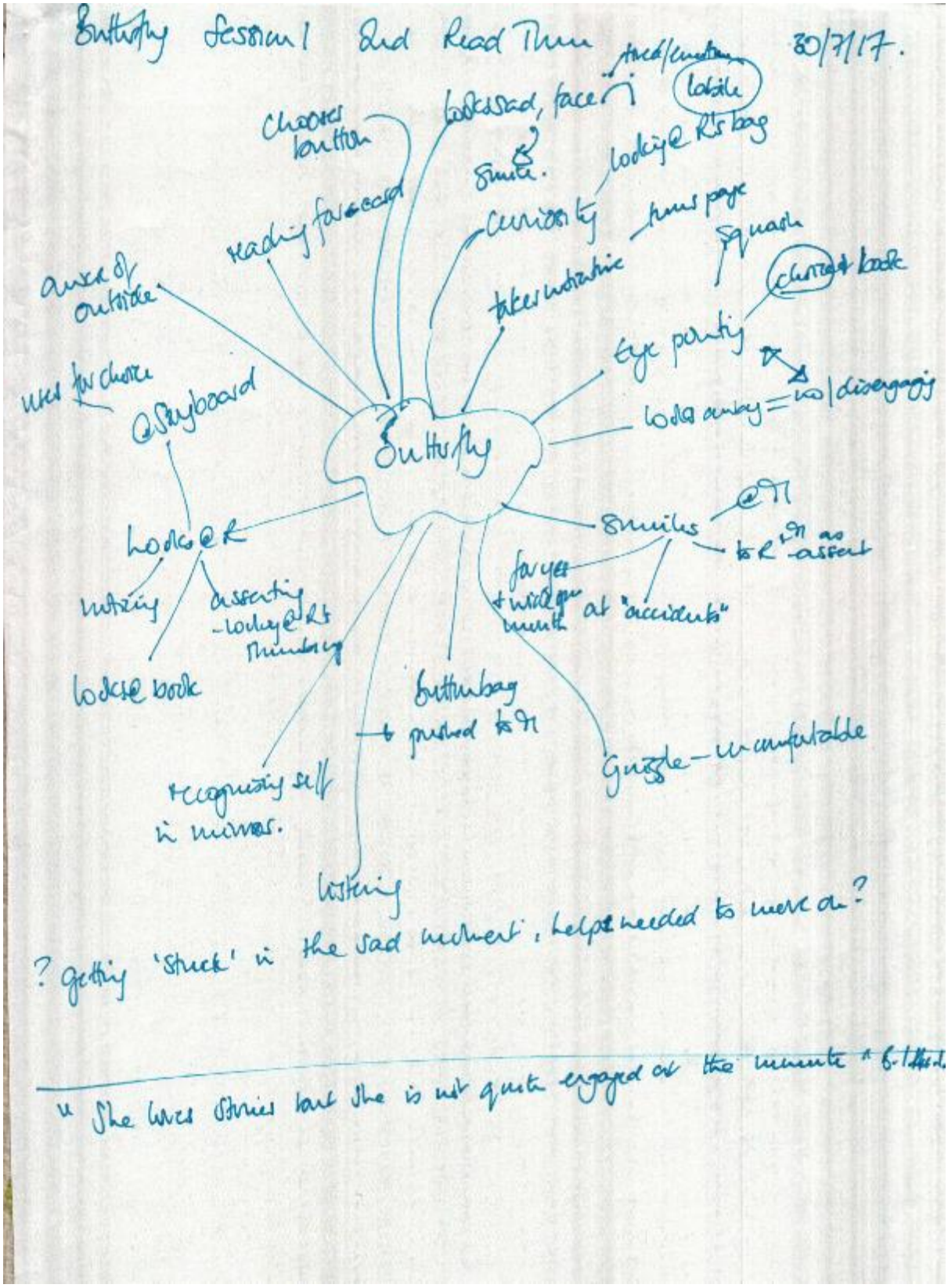
Superman has been transferred by one of the carers into her P Pod seat, wheeled over for me to work with her. Superman facing R sideways, R sitting on her left, facing her. Carers are providing personal care to other twin.

1	S		Grrrrr sound	Lots of discussion in background, M and D sorting out who will be giving meds
2	R		Hello,	
3	S		Grrr	
4	R	a	I'll put the recorder up there.	i M offering R a cup of tea.
		b	You want my hand.	
		c	Oh, you are closing your eyes.	ii S reaches for R's hand and holds it. Lots of background noise. S takes her hand away from R and reaches for her foot.
		d	Has it been a long week, your knees are curled up, you're holding my hand.	
		e	Is that a good foot to hold.	iii

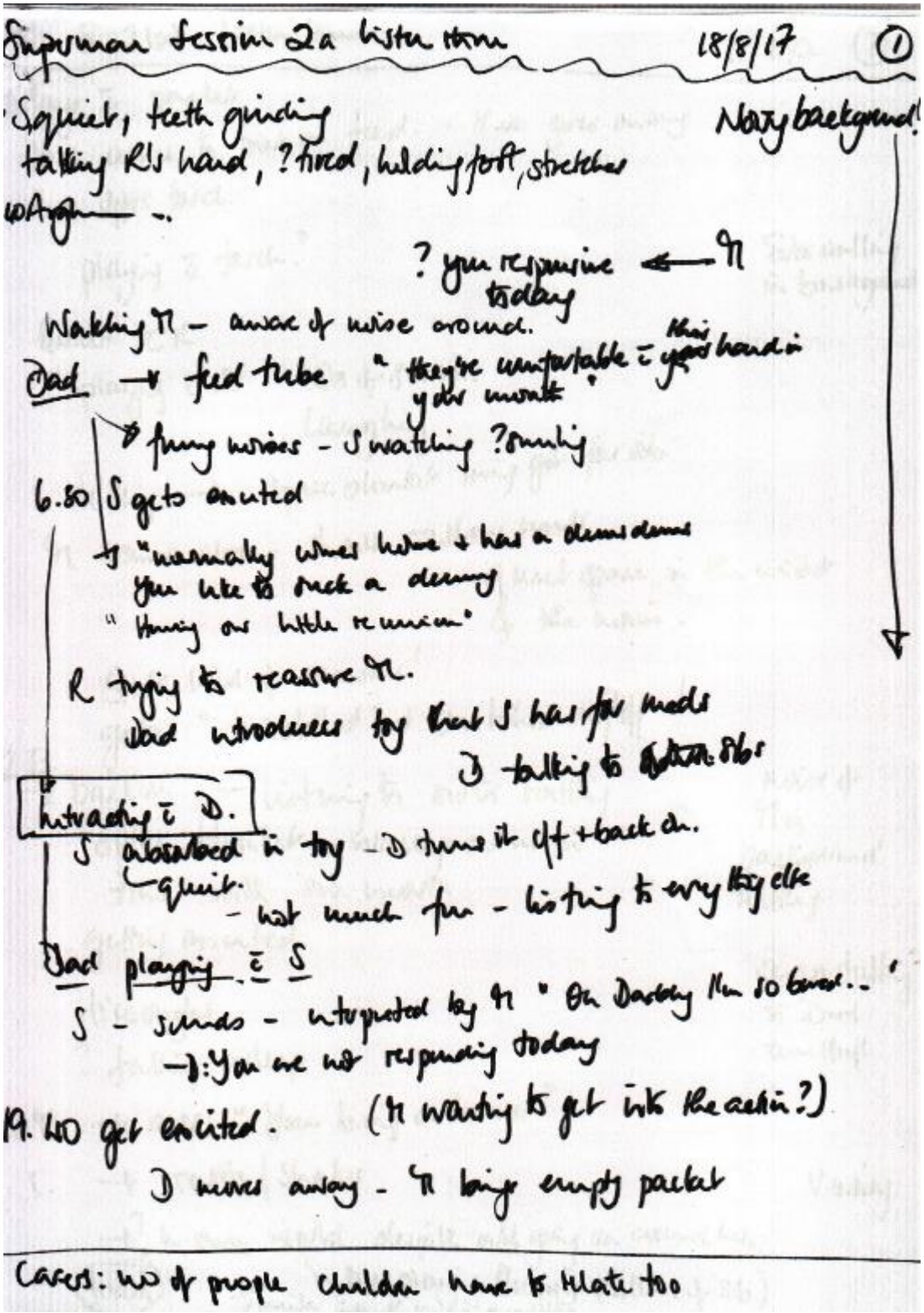
Appendix: 12: Example of First Read Through Notes Page. (Stage 2)



Appendix 13: Example of Second Read through Notes Page (Stage 3)



Appendix 14: Examples of notes from Repeat Listening to recording (Stage 4)



S. 2(a) Written [illegible] 18/8/12 (2)

Plays c̄ packet

Dad comes to put on feed. then goes away

R – offers torch

playing c̄ torch? — Sibs calling in background

Quiet c̄ R

? playing c̄ R — lots of smiles laughing

looking → space blanket being got for sibs

R comes close – shows cashew nuts — quiet space in the midst of the noise.

Gets hold of recorder!

gets "twiddled" + switched on/off!

R.E.

→ back on – listening to sister talking — noise of S1 in background talking

space blanket – waving arms in time with sis. words

getting excited. — Carer talking to Dad [illegible]

Hiccoughs

? falling asleep

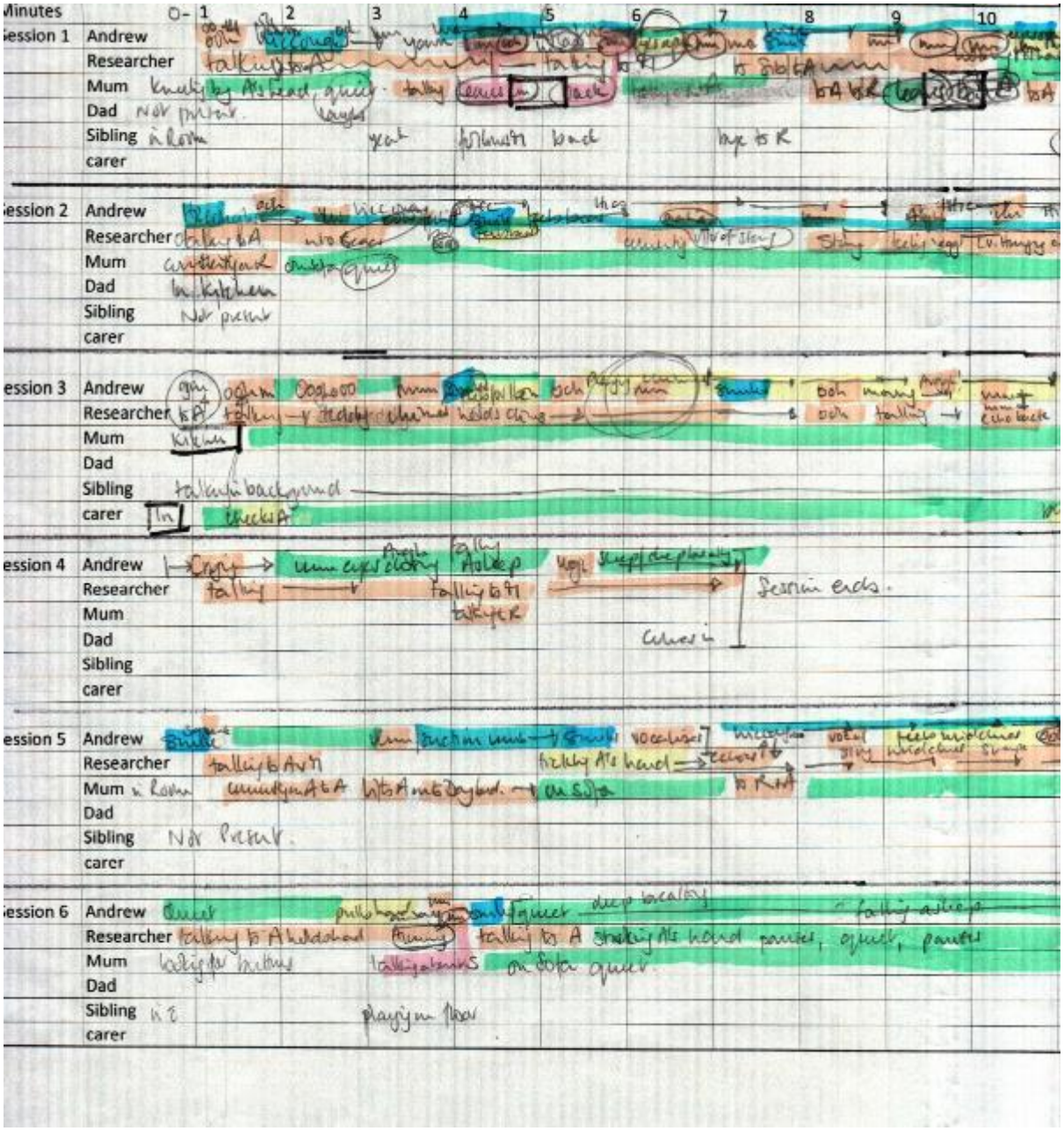
.0097 → over "You being a horror?"

5. → rattle | shaker — V. noisy

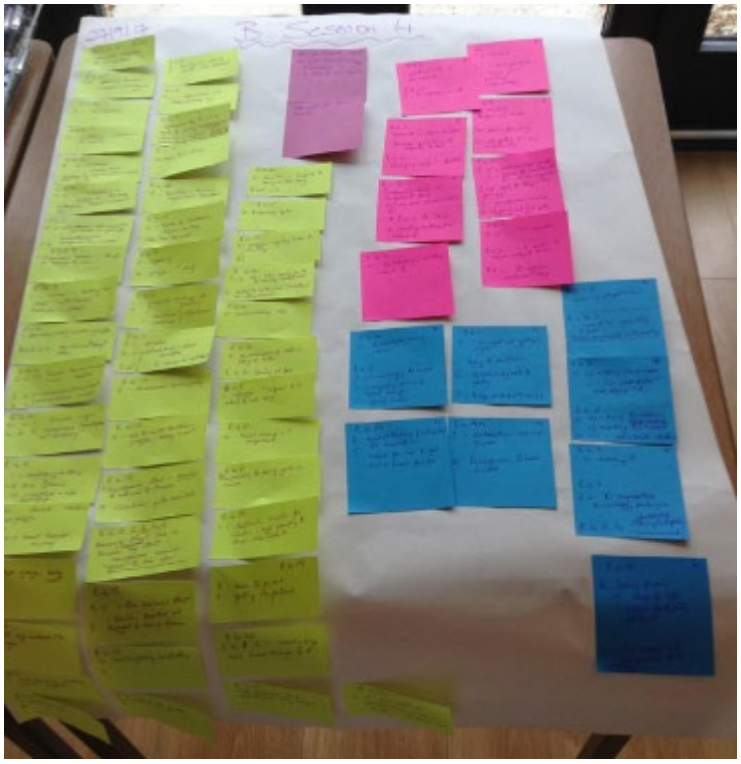
→? in own world despite all going on around her.

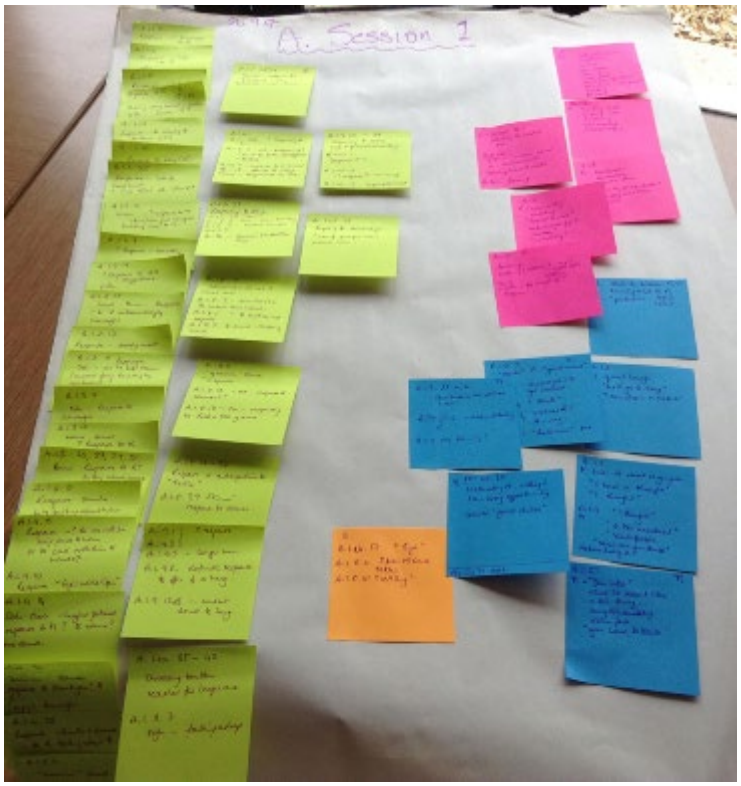
(tired) — own playing (copying actions of sib.) — Smile as R says goodbye.

Appendix 15: Example of Content Analysis (Stage 5)



Appendix 16: Example of Coding with Sticky Notes (Stage 6)





Appendix 17: The Initial Groupings of Codeable moments for each child. (Stage 7)

Category	Andrew	Butterfly	Dragonfly	Elsa	Olaf	Superman
Responding to researcher						
Responding to mother						
Responding to father						
Responding to sibling						
Responding to carers						
Responding to object						
Medical needs						
Silence						
Body movements						
Disengaging						
Wanting attention						
Not responding						
Vocalising						
Anticipating						
Grizzle						
Breathing						
Communicating						
Choosing						
Unhappy						
Awareness of self						
Distress						

Smiles						
Awareness surroundings						
Startle/ hypervilgilance						
Vicarious						
Curiosity						
Touch						
Playing						
Tired						
Tapping pattern						
Own Zone						
Excited/ animated						
Significant programme						
Singing						
Eating						

Appendix 18: Example of Excel Spreadsheet collation

Reference	Category	Response type	comment
D.4.5.2	Engaging, Responding to R	vocalises, eye contact smiles	at R
D.4.2.2	Engaging, Responding to R	laughs at R	finding' her - hiding behind card/book
D.4.1.18	Engaging, Responding to R	laughs at R, grins	R - are you hiding?
D.4.1.2	Engaging, Responding to R	responding	R talking to her
D.3.10.2	Engaging, Responding to R	eye contact with R	R talking to her
D.3.2.17	Engaging, Responding to R	smiling at R (M sorting out gastro site)	R playing round and round the garden
D.2.3.14.ii	Engaging, Responding to R	takes R's hand	uses it to tap shaker
D.1.5.12	Engaging, Responding to R	reaches for R's hand feels it	R talking to her, D looking away
D.1.4.15	Engaging, Responding to R	? Interest in round and round the garden	
D.1.3.7,9	Engaging, Responding to R	reaches for R's hand	smiling
D.1.2.9.vi	Engaging, Responding to R	reaches for R's hand	exploring R's hand
D.1.2.3.	Engaging, Responding to R	smile at 'dragonfly'	consistent
D.1.2.1.c	Engaging, Responding to R	angel card held to face	
D.1.2.1.f	Engaging, Responding to R	laughing at rainbow card	
D.1.2.1.g	Engaging, Responding to R	grin at Dragonfly card	

Reference	Category	Response type	comment
D.2.4.12	noises	raspberries	
D.1.2.9.i	noises	raspberries	
D.1.1.4	noises	vocalising	?response to R talking to her
D.1.4.10	noises	giggles	m and r join in ?cause
D.1.4.1.3,6	noises	laughing	breeze blowing packaging
D.1.5.3,5,7,9	noises	raspberries	v active
D.2.4.8	noises	mmmm	?response to R's mmmm
D.5.1.20	noises	sucking sounds	? Response to like a story?
D.5.1.15	noises	pfffft	?response to R asking if ok to work with her

Appendix 19: Final List of Codeable Moments

Play	Silence	Physical/ Medical	Own World	Wider World	Other
Facial expression Stories Technology 'conversa-tions' Curiosity Anxiety Playing with objects/toys	Slower breathing Silence Active silence Stillness Not needing anything else Listening Watching	Unsettled/ pain/ Discomfort Fatigue/flop Effort to do things Hyperalert Bodily functions	Awareness of self Absorbed in Ipad/tele-vision/toy Not engaging Excitement with no apparent cause	Including researcher into world Carers involved in their world Aware of people coming into house	Thanking people Siblings distracting researcher

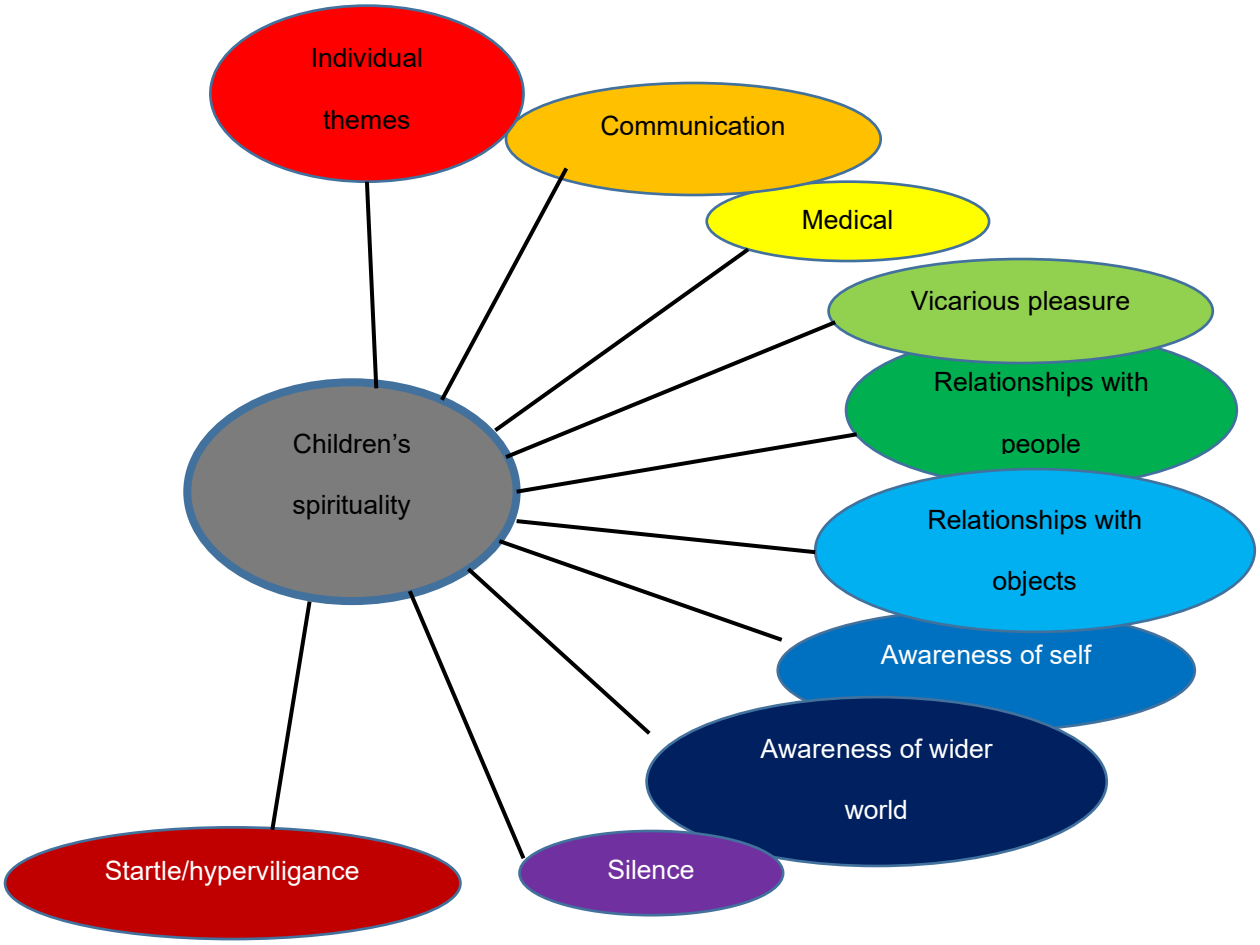
Imaginative play Humour Relating to parents Laughter Singing Finger and eye pointing Perman-ence or non-permanence of objects Playing with own body Not playing Recognition, memory	Not engaging Quiet after activity		Own Zone Presence of primary carer Distress/ protest	Accessing memories Aware of world outside of immediate family.	

Regrouped into:

Own World	**Wider World**
Awareness of self Absorbed in Ipad/television/toy Not engaging Excitement with no apparent cause Own Zone Presence of primary carer Distress/protest Unsettled/pain/ Discomfort Fatigue/flop Bodily functions	Including researcher into world Carers involved in their world Aware of people coming into house Accessing memories Aware of world outside of immediate family. Thanking people Siblings distracting researcher Effort to do things Hyperalert Active silence Listening Watching

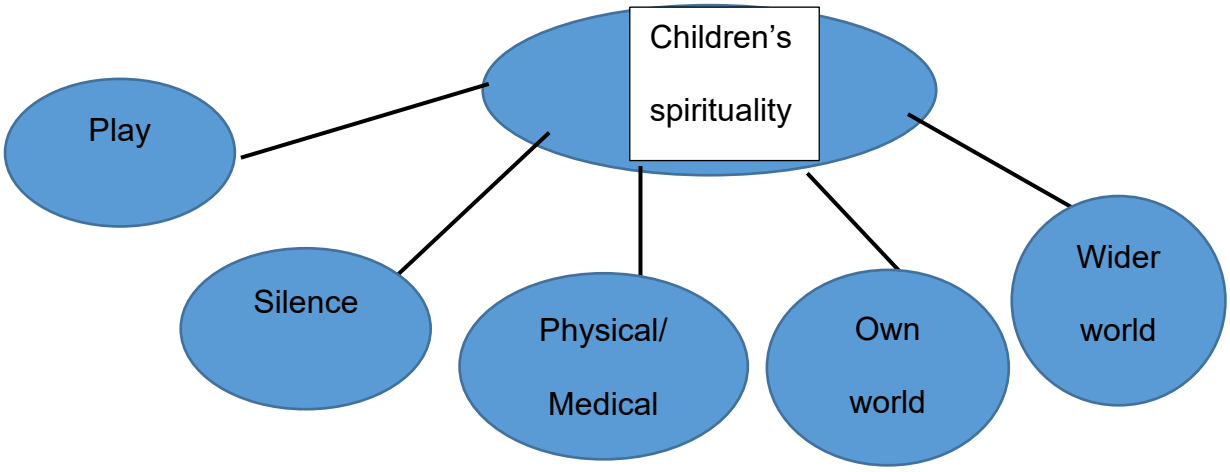
Slower breathing	Stillness Recognition, memory
Silence	Stories
Not needing anything else	Technology
Listening	‘conversations’
Watching	Curiosity Finger and eye pointing
Stillness	Permanence
Not engaging	Playing with objects/toys
Quiet after activity	Imaginative play
Not playing	Humour
or non-permanence of objects	Relating to parents
Playing with own body	Facial expression
Facial expression	Anxiety
Anxiety	Laughter
Laughter	Singing
Singing	
Relating to parents	

Appendix 20: Findings Maps

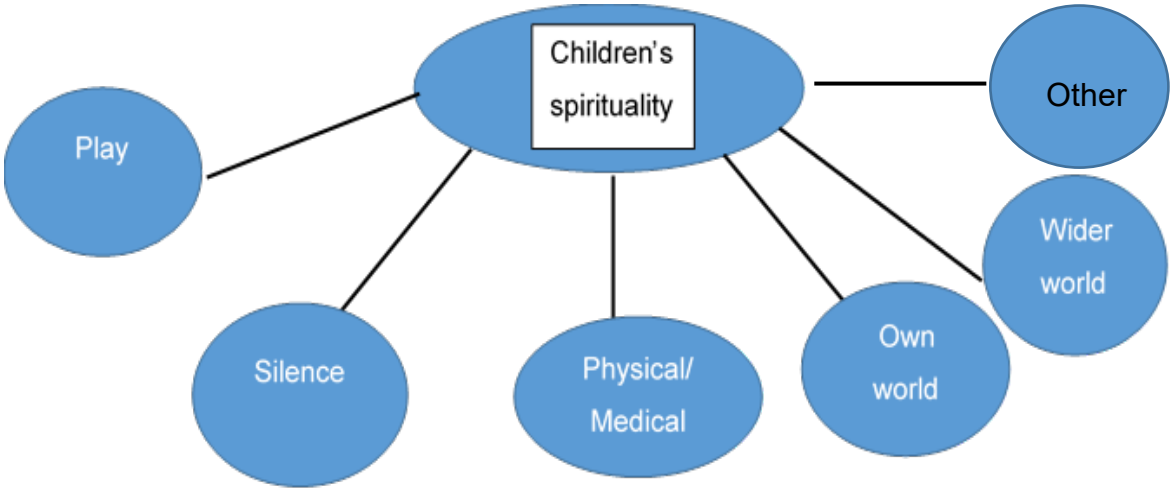


First Map

Second Map



Third Map:



Appendix 21: Findings from my research journal (Stage 12)

Own Stuff. Andrew 17/1/18

About me

inadequate
can I reach the depths
on a level
elevated me
bring attention
this felt ordinary
felt adult led
arriving feeling v. tired,
leaving feeling refreshed, calm,
energised + peaceful
had a time & quiet
just enjoyed being ε Andrew
being quiet
letting me touch his finger
session ended too soon
I disrupted the mood → doing
distracted by sibling
I assumed ok ε him to withdraw
leaving feeling relaxed
session didn't feel too long
aware that parents also silenced
- they are people too.
hearing ε sense of calm, from
being ε Andrew.
impact of his medical
condition.
Difficulty for me to concentrate
on being.
Sticking hand in mine to his
breathing.
NB - I don't comment on his
tickling my hand in this reflection!

About Andrew

subtle
playing around him
the daily routines
smiles - for definite things
vocalises
time
process
listening: to sister, to mum
concentrating
different reactions to different people
Have quiet.
ready to engage
He enjoyed this
happily exploring
happy, wriggly, delightful mood
pleased to see me
stunned - not happy, wanting
to engage
other children want to be near
him.
Adapted figure
being quiet
happy sounds
being in the moment
Fully present to his surroundings/here
thing One thing fully at a time.
Content
quiet
V.V. calm
sleeping
seen by school as having a
"magical nature"

Findings from my journal for each child:

Child	Additional comments/information
Superman	No access to adaptations, little privacy, Screams of excitement, giggles, lots of smiles, living in the moment, eye contact, engaging, times of contrast – silence and noisy, serene, very excited, tactile, laughter, 'just pleased to be there', animation, hand dancing, gazing round, still, staring, decreased happy sounds, puzzled looks. Tired, No reaction to siblings, interacting with father, responding to one sibling, deep gazing into mother's eyes, rustle conversation, left alone at the end, left alone with myself for most of Encounter 6.
Olaf	Timing of visits: just back from school, wider world – the unpredictable Options given by mother – wondering if it would be better if she stepped out of the way, but not able to do so until later encounters, worried he hadn't performed for me. Calm – relationship between mother and Olaf. Playing with mother. Story of shop assistant from Mother – 'you've done it again, O.' Bottom lip trembles when unhappy, shakes head, yes. Frustration, tired – didn't sleep well the night before. Flitting, but also times of concentration, restlessness, v. tired, sagging. Not happy to see me. Hungry – then able to concentrate once had food. Ok being with me for short periods of time. Importance of Mr T. Following his lead. Grizzled when not being talked to/about.
Elsa	Responsive or totally in her zone. Invites you in or totally ignores you. Awareness of body – pleasure. Repetitive patterns. Animated with parents and carers – becoming more so with me. Flop/tired Noticing sib. Own zone – broken by sib's laughter. Her world expanding. Playful – her world, moves between.

	Giggles, eye contact. No eye contact hiding behind board. Choosing not to engage. Indifferent to me. Big smile as I enter the room, leads me into a catching game, lots of fun and laughter. Switched into own world. Growing awareness of sibs. Moment of stress/panic. Who has the power? Amazing little girl. Registering me Mum's enjoyment of her laughter, pride in her achievements
Dragonfly	Very active movements, Active delight. Excited, whole face lights up. Whole body on the go, Smiles, laughter, with mother. Got the giggles, Gazing, Hot and grumpy – distress, Happy to be in the moment. Oasis in the midst of business. Not reacting to hustle and bustle. Time of squealing, pleasure laughter Getting excited. Tired as she came into house. Drifting off to sleep. ?wanting 'me time.' Alive whenever her mother came near. Reactions to mother. Every time mother is in Dragonfly's space – beaming smile. Enjoyed engaging with mother People disappearing in and out of her world
Butterfly	Talks with her eyes, Curiosity. Looks directly at you, Continuum of smiles, Humour finding things funny, patience, Definite choices, Notices all the time, Restless. Reacts to every sound and movement. Enjoys being involved in the doing. Amazed at seeing the butterfly toy. Twinkle in her eye. Definite sounds for unhappy. Likes conversations about herself. Anticipates. Real distress. Fragile world, easily wobbled. Upset when I go. Aborbed in TV programme. Effort to suck a sweet Butterfly's gift of engaging with people, Lovely to be with. A smile that invites you in.
Andrew	Subtle. Smiles for definite things. Vocalises. Time, Processing, Concentrating, Ready to engage, He enjoyed

	this, Happily exploring, Happy wriggly delightful mood. Pleased to see me. Unwell – not happy, not wanting to engage. Prolonged seizure, Being quiet, Happy sounds, Being in the moment, Fully present to hiccoughs next thing – one thing at a time. Content, Quiet, Vv calm, Sleeping Different reactions to different people Listening to sister, mother, Playing around him, The daily routines, House quiet Other children want to be near him. Seen by school as having a 'magical nature.' Is complete in his being as he is. Mind and body all the time.

Findings concerning myself:

Superman	Trepidation going in. Tired going in, coming away energised x2 Snapshot into their world over 6 weeks. Mother offloading anxieties – every session, house move. Takes my attention away from Superman Distracted by carers. My intrusion into family space. Busy, noisy, stressed household, getting ready for house move, difficulty of compromised space. Carers integral to family life, carers intrusion – caused me to finish early sometimes 'how long will she be here for?' How siblings saw me Being present. Being witness to her relationships with others – sibling, Dad, mother, 'When she fixes her gaze on me, there is nowhere else to look.' Difficulty of final visit in new property. My presence on final visit some reassurance for mother. Feeling in the way.
Olaf	Interrupting his return home from school routine

	Some interacting, increased over the 6 weeks. Kiss sound from Olaf. Frowning at me, allowing me to sit next to him. Yes to sitting on my lap. (nb recording incident.) What prompted mother to suggest this? Her comment that if she had done this earlier he would have screamed. Not part of his world. My feeling of empty, negative, frustrated after first visit, nothing offered was right. Calm sense of peace, glimmering that I might be invited in. Being in a contained area. The importance of being with. Calm and happy. Chaos at start of the session. Nothing much happens – but being in the presence of something more than what is there. Being totally in the moment. Hospitality from family. Mother offloading on my arrival. Supporting Mother – to go to the loo. Witnessing M and O's relationship My attention drifted
Elsa	Annoyance at losing first three reflections – computer saving error. Challenge of Elsa, Elsa has definitely got to know you. Elsa as self sufficient. Smile of recognition as I came in. Not invited into her world. Challenged amused, respectful. Elsa is a challenge. Different type of being with. Presented with choice. Lots of silence recorded. Awareness of mum's fatigue, toughest time of day for mum, please come at this time for the next couple of years Elsa's disturbed sleep disturbing whole household. I sat back, Hard to sit back. Use of self to recognise spirituality – how is this child making me feel. Need for self-awareness I came away feeling tired/fatigued. My irritation with Elsa's 'twiddly, comfort zone pattern.' – I am ignored Feeling drained, energy drawn out of me. My unhappiness at leaving her on her own.

	Easy to engage with sibs. Hard to stay focused on Elsa.
Dragonfly	General melee Physical space – noisy, busy, difficult to find a quiet space. Good to be outside. Taken feely bag Mother pleased to see me. Mum – restless and anxious, on the go all the time. Mother, fully present to Dragonfly. Easy to engage with mother, Giggles, seemed aware of me Apprehensive before visiting. Left feeling peaceful Left feeling puzzled. Feeling exhausted at the end (D tired at start) Sense of fun at the end D Yawning, tried to appreciate that she was tired, didn't offer things. Quieter in final session – tired, didn't really want to play. Pushed away from me – mother described this as 'naughty' Made very welcome. I'm a 'tolerated intrusion' Hospitality: tea, importance of food Carers – confusion between spirituality and spiritualism
Butterfly	Felt it important to finish when I did On the verge of something Involving her with the recorder. Offer less choice. A need to play. Vulnerability My imagination, not hers Being a distractor Did I go too fast? Did I move her without consulting her My presence not enough to make it feel safe for her Sitting next to her, me on the floor watching TV together. Being prepared and able not to use any of the material that I had taken with me, but going with the child. Difficult to say goodbye to Butterfly, she holds onto you. I come away every time smiling after spending time with her. Giving mother a break. Mother's comment – non-verbal child manipulating two verbal adults.

Andrew	Feeling inadequate, can I reach the depths, feeling overwhelmed, nothing to bring. Bring attention. Felt adult led. I assumed it was ok with him to involve sibling Impact of his medical condition On a level, Tolerated me This felt ordinary Letting me touch his finger Had a time of quiet, being quiet Difficulty for me to concentrate on being. Nothing else needed – just be with him. Session ended too soon Session didn't feel too long I disrupted the mood – doing Distracted by sibling Aware that parents are also silenced They are people too Stroking hand in time to his breathing I don't comment on him tickly my hand in the reflection, only spotted it in the transcribing Arriving feeling tired, left feeling refreshed, calm, peaceful and energised. Just enjoyed being with Andrew Leaving feeling relaxed. Having a sense of calm, from being with Andrew From mother: if he is in a good moment, I can't help but be in a good moment too. Oh he is so good to chill out with, he is very calming.'

Additional Information to add to the children's individual signatures.

For Andrew, I have recorded how in Encounter 3 he was in a 'happy, wriggly, delightful mood' and that he was pleased to see me. I have also made the observation that he 'is complete in his being just as he is.' I've noticed how he is mind and body all the time. I was intrigued to notice that the significance of Andrew tickling my hand in the final encounter is not recorded in my log, I only picked this up through the transcript. What I have reflected in my log is the sense of calm and peace I felt from spending time with him. I have written: 'If he is in a good moment, I can't help but be in a good moment too'. I have recorded the observation his school made about him 'having a magical nature' and how other children seek him out to spend time with him and they become calm. This was shared with me by his mother as was the following comment: 'He is so good to chill out with, he is very calming.'

For Butterfly, I have noticed how she talks with her eyes and that there is a twinkle in her eyes. I've noticed how she has a smile that invites you in and that it is difficult to say goodbye to her as she holds onto you. I've recorded her sense of wonder at the Butterfly toy being revealed in The Very Hungry Caterpillar story. I've had the sense of being on the verge of something when being with her, noticing how 'lovely she is to be with'.

For Dragonfly I have noticed how people move in and out of the physical space in front of her and so it must seem that people suddenly disappear and then re-appear for her. I've described her as 'active delight' and being very much in the moment. I'm also very struck by her powerful action of pushing away from me.

For Elsa I have observed how she invites you in or totally ignores you. I've used the word 'challenge' about being with her and noticed her impact on the family.

For Olaf, I have recorded a further anecdote that illustrates how he connects with the wider world – his mother had taken him shopping with her, he had waved at a shop assistant and blown her a kiss when she complimented him on his beautiful eyes. As they left, his mother had turned back and spotted how this shop assistant was 'beaming and glowing' – and she remarked to herself – 'Oh Olaf, you've done it again!'

For Superman, I have recorded my impression that she was 'just pleased to be there' in the midst of her family life going on around her. I've noticed how little privacy she had at the time. I have also observed the impact of her deep gaze – with her mother, and with myself.

For all of the children, the sense of them being fully in the moment comes through in my reflections.

Further observations about the relationships between the children and their families

What emerges very strongly through my reflections is my sense of being a witness to the strong and significant relationship between the children and their parents. There is an intensity about this relationship. The parental pride in their children comes through, and their delight in any achievement, no matter how small is also evident. There is concern at times that the children have not done as well as they could have done for me – although I have consistently re-iterated that is not what I am concerned about, I wanted to see what it

was like being with the children. What the children actually did was not important, how they were being was what I was trying to capture and explore.

I've observed several occasions where the parents have looked tired and exhausted or stated that was how they were feeling. What came through was the complexity of caring for a severely disabled child as well caring for other siblings and running a household. One mother remarked that she felt guilty when she left the child in the research project alone whilst she cared for the other children, 'but she is alright, this is how we manage.' For another mother, caring for all of the siblings by herself was stressful – 'I hate it.' However, the parents were always calm and engaged with their children. Their love and affection for their children is palpable.

Observations about the fieldwork

There were practical problems concerning the recording device. For Dragonfly the recorder became something to hold at one point, which meant it got turned on and off. With Olaf, most of Encounter 5 wasn't recorded as a toy had fallen onto it and turned it off. There were also times when it slipped behind one of the children's head rest and so the sound became very muffled.

I learnt to set a timer on my mobile phone for 60 minutes as this seemed a reasonable length of time to spend with a child. Many of the sessions came to a natural conclusion and were shorter than an hour. However, there were a couple of occasions when myself and the child could have continued, but I sensed the unspoken pressure either from the families or the carers that they need to get on with the care routines for that child and it was time for me to go.

Observations about the impact of the fieldwork process on the families and children and vice versa. (Intrusion of the wider world.)

All the families welcomed me into their homes and were pleased and interested in taking part in this research. Their hospitality was warmly appreciated by myself – it was difficult to refuse cups of tea or a taster of homemade soup as happened on one occasion without appearing very rude. I was aware that I was with the children in the midst of a busy family time. One mother commented that my visits were at the worst time of day for her usually. My being there at that time was a help and she was keen that I continued to visit her for the

next couple of years to help out. For Butterfly's mother, my being there, meant that she was able to sit back for a short while, and take a short break.

For some parents my arrival at their house gave them an opportunity to off load some of their concerns and worries of the day – this might happen whilst we were waiting for the children to be brought back from school. They seemed to appreciate having someone available to hear some of their story. It also gave the parents time to go and drink a cup of tea or go to the toilet. However, once the children were at home and settled, all the parents freely let me spend time with their child.

The parents gave me feedback on how they saw my relationship with their child – such as 'Elsa has definitely got to know you over the weeks', 'I think Andrew is excited to see you', 'Olaf would not have tolerated that three weeks ago.' It gave me a sense that the parents trusted me with their children and that they were interested in what was happening. However, I was also aware that the parents were making sure that how I was interacting with their children was not going to cause the children any upset. I had a sense of a gentle watchful eye being kept on me.
Butterfly's mother made the interesting observation that she was aware of how a non-verbal child had managed to manipulate two adults into doing exactly what she wanted them to do.

I was very aware how my visits interrupted the usual daily routines for the families. This was especially evident when paid carers were around, waiting to provide personal care for the child I was with. This gave rise to such comments as: 'how long will she be here for?'

Whereas the families would join in with me or dip in and out of the encounters, the carers were very much observers – and I needed to be aware of how to manage that. I also felt that I was being observed by the carers. I feel this influenced me into 'doing' things with the children. I became aware of this and as the fieldwork continued, learnt to relax about this more.

What comes through from my reflections, more so than from the transcripts, is how the wider health issues of the children could also affect them during the encounters. Olaf often had disturbed nights – this meant that his mother did too. It also meant that he struggled with any change in his familiar routine, simply because he was tired. Elsa was developing a pattern of more and more sleep disturbance which was not only causing problems for the

whole household, but also meant her parents were having to consider and decide on possible medication that could help. This was not an easy decision to make.

Some of the siblings knew me from the hospice and were surprised to see me in their home. They asked if I was 'that hospice worker' and wanted to know what I was doing. Once that had been answered, they then ignored me for the rest of the encounters, but were aware that I was there and present in their house. It was more difficult with some of the younger siblings who accepted my presence without question and who wanted to engage with me, inviting me into their world.
Interestingly, I have only got two observations about spirituality or God recorded in my reflective logs. One observation comes from a carer who was working with Dragonfly and wanting to know what I was doing at the house. I explained that I was trying to explore Dragonfly's spirituality. Her response was 'As in God or as in spiritualism?' Both Dragonfly's mother and I quickly clarified that the project was nothing to do with spiritualism, but to try and gain an understanding of what made Dragonfly 'Dragonfly.' 'Oh that is interesting, she has got bags of personality' was the rejoinder.

Superman's mother talked about praying and finding reassurance from God concerning the families' imminent house move, which she was very anxious about. This was the only direct reference by any of the parents or carers to religious practice or religion noted within any of the 35 encounters.

Observations about the impact of the fieldwork on myself
Carrying out the fieldwork was part of a huge learning curve. Looking back, I can see how I learnt to relax more into the process and learnt to move from concentrating on doing things with the children to learning to be with them. I learnt to sit back and just let whatever was going to happen just happen.

This process also meant that I enabled the encounters to change from being adult led to becoming more led by the children and whatever they were engaged with at that moment. I have recorded that I felt overwhelmed and unsure about what I was trying to achieve at the start of the fieldwork – which may have been why it took me time to move from 'doing' to 'being' with the children.

I also had to learn to cope with the unpredictability of each session. Recorded in my reflective log on several occasions is my feeling of apprehension before the visit as I never knew what I would be walking into. An activity or a game we may have enjoyed together the week before would often be of no interest at all on the following encounter. I learnt not to expect anything but to accept whatever occurred – I may be invited in to the children's world or I may not be. I learnt to go with things prepared and to expect that none of that would be used. This was particularly so with Butterfly – I found it very amusing that the more I took with me, the less likely she would be to want to explore it, despite her curiosity. It was a case of less is more – it was worth offering less choice, allowing the children time to process what was being offered. As already mentioned, the importance of the encounters was not about the doing, but about trying to understand the being that was happening at the time.

I notice that there is a sense of anxiety in my notes – I state that 'I brought nothing to this encounter except attention' and 'this felt ordinary, almost nothing.' This was from the first sessions with Andrew, who was the first child I visited. This sense of anxiety decreases as I gain confidence in being comfortable with 'just' bringing attention, and being in the ordinary. I came to appreciate that it often felt as if nothing much was happening, but I was aware of being in the presence of something that was more than what was going on.

I became increasingly aware of the power dynamics and allowing the children to be in charge. So although I must admit to feeling irritated sometimes when the children chose not to engage with me – such as Dragonfly pushing herself away from me, Elsa going into her own 'sensory, twiddley zone', I learnt to relax and allow the children to be - for this was where they were at that moment. As an Occupational Therapist, working with children, I am promoting interaction, working on engagement, looking for purposeful occupation. I had to learn to stop being an occupational therapist, and just be myself. I needed to be very self-aware. It felt very good when the children did chose to engage with me. I noticed that my relationship with them changed over the course of the six encounters. For all of them except Dragonfly, it appears to have deepened. For Dragonfly, she did not want to engage any further after Encounter Three.

With all of the children, in my reflection notes, I have noticed that there were occasions when I had visited the children feeling tired. After the encounters I was aware that Dragonfly had energised me, Andrew had created a sense of calm and peace within me just by being with

him, Butterfly made me smile. There were also occasions when I visited with energy and left feeling tired – this happened with Olaf and Elsa on a couple of occasions.

I really enjoyed working with all of the children, no matter what happened in the encounters and how I might have felt with them at the time. I remark in my journal 'I just enjoyed being with Andrew', 'I come away from Butterfly smiling'. I note a 'joyful encounter' with Dragonfly, how 'today was totally amazing' with Elsa. With Olaf, I was excited when I had a spontaneous 'thank-you' kiss sound from him that only happened once. With Superman, I notice how she is her 'usual bubbly self' as she comes home from school into a busy household.

I found it a deepening experience and a sense of becoming very close to these individuals. It was difficult to leave them at the end of a session if it meant that they were going to be left alone – but that was acceptable to their families. I loved them all, just for who they were and the fact that they allowed me to be with them. As I noted for Superman: 'when she fixes her gaze on me there is nowhere else to look.' In all the encounters with the children, there really was only one place to look.
All these findings – the individual signatures, the parent comments, the combined analysis of all the children's signatures and my own reflections - leave me with several questions – what is being said about these children's spirituality and how it is expressed? Do any of the descriptions and descriptors that I have argued for fit into the stories of the child? How do these findings help answer my research questions and meet my research objectives?

Appendix 22: Overview of the Encounters

Andrew

Session 1 – 27 minutes. Introductory session, Andrew's medical needs dominated for 10 minutes, from the start of the session. I was on the settee, next to Andrew, his mother and sibling in room. During the session I was doing most of the talking. Andrew appeared to be very passive and quiet, in fact he was making lots of vocalisations. His mother was very quiet, occasionally getting involved, moving in and out of the room to the kitchen twice. This was noted by Andrew but it didn't make obvious difference to his vocalisations or interactions. Andrew was falling asleep at the end of the session.

Session 2 –39 minutes. Andrew's medical needs dominated for 15 minutes. These started at the beginning of the session. I used stories and the wind chimes in this session. His mother was in the room, on sofa, left once to go to the kitchen. His father in kitchen preparing meals. Andrew's sibling not present for the session. Many vocalisations during session. Andrew falling asleep at end of session – disengaging from working with me. (A.2.9.31 – 41)

Session 3 – 48 minutes, medical needs dominated for 6 minutes, towards the middle of the session, not right at the beginning. I used stories with props during the session. His mother in the kitchen for most of the session, his carer was in the room with Andrew for the session, his sibling in and out of the room. His carer was quiet throughout the session, intervening for medical needs as necessary. Andrew was quiet at end of session – disengaging, had been making several vocalisations beforehand. His sibling was very involved in this session – choosing stories, asking for more stories, also getting distressed at the end of the session as I had asked her to do something which she found difficult to carry out. Andrew awake at the end of the session.

Session 4 – 7 minutes. Andrew unhappy and distressed, recovering from a difficult day needing several medical interventions. This can be a typical pattern for him. Comment from his mother: 'to be honest, I can't believe he hasn't done so (ie become unwell) over the past three weeks.' Session kept very short. Medical needs dominated whole session, Andrew falling asleep.

Session 5 – 49 minutes. Session starts with him in his wheelchair, in the kitchen but then mother moves him onto his day bed in the living room. Sessions lasts long, medical needs dominated for 16 minutes, from beginning of the session. I used stories with props. His mother left the room after providing medical care, his father then came into the room and stayed with Andrew, sitting near to him, in close proximity to his head. Andrew was quiet during the story, exploring the props with his fingers. Andrew quiet and smiling at end of session. His sibling not present during session. Andrew noticeably giving fewer vocalisations throughout session. Andrew awake at the end of the session.

Session 6 – 32 minutes long, This was a very quiet final session, medical needs dominated for 2 minutes. Session started with his mother and sibling trying to find his button bag which sibling had hidden. Andrew seemed to find this amusing. Andrew and I were quiet for majority of the session, very few vocalisations from Andrew. His mother was sitting on sofa,

quiet too. When she left the room there was no discernible difference to Andrew's behaviours/reactions. Andrew falling asleep at end of session, however, as I was leaving the room, he seemed to wake up.

Contrast between first and last session: First session very busy, last session very quiet and peaceful.

Butterfly

Session 1 37 minutes long. Introductory session choosing name, explaining how button bag worked, explaining how sessions may work using the story board. She chose to have a story read to her by myself. Butterfly was initially in her standing frame but moved into her wheelchair by her mother. Her mother remained next to her for the whole of the session. Story used: *Frederick* by Leo Leoini

Session 2 50 minutes long. Definite choosing from the story board for a story and choice of story made by Butterfly. She deliberately put her finger onto the book that she wanted to continue first *Frederick* and to then have *The Very Hungry Caterpillar* using the props that I had brought. However, Butterfly became very distracted during the session when a neighbour posted some keys through the letter box and could not settle until she had the keys in her hand. Her mother remained next to her for the whole of the session. Overall pace of session slower than session 1, I was aware of the need to slow down.

Session 3 Session cancelled as Butterfly was unwell.

Session 4 47 minutes long. When I arrived Butterfly was in her wheelchair dressed up in party clothes. It became clear that Butterfly and her mother were going to a school friend's birthday party. Butterfly had been off school all week, although much better and was obviously looking forward to going to the party. It was also clear that she was more interested in that than in working with /being with myself. There were more vocalisations throughout this session – grizzle type sounds. Much of the interaction was between her mother and myself, as we tried to distract Butterfly whilst they were waiting for the taxi to take them to the party. Both her mother and I were with Butterfly throughout the session. At the start of the session, her mother described her as being in a grumpy mood.

Session 5 26 minutes long. This session was finished early as Butterfly was becoming increasingly distressed and unhappy. She was crying and very definitely did not want to

engage with me. What was notable and significant was that although her mother was within the same ground floor living space as Butterfly and myself, Butterfly could not physically see her. This seemed to be the underlying cause of her distress.

Session 6 56 minutes long. On arrival, I found Butterfly stretched out on her special bench watching television. I sat on the floor next to her and together we watched a programme that Butterfly was engaged with and enjoying. She was then moved into her wheelchair by her mother. The rest of the session was spent with her mother and myself, talking with her about various things. Using eye pointing, she very clearly indicated that she wanted a sweet and wanted to offer one to me as well – this was a shared experience between us. It is significant to note the effort it took Butterfly to be able to extend her tongue to then be able to lick the sweet. This took 6 minutes of concentrated effort to achieve this. Butterfly is a determined person and knows what she wants to do.

Final session had a different feel to it than first one – no expectations from any one, more relaxed, just being together.

Dragonfly

Session 1 28 minutes long. This took place outside, Dragonfly sitting in her comfy chair, myself and her mother sitting either side of her at the start. Her mother left Dragonfly after the first few minutes but was then back and forth. Introductory session. Lots of laughter from Dragonfly, cause not apparent, her laughter is infectious and made her mother and I laugh too.

Session 2 30 minutes long. This took place within the open plan living space. I introduced the feely bag to her and invited her to explore the different things inside. Movement of mother spending time with Dragonfly and then leaving to attend to other tasks. Noisy busy household, Dragonfly surrounded by noise but not distressed by this. More interested in the people around her than in objects being offered for her to play with.

Session 3 48 minutes long. This session took place outside in the garden. At the start of the session, Dragonfly had just come back from school and was very distressed. Her mother made the decision to take her out of her wheelchair and lie her down on a mat in the garden to sort out the problem. Her distress lasted for the first 7 minutes of the session. Her mother discovered that the cause of the distress was Dragonfly's gastrostomy site. Once that had been sorted out and appropriate medical intervention provided, the session

continued outside. Her mother moving between time with Dragonfly and time with household tasks.

Session 4 30 minutes long. Indoors, Dragonfly sitting in her comfortable chair. Dragonfly playing with things from my bag as well as with packaging. Mother spending middle section of session away from Dragonfly but there at the beginning and end of the session. Dragonfly seemingly absorbed in her own world in this session.

Session 5 41 minutes long. Indoors in family area, Dragonfly sitting in her comfortable chair. Usual busy household, visitor also arrives. Mother forward and back to Dragonfly also looking after visitor and other children. Story read to Dragonfly by myself – mother thought that she would like this. Dragonfly quiet during story but must be noted that at the beginning of the session and at the end of the session Dragonfly intentionally pushed herself away from me. Dragonfly did not engage with me in this session.

Session 6 40 minutes long. Mother present for majority of the session. Again, Dragonfly intentionally pushing away from me. Engaged in a sound conversation with mother (3 minutes long) and deliberately played with the space blanket for a prolonged period (6 minutes) with me. Lots of laughter but not necessarily directly engaging with me.

Elsa

Session 1 52 minutes long. Present – mother and siblings, father also coming home in the middle of the session. Lots of excitement and interaction with both parents, Elsa able to choose her name, supported by mother. Parents and siblings had left the room after 45 mins into session. Last 7 minutes of session – Elsa was silent and in her own world, not interacting with me.

Session 2 55 minutes long. Mother and siblings also present. Elsa very quiet throughout session. Most of the session was spent by Elsa in her own world. Once mother left the room with siblings at 34 minute mark, Elsa vocalised, using distress cries. Had calmed by the time I left.

Session 3 47 minutes long. Elsa arrived after I had. She had been out to see a film with her carer during the day as it was half-term. Elsa was very excited when she got back home, very pleased to see her mother, lots of interaction between them. She was in a very happy mood and taught me to play a game with her – Elsa would discard the disco torch and

it was made very clear by Elsa that my task was to retrieve the torch so that she could discard it again. This lasted for 4 minutes, with lots of laughter and animated body movements. Elsa then suddenly stopped – becoming very tired. The rest of this session was quieter, especially the last 16 minutes when mother had left the room.

Contrast between this session and the previous one.

Session 4 60 minutes long. For the first 9 minutes Elsa was on her own with me as her mother was attending to the siblings. Elsa concentrated on her iPad, not interacting with me. Mother and siblings then in the same room and were present for the next 45 minutes. Elsa allowed me to move her into her special chair and to play a ball game with her. Lots of animation, laughter and sounds, then Elsa suddenly became tired and needed to lie back down on her mat. Elsa was noticeably quieter for the rest of the session. For the last 30 minutes of the session she was in her own world, her own patterns. During this session I recorded a response from Elsa when a sibling called out – the first time I had observed this reaction.

Session 5 48 minutes. Elsa was in a more subdued mood throughout this session, absorbed in her own patterns, making very few vocalisations, with some interacting with her mother, but none with me. Elsa and I were together for the last 24 minutes of the session, Elsa very much in her own world. Seemed to be blocking everyone out, not wanting to engage with anyone. Different mood to other sessions.

Session 6 59 minutes long. Elsa was in a happy mood right from the start of the session, smiling, engaging with both myself and her mother. She seemed to be more aware of her siblings, watching them, vocalising back to them, as well as responding to her mother. Elsa moved herself on her mat to be as close to her mother as she could be. Elsa allowed me to play a game with her, similar to the one she had played with her father in session One. When her mother and siblings left the room for the last 30 minutes of the session, Elsa was quieter, interacting less with me, and occasionally going into her own world pattern.

Olaf

Session 1 18 minutes. Introductions, Olaf reluctant to choose a name, wanting to watch television, not wanting to engage with me. Session held in the living room. His mother very involved with Olaf and with the session. His mother appeared concerned that session wasn't going well, but was reassured by me that the session was valuable whatever happened.

Noticeable that Olaf needs two things to interact with at the same time – e.g. television and toy, television and phone.

Session 2 50 minutes. Session in the living room. Olaf was grizzling, unsettled for most of session, he wasn't sure about what he wanted to do, there was constant change. I became the observer for most of the session, watching/witnessing the interaction between Olaf and his mother. The session was held in the living room. He had had a very unsettled night, the night before. Olaf appeared to ignore me for most of the session.

Session 3 49 minutes. Session in his bedroom, in the sensory corner that his mother has set up for him. Main interaction throughout the session was between Olaf and his mother. At his mother's invitation, I got involved in the marble game. Olaf shook his head when mother asked if I could come into his bedroom –not clear that he gave consent for me to be there. Shake of head sometimes means yes and sometimes means no. I was mainly an observer for this session. Overall, this session was calmer than the previous two, but Olaf was flitting from activity to activity and from choice to choice. His mother involved me by getting Olaf to pass things to her, which Olaf did.

Session 4 60 minutes. Session in living room. I had a few minutes of time alone with Olaf. Key issue was that he was hungry – once fed much happier and more willing to engage. Lots of singing. More interaction between Olaf and myself, however, Olaf still flitting from choice to choice. Session calmer that previous three, Olaf coping with mother being out of the room whilst she got his supper, coped with being alone with me. First time (O.4.29.1) I observed mother sitting back in her chair and relaxing for a few minutes whilst Olaf absorbed in an activity.

Session 5 25 minutes recorded, recording ending prematurely as toy fell on recorder and switched it off. Actual length of session 50 minutes. Session in living room. After recording had been turned off, Olaf wanted the iPad, and was put onto my lap whilst mother went and got it. Olaf tolerated this, again much happier once iPad given to him. I was more involved when mother not in room, when mother in room, I became the observer.

Session 6 50 minutes. Olaf much happier, played 'hide and seek' with mother and me. Again, wanted his supper. Copied with mother not being there and staying with me whilst his supper was prepared. I was more involved in the session, more participant than observer.

Definite pattern of increasing interactions with myself over the 6 sessions, as I moved from being an observer to being a participant.

Superman

Session 1 33 minutes. In the kitchen/diner area. Session concentrated on introductions and choosing her project name. Superman was in her relaxing chair. Notable that towards the end of the session Superman became very quiet. In contrast was very animated whenever her mother was near or was interacting with her.

Session 2 42 minutes. Father was present for this session – he was home early from work. Superman became very excited as she came in from school and realised that he was there. I was able to observe their close relationship. Seen in Kitchen/Diner area. Superman was in her relaxing chair. Father having most interaction with Superman, mother less so in this session.

Session 3 46 minutes. Lots of interaction with myself during this session – playing with my hand. Her mother was in kitchen area, moving in and out of Superman's space. Superman had a time of giggles – cause unclear, but was laughing and giggling for a prolonged period.

Session 4 47 minutes. Lots of hustle and bustle going on in the living area, Superman very animated throughout session, responding to sibling, to her mother and myself. Appeared very animated towards the end of the session, laughing and giggling and then suddenly became very tired and then went quiet.

Session 5 45 minutes long. Superman found the recorder and enjoyed playing with it. It meant that the recorder kept being turned on/off throughout the session. Superman was in her relaxing chair. Lots of play going on with her mother and with myself. Lots of animation from Superman. She appears to be more interested in people that in objects.

Session 6 25 minutes long. In the new property, Superman very quiet and still, remained in wheelchair for whole of session. Spent a lot of the session gazing round the living room where she had been placed by her mother. She was very aware of the new surroundings. Very little interaction from her mother in this session, she was distracted by having just moved in and trying to sort everything out. Contrast to animation seen from Superman in previous session.