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Constructing Mortality: Ethics and Conflicts of the Religious Education of Children and Adolescents with Severe Intellectual Disabilities

by

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ABSTRACT

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The delivery of Religious Education to children and adolescents with severe intellectual disabilities is based upon the implicit assumption that such pupils have the cognitive capacity to comprehend religious principles in the first place. Furthermore, the concept of immortality, in its various forms, originates from the cessation of a corporeal existence, although there is little evidence that the intellectually disabled have any understanding of the finality of death. Additionally, while religiosity may be assumed, spirituality is almost completely neglected. This renders the intellectually disabled increasingly vulnerable to medical and judicial ethics in relation to 'quality of life' decision-making, as only the neurological and motor functioning of the person is assessed and valued. Furthermore, therapeutic interventions such as bereavement counselling and palliative care should address the totality of the person. However, this is difficult to achieve with existing assumptions and knowledge.

The pedagogy of 'Special' religious education's taxonomy is hierarchical in its exposure to non-Christian religious and spiritual interpretations. Alternative belief systems may be more accessible to the intellectually disabled, enabling the person to make sense of their own and others' mortality. This thesis presents phenomenological accounts from six intellectually disabled minds: from within such complex but impaired chambers, it represents the search for both gene and genie.

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Thank-you to Michael Erben for setting me on my way and supporting me through the experience.

This work is dedicated to Emma and Frances.

Introduction to the study

The conceptual aim of my study was to explore the Religious Education (RE) of severely intellectually disabled (ID) children and adolescents. These young people were classified as having an IQ below 50 and include those with no speech and profound and multiple disabilities. However, early in the study, a complex set of interacting domains began to emerge. Whilst unpicking the pedagogy of RE, I drew the conclusion that, fundamentally, death stalked the heart of religion (Gates, 2002). Consequentially, the study adopted a title that reflected the dualism of mortality and theology. To conduct such an enquiry required consideration of the participants' relationships with their biological, psychological, social, and transcendent history. Such a conclusion assisted in the formulation of the following aims for my research:

Primary aims. To:

i. Explore understanding of the concept of mortality from the perspective of young people with severe intellectual disabilities.
ii. Investigate the assimilation of religious education in pupils with severe intellectual disabilities.
iii. Identify the transcendental beliefs of young people with severe intellectual disabilities.
iv. Make recommendations in relation to the delivery of RE in special schools.

Secondary aims. To:

i. Discuss the findings in relation to medical and judicial debates on 'quality of life'.
ii. Consider the above findings in relation to therapeutic interventions (e.g. bereavement counselling) and palliative care.

While identifying the age range of the participants in my study is important, it has less significance compared to similar studies of non-disabled children, as cognitive impairment locates all participants within a single intellectual bracket. However, I have emphasised the participants' diagnosis as being 'severe' for sound hermeneutic reasons. It is a common failure of research into people with ID to acknowledge the severity of disability. For example, Turner et al.'s (2004: p. 162) study into religious expression describes their participants as being 'adults' with 'intellectual disabilities'. The participants' cognitive and expressive ability is assumed to be consistent with a moderate disability, a conclusion drawn from their articulation and description of their social interactions. Therefore, due to the missing adjective (i.e. commonly described as mild, moderate or severe), I contacted the authors to verify the status of the participants' disabilities:

> People with more severe disabilities were not included, not because we doubted that they have the capacity to be religious people, but primarily because we wanted to hear from individuals with learning disabilities themselves. This may not have been possible for individuals with more severe disabilities without some input from staff or carers.
>
> Turner (2005)

This quote suggests that children and adults with severe ID were assumed to have the 'capacity to be religious people' but that their cognitive and communicative competencies to make a contribution were dismissed.

Another prominent author's work in this field also lacked the necessary adjective to identify the participants' diagnosis. A similar enquiry revealed the following:

> The answer to your question is no, people with severe learning disabilities were not included. There are two reasons for that. Firstly the method we used is very much word oriented which has obvious implications for excluding certain people. Secondly, we began with the intention to include people with profound and complex needs, but it very early on became clear that what was needed was a separate piece of research which focused specifically on the needs of people with these life experiences.
>
> Swinton (2005)

While I accept that the assessment and categorisation of ID can be contentious, and appreciate the motivation behind the rejection of negative labelling, the missing adjective is vital for research. For example, the cognitive gap between some children with mild ID and some of their non-ID peers may not be too great in the first place. Additionally, the adjective informs us of the likely life experience of the person, e.g. their education and socialisation. It appears that the communicative aspect is regularly cited as a reason for excluding the severely ID from qualitative studies. Of course, we need to be realistic; in my own study, some participants failed to make any meaningful contribution at all. However, research still appears to regularly rule out those with severe ID as credible participants by selecting the mild or moderately disabled to represent all groups.

Early in my thesis, I have found it necessary to challenge a number of previously held assumptions concerning both the researcher and the researched. I deconstruct the concept of ID to consider identity, politics, hierarchy and agendas. In order to establish the credibility and integrity to undertake such a study, I confront the often hostile and offensive criticism of non-disabled researchers conducting disability studies.

In relation to the structure of my thesis, while participants' quotations may bulk out other types of qualitative studies, a study of the ID does not present such an opportunity, for two main reasons. First, the length of the interviews was restricted due to the participants' generally poor concentration levels. Second, responses were often individual words or individual signs. Subsequently, the thesis' size and shape is to some extent dictated by the data available. However, the answer to this problem was not to increase the sample size, as saturation appeared to be reached more quickly due to the limitations of both the participants' knowledge and their experience. Therefore, simply increasing the number of participants would not significantly improve the quantity of data. Furthermore, the additional logistics would compromise the time-scale of such a study: gaining access to children with disabilities as participants is time consuming and increasingly difficult. The majority of parents requested that the interviews be undertaken during school hours, an understandable request in relation to work commitments and the additional care required for children at home. However, practical arrangements such as finding appropriate accommodation and a teacher to support the child proved problematic. However, importantly, while the quantity of data from this study is limited, this is not at the expense of quality.

Finally in relation to the structure of my thesis, I provide a number of examples of health inequalities for the ID. This section is intentionally comprehensive as it is essential for public health decisions and actions to address such important health issues for the ID.

My literature review is presented under four main headings: death studies and the psychology of religion, mortality, religiosity, and education. Such an ontological, theological, and pedagogical enquiry required this section to be significant in size. The review is the result of an in-depth, analytical and synthesised process of identifying topics that serve a purpose for the study while illustrating specific gaps in understanding.

The way in which children assimilate both a biological and a religious perspective on death, and the extent to which they regard them as compatible, has never been systematically studied (Harris & Gimenez, 2005). I wanted to know exactly what the severely ID understood of their own and others' mortality, for a number of reasons. First, despite concerns over health screening, my literature review identifies a progressively increasing improvement in the population health status of adults with ID. Although individuals in the current generation of older adults with ID still generally die at an earlier age (on average) than do adults in the general population, many older adults with ID are living as long as (or longer than) age peers in the general population. The life expectancy of successive generations of adults with certain IDs, not otherwise compromised, will soon approach that of the general population (Puri et al., 1995; Strauss & Eyman, 1996). People with ID are therefore progressively more likely to be exposed to experiences of bereavement and palliative care, and in relation to the latter, not only for disability-related conditions. For example, Evenhuis (1997) cites cancer in older disabled people as being a particularly prominent cause of death.

Second, many theorists (e.g. Chadwick 1994; Holland 1997; Leaman 1995) believe that non-disabled children already have a 'second-hand' experience of death, gained particularly from TV and film. However, death remains very much a taboo topic in our society, with many theorists believing that it has replaced sex as the last taboo (Chadwick 1994; Wagner 1995). Bowie (2000) suggests that death and dying are topics that all children think about to some extent, showing a marked curiosity regarding the subject. However, children from schools that educate pupils with profound and multiple disabilities are much closer to this issue, as a minority of their cohort will have short life expectancies.

Exposure to mortality is therefore increased for these children, a statement quantified by the deaths of three pupils during my study. The subsequent school assemblies that were held for the deceased children were both religious (e.g. inclusive of ritualistic prayer) and secular (e.g. celebratory). However, it was impossible to know what the children and young people really understood of death and their ongoing relationship with the deceased.

Third, I believe RE to be incoherent without being able to comprehensively locate the corporeal and incorporeal within linear or cyclic theological explanations. The subject of death is delivered chronologically through the National Curriculum (NC), both implicitly and explicitly, in subjects such as RE, History, and Science. For example, at Key Stage (KS) 1 (age 4–6) children are confronted with issues of causation, e.g. disease (Black Death), war (Florence Nightingale), and the study of life processes (Alive and Not Alive). However, there is little evidence to suggest that the ID have a grasp of the finality of death within the many intangible concepts of theology. Therefore, similar to Turner's (2005) assumptions, the delivery of RE will surely continue to be speculative in relation to pupils' comprehension of the principles that underpin religious phenomena. In other words, if we are teaching a belief system that may not be fully comprehended, perhaps we should consider 'alternative' (although only 'alternative' in the sense that belief systems are taught hierarchically) explanations that would enable greater understanding? Existing pedagogical practice for the ID is akin to teaching algebra to those persons who cannot undertake addition or subtraction. In our haste to educate children in the Christian faith, we consistently overlook the philosophical nature of the subject and the complexities that lie within such a faith system.

It is the relationship between cognitive (im)maturity and RE that presents a number of contradictions. If a young child describes himself or herself as being *Christian* or *Muslim* we may assume this reflects the child's formal and informal religious education in a particular belief system. However, it may be considered absurd, or perhaps even pretentious, if the child describes his or her political allegiance as being to New Labour or Hezbollah. Additionally, if the child were to illustrate views consistent with prejudice, we might take the view that the child had been conditioned by the beliefs of his or her parents and/or community.

The pedagogy of 'Special' RE is fundamentally a modification of mainstream curricula. A more phenomenological approach to the subject would accommodate the plurality of faiths in a multicultural Britain. However, hostility to such an approach has led to religious hierarchy and the compartmentalisation of belief systems: "Religious education is now seen much more as supportive of the nurturing of separate religious communities" (Bates, 1994: p. 5). This lack of exposure to other faith systems may be perceived as being indoctrinatory, as the ID child will not have the same opportunities as his or her non-ID peers to consider a broad raft of concepts as they develop both cognitively and emotionally. After consideration of the social texts of psychology, the evidence suggests how a person with an IQ below 50 may not have the capacity to fully comprehend certain fundamental Christian concepts. However, the existing framework restricts meaningful engagement with non-Christian belief systems that may be more accessible to the severely disabled mind.

In my study, the separation of spirituality from religion is entirely intentional. The dearth of documentation relating to the spiritual beliefs of people with ID (Selway & Ashman, 1998) supports the impression that there has been little interest in the spiritual aspects of this group. Apart from do Rozario (1994), Vash (1981) is one of the few writers who have mentioned spirituality in relation to disability. She explored the concept of transcendence as a means of moving beyond the limitations of the human condition to embrace a more holistic vision of life. Vash commented, "One's spiritual belief system and philosophy of life shape the meaning of disablement for each affected person; this, in turn, influences the ways in which one reacts" (Vash, 1981: p. 18). Currently, it is only from occasional case studies that we can gain glimpses of the spiritual aspirations, frustrations, and existential concerns of persons with a disability. Social researchers may believe there are too many fundamental issues still to be addressed for persons with a disability (i.e. health, education, community access) before the topic of spirituality can assume priority. Whatever the reason, the relative absence of studies on the spiritual lives of people with a disability seems an oversight in terms of gaining greater understanding, awareness and appreciation of their lives. In the past, the cultural definition of spirituality in the West, linked strongly to the Christian tradition, has been partly blamed for the lack of information available on the spiritual lives of disabled people (Hillyer, 1993) and a narrow Christian definition of spirituality may be partly to blame for the absence of documentation (Selway & Ashman, 1998).

To establish a spiritual status for the ID is important for a number of reasons. The Human Rights Act (1998) increasingly takes life-or-death decisions out of the hospital corridors and into the courtroom. Decisions about medical treatment that has consequences for the timing and nature of a person's death engender strong emotions in both health professionals and the public, and raise difficult ethical issues for all concerned. They can often be a source of conflict between health professionals and patients' families, or between health professionals within a healthcare team. Ethical dilemmas arise when there is a perceived conflict of duty to the person, such as a conflict between a duty to preserve life and a duty to act in a person's best interests. While it is outside the scope of this study to discuss the quandary of the sanctity of life in great detail, it is clear that the spiritual aspect, or prospective spiritual aspect, of a person is rarely, if ever, considered. Taking into account the generally low status of the ID within the community and their subsequent low social capital, without consideration for what may be termed *transcendent* ethics, 'quality of life' decisions are based purely upon the physical functioning of the person, and often only in relation to pain tolerance. Within the crucible of a genetic revolution, perhaps by identifying what makes us human, we reduce the potential for disability bias of eugenics in the form of gene therapy, abortion, infanticide, and euthanasia.

Without a balanced view, I am intentionally provocative to suggest there is no difference in 'quality of life' decision making between the medical and veterinary professions. Certainly Singer's (1975, 1979, 1995) animal rights fundamentalism argues for circumstances where the chimpanzee has a greater right to life than a disabled human infant. He suggests that humans with lower levels of consciousness, intellectual capacity, rationality or capacity for relationships are non-persons. In response to this view, perhaps as Fernandez-Armesto (2004: p. 32) suggests, it is necessary that we go 'soul searching' to identify what it is that makes us human.

The ethics and conflicts of my study emerge from within assumptions and bias relating to children and adolescents with ID. These include: homogenisation of disabled people; communicative functioning; cognitive capacity for religious thought; exposure to death and dying; indoctrinatory practices; spirituality; receptiveness to therapeutic interventions; and palliative treatment. The interconnection of mortality, RE, and spirituality presents an individual's holism in relation to the above. Ultimately, we need to enable critical thinking so that children and adolescents with ID can identify with a range of religious and metaphysical explanations to find something that helps them to make sense of their world. My own view is that it does not matter if we believe that we simply decompose to bones, assume angelic status, or reincarnate in animal form, as long as this belief has been formulated by choice and is not the product of indoctrination. However, it seems that the opportunities to consider such beliefs may be discouraged if they conflict with the Christian versions of events of the ID child's parents or school.

Finally, it is important that I briefly explain what I intentionally left out of this thesis. The importance of the Church was not explored in any great depth, as the participants had minimal involvement with such institutions or their activities. Furthermore, the clergy were not consulted as I found much of the theological literature relating to those with ID, although well intended, was *religiose* and uninformed. Input from teachers was not included as the study was phenomenological and I wanted to capture only the participants' experiences as described to me. Similarly, input from parents was not invited, other than some assistance with clarification during the interviews, where their contributions have been identified and included.

The concept of religion as a 'meme' received considerable attention, including my attendance at lectures from leading advocates of the theory such as Richard Dawkins and Susan Blackmore. A meme is a cognitive or behavioural pattern that can be transmitted from one individual to another one. Since the individual who transmitted the meme will continue to carry it, the transmission can be interpreted as a replication: a copy of the meme is made in the memory of another individual, making him or her into a carrier of the meme. This process of self-reproduction (the memetic life-cycle), leading to spreading over a growing group of individuals, defines the meme as a replicator, similar in that respect to the gene (Blackmore, 1999; Dawkins, 1976). It could be argued that a meme carries the same fear-driven psychological motivator as a chain letter.

Despite my initial interest in this concept, originating from Burhoe's (1976, 1977) theory of gene/culture symbiosis, none of the material on memetics was included in the final thesis. I considered that its inclusion would undermine the phenomenological experience of the participants by the over-representation of atheistic interpretations. Additionally, the term itself has started to condition scientific discourse into describing memes as genetic. However, I believe memes are simply the evolutionary behaviours of observation and replication where the transmission of information occurs through memory, language, tradition, education, and social institutions rather than being in anyway genetic. Additionally, in the context of this study, as the ID are often perceived as being 'eternal children,' I wanted to distance any perceived simplistic relationship between immaturity and imitation.

I accept that people with severe ID engaged in phenomenological research are at the extremities of language-based methodologies. The participants in this study who failed to embody their thoughts into language remain in Vygotsky's (1962) linguistic 'shadows', some frustratingly just out of reach. However, the findings represent rich data drawn from previously uncharted domains.

Chapter 1 Literature review

1.1 Introduction

Death is universal: we all die, and that is a brutal fact. However, those people with ID may be shielded from the subject of death and dying by well-intentioned carers (Kennedy, 1989), as illustrated by Todd and Shearn's (1996) finding that families often regard their adult offspring as eternal children who will never grow up. Because people with ID may be unable to express themselves as directly and fluently as non-disabled people, there is still some mystery around their understanding of death and the meaning that they attach to it (MacHale & Carey, 2002). Goffman (1968) argues that, faced with a culture that places little value on a person with a disability, it is not surprising that many parents construct a 'protective capsule' around them.

Death and life after death have been central to Christian belief systems (Bowker, 1991). Without the prospect of heaven and the fear of hell there would be no Christianity (Walter, 1996), and without the terrors of the latter, the joys of heaven begin to lose definition (Kselman, 1993).

In this first section, I consider the effect of religion upon palliative care and vice versa. This enables me to present a contemporary view of death and dying to illustrate influences from religious and secular dogma to an 'openness' (Walter, 1996: p. 353) of mysticism and contemplation. Secondly, I turn my attention to the interface between religion and science. This area can be subdivided in various ways. In more general, more abstract terms, one might say that psychologists attempt to analyse and conceptualise religion in meaningful psychological terms (Paloutzian, 1996). As is well known, *religion* is a rather broad term, which has not yet been defined in a fully satisfying manner (Reich, 1998). Religion has at least explicatory and expressive aspects. Correspondingly, there is no lack of themes for particular studies such as religious *knowledge* and *beliefs,* religious *feelings* and *experiences* (including the mystical), religious *practices* (prayer, pilgrimages), and the positive or negative *effects* of being religious (on morality, health, social and political attitudes, and death). However, the study of the *motivation* for a person's religiousness is particularly difficult, notably because people may not be (fully) aware of it themselves (Reich, 1998).

1.2 Death Studies and the psychology of religion

1.2.1 The 'problem' of death

Religion, particularly Christianity, has for centuries been deeply concerned with the 'problem' of death (Walter, 1996: p. 353). Therefore, in order to study the more recent evolution of Christianity, a promising strategy is to look at the modern way of death and in particular, the care of the dying. Until the development of adequate nutrition and modern medicine, death occurred frequently, usually at home, with people lasting only days after falling ill (Walter, 1996). The official discourse within which death was understood was that of the church. However, in the twenty-first century, children no longer witness death as a normal part of growing up; death typically occurs not to the young but to the elderly and it takes place not at home but in hospital; and the managers of the process of dying are not family and clergy, but doctors and nurses. As a result, death is hidden from everyday life (Aries, 1981).

In the late twentieth century a new trend emerged, termed 'post-modern' (Walter, 1998), in relation to the killer diseases of our time, i.e. cancer and heart disease. Improved screening means these conditions can be diagnosed years or even decades before death. However, improved treatments typically extend life but fail to cure the disease. HIV/AIDS, though affecting far fewer people, at least in the West, has the same profile. Consequently a significant minority of the population suffer from life-threatening disease, and even when they become terminal may still take months or years to die. Palliative care (a term that replaced terminal care in the 1970s), pioneered by the hospice movement in the 1960s onwards, responds to the new trajectory of extended dying and aims not only to palliate pain but also to improve the quality of life for those nearing death. Therefore the concern to hide death is giving way to learning how to live with dying (Loftland, 1978).

This post-modern context for dying appears to have re-opened a space for the spiritual. Once the goal shifts from cure to improving the quality of the remaining time, attention spreads out from the biological to the whole person. Palliative care has promoted the idea of holistic care for mind and spirit as well as body, involving a multidisciplinary team of doctors, nurses, social workers, therapists, counsellors, clergy and volunteers. A second reason for the new interest in the spiritual aspects of care is that many hospices have been founded by believing Christians, often Evangelicals or Catholics. A third reason concerns the professionalisation of nursing. One way in which nurses claim professional status is through caring for the whole person – as a physical, social, emotional, spiritual being – referring the patient on to more specialised experts as and when necessary. However, nursing discourse still speculates what the spiritual dimension might actually refer to (Highfield & Cason, 1983; Carson, 1989; Burnard, 1990; Bradshaw, 1994; Harrison & Burnard, 1995).

So for at least these reasons there is a new interest in caring for the spirits of the dying as well as for their bodies. However, in this post-modern context, the role of the church is much diminished, patients may not be regular churchgoers, and the paymaster is the secular state (charitable foundation hospices typically having contracts with the National Health Service).

1.2.2 Spiritual approaches

Consider the various approaches presently employed via the medical-social holism of care:

(i) *The religious approach*

In medieval hospitals, patients were often confronted at the end of the ward by a large altar painting of the Last Judgement; they were in no doubt that one task to be completed was to ensure they were 'headed for the right place' (Walter, 1996: p. 355). However, Christians founding modern hospices have been motivated more by Christian compassion than by any desire to achieve deathbed conversions. Nevertheless, in their early years at least, such hospices were pervaded by a distinctly Christian atmosphere, which led to conflict as the organisation expanded, and new staff were appointed who did not share the original vision (James & Field, 1992; Bradshaw, 1996). For example, Walter (1996) explains how in open meetings, Christians praying in detail for patients' needs breach medical confidentiality.

Therefore, the problem with the religious approach is that it sits uneasily within a secular society in which many patients, and staff, do not share the same beliefs.

(ii) *The ecclesiastical approach*

By far the most common approach in British hospitals is to abandon any traditional Christian *ars moriendi* and go along with the dominant notion in Britain that only a minority of people 'get religion' (Walter, 1996: p. 355). Beyond noting denominational or religious affiliation on the admission form, staff hardly intrude into the patient's religious life. If a patient indicates a religious concern, then nurses or other staff are likely to call in the relevant minister. This approach clearly identifies religion as the domain of the ordained clergy and 'lets doctors and nurses off' (Walter, 1996: p. 355) confronting this subject. However, the problem is that a holistic approach that provides care for the dying person's body, mind and spirit, in fact only provides care for the body and mind.

(iii) *Interfaith approach*

However expert the doctor or nurse, it is the patient who is about to cross the once-only threshold of death. It may be that one of the attractions of caring for the dying may be homeopathic: the opportunity to listen to and learn from those facing what the carer has yet to face. Walter (1996) suggests that while one can ignore or dismiss the effect of another's faith on their life, it is hard not to take note of its effects on their dying, perhaps 'faith's ultimate test' (Walter, 1996: p. 356). In a working context in which doctors, nurses and chaplains are day in day out listening sympathetically without trying to impose their own values and beliefs, it would be surprising if they did not develop a sense of the values of all faiths (Walter, 1996).

(iv) *The spiritual approach*

Another approach speaks not of the religious but of the spiritual, the spiritual being defined as 'anything that gives meaning to a person's life' (Walter, 1996, p. 356). The teaching of Cicely Saunders (1988) has been particularly influential in spreading this concept and she in turn appears to have been influenced by Viktor Frankl's (1987) logotherapy – a therapy that enables the client to discover whatever it is that gives their life meaning and purpose.

This approach makes holistic care a reality, for, on this definition, everybody has spiritual needs. Furthermore, as Walter (1996) suggests, this approach can be employed with only a modicum of training. In this model the clergy can still deliver prayer, absolution, communion, etc., for those who request it. Other staff can be involved in spiritual care without probing into patients' religious beliefs and without having to reveal or even consider their own – thus the 'whole person' can be administered to without raising the tricky subject (in Britain at least) of religion (Walter, 1996). Both staff with personal religious faith, and those without, can help patients to identify the individual meaning of their life and death. Many dilemmas are largely resolved by the Saunders/Frankl method. The emphasis shifts from communicating the carer's own faith to enabling patients to discover the truth of their lives for themselves.

Some chaplains who want to expand their area of work beyond providing ritual comfort to the already converted, can both provide 'logotherapy' themselves and can teach nurses and other hospital staff how to provide it. However, the fight for the soul of the person may lead to nurses reclaiming this area from the clergy to expand their own sphere of influence, perhaps the ultimate medical model [1], which may lead to 'territorial' disputes (Walter, 1996). Therefore, if spiritual care is everyone's business, the chaplains' role becomes more diffuse and open to challenge.

It is difficult to see why an approach that deals in the meaning of human existence should be termed 'spiritual' rather than 'existential' or 'humanist'. After death, in Britain at least, a funeral that concentrates on neither the love of God nor the soul's post-mortem journey, but focuses instead on celebrating the deceased's life and what it meant to him or her, is usually designated a humanist funeral (Walter, 1989). So why should a similar focus on individual meaning before death be characterised as 'spiritual' rather than 'humanist'? Walter (1996) suspects the main reason to be the introduction of palliative care by practising Christians – indeed in continental Europe, where Christians may have been less involved in its promotion, this approach is typically termed 'existential'. One could certainly argue that any view that places ultimate importance not on revealed religion but on how the individual makes sense of his or her own life is essentially a humanist view (Young et al., 1996). This raises the question whether this approach to spiritual care entails an unwitting secularisation, or a recovery of a traditional Christian calling, or perhaps an imaginative expansion of Christian ministry into an area of care abandoned by others.

1.2.3 Individualised religion

There appears to be a move away from external authority towards the authority of the self (Walter, 1995). Walter (1996) suggests that hospice and to a lesser extent hospital staff may realise the inadequacy of past religious answers after sitting day by day listening to the dying. At the same time, the non-believing staff can become aware that there is much about death and dying that has yet to be explained by science.

Whatever a patient's previous faith, it is likely that when a person is facing a premature death, the person's faith, his or her construct, will be confronted. Previous religious formulae may not be plausible in the way they were in healthier days. This could be seen in terms of Fowler's (1981) theory of faith development as a process of spiritual maturing in which life events challenge the dogmas learnt at Sunday school to evolve a more personal faith (Walter, 1996). It also fits the socio-historical trend toward the individualisation of religious belief identified by Luckmann (1990). If in a traditional society people were born into a church, and if in a modern society they choose the church of their preference, in post-modern society they concoct their own mix-and-match spirituality (Walter, 1996), an 'ethical jazz' (Holloway, 1999: p. 21) from anywhere and everywhere, where anything goes as long as it articulates one's own personal experience, hopes and values. God is no longer the property of the churches, but is whoever or whatever you conceive God to be. This in fact is the direction that non-fundamentalist Christianity has been moving for at least a century, and it reflects the growing influence of individualism. There is evidence from Scandinavia that this post-modern spirituality is particularly embraced by younger women (Riis, 1993) who are disproportionately involved in caring work, not least of the dying.

1.2.4 New Age care

Walter (1996) describes New Age spirituality as moving beyond both the confines of dogmatic religion and an enclosed secular view. He describes it as uncannily similar to spiritual care as advocated by Christians and others in palliative care – yet most Christians working in this field repudiate such a connection; indeed, some display the characteristic evangelical hostility towards the concept of New Age. Despite such behaviour, there are clearly similarities between hospice philosophy and New Age ideas [2]. There would appear to be three specific areas of convergence between the two:

(i) New Agers tend to be open to the possibility that there is some kind of existence after death, many believing for example in reincarnation. Over the past decade there have been many more New Age than Christian books published on life after death (Walter, 1993). Although their currently fashionable post-mortem destinations may not look particularly Christian, the very fact that New Agers see death as a passage rather than as the end immediately distances them from secular materialism. In both palliative care and the New Age, death is something to be faced up to.

(ii) The concept of personal growth is central to both palliative care and to the New Age. The roots of the New Age in the philosophy of personal growth and in the human potential movement are well known (Heelas, 1993). In palliative care, though the body may not be cured, there may be potential for personal growth, for self-awareness and for resolving old issues. If, as Ernest Becker has suggested in his reworking of psychoanalysis (Becker, 1973), it is our mortality as much as our sexuality whose repression forms the basis of character formation, awareness of impending mortality becomes a key time for identifying and developing a more authentic character. As the title of one book edited by Elisabeth Kubler-Ross puts it: 'Death – the Final Stage of Growth' (Kubler-Ross, 1975).

(iii) Though palliation of pain and symptoms is based on the skilled use of conventional drugs, modern palliative care is often open to the use of the complementary, 'natural' healing methods favoured by New Agers, controversially high on the NHS agenda in 2006. Both palliative care and natural healing use a holistic approach. The philosophy of palliative care asserts that the well-being of the whole person is important if pain is to be reduced. So both palliative care and natural healing reject a crude bio-medical framework or at least would complement such a framework with a more holistic approach.

1.2.5 Evolutionary theory

I now turn my attention to the interface between religion and science. I begin this analysis with the Darwinian assumption that human beings share with all life-forms a fundamental predisposition towards self-preservation in the service of individual survival, which in turn enhances the reproductive success of the individual and hence fitness of the species (Solomon et al., 1998).

Ralph Burhoe's (1967, 1971, 1972, 1976, 1977, 1979) attempt to explain religion to scientists dealt both with the processes of its emergence and also with its function. With respect to its emergence, he recognised that religion must be understood in continuity with the entire process of evolution, beginning with the descriptions of nature provided by physics. Burhoe argued for the emergence of biological reality within the matrix of physical reality by considering genetic evolution, particularly in the ontogenesis of human individuals.

The key factor to be noted in this ontogenesis is the emergence of the human brain as a fully biological organ. Burhoe (1976, 1977) suggests that here in the brain something extraordinary occurs – genetic information gives rise to an organ that also generates cultural information. The interaction between the genes and cultures came to be the centre of Burhoe's scientific concern, just as it also became the focus for elaborating the significance of his theological theories (Burhoe, 1976, 1977). He constructed a theory of *symbiosis* to describe the emergence and interaction of genes and cultures. The human being is thus the creature who could be termed a genes/culture symbiosis (Hefner, 1998).

Burhoe (1979) suggests it is religion that transforms *Homo*, the 'ape-man,' into *Homo sapiens*, the human being. Burhoe speaks of this transformation that constitutes human culture as the source of civilisation in some places and in others as the altruism that enables viable complex social organisation through the emergence of *trans-kin altruism* (Burhoe, 1979). The work of experimental psychologist Donald Campbell enters here as a fundamental conceptual underpinning for Burhoe's thought. Campbell argued that civilisation is impossible unless humans as biological sexual competitors are transformed into socio-cultural co-operators (Campbell, 1975). Campbell suggested, and Burhoe argued vigorously, that religion is critical here as the agent of transformation (Hefner, 1998).

Burhoe proposed that selection has been at work in the entire scheme of things, and that religion has an evolutionary function, and therefore is as much as a phenomenon of nature as any other item that scientists study and about which they theorise (Hefner, 1998).

Burhoe's legacy comes into play directly in the arena of certain issues that flow from his basic set of theories and which, quite apart from his thought, have taken centre stage in current thinking about science, culture, and religion. Since the distinctive element in human evolution is the emergence of culture, and since the conduct of culture is the key to human flourishing or degradation, theoretical discussion of how science and religion interact will move directly to questions of value and morality. This was central for Burhoe: since religion has a scientifically describable function within the evolutionary process and since that function has to do with enabling the most authentic human living, both as individuals and as societies, reflection on values and morality is intrinsic to the relationship between religion and science (Burhoe, 1967, 1971).

1.2.6 Existential psychodynamic theory

Ernest Becker's (1973) theory about death denial was driven by the question: 'What makes people act the way they do?' In this work, Becker suggests that human beings live at a different level of self-conscious awareness from other animals, but this is both a blessing and a curse. The blessing is that it has made us a very successful species. The curse is that self-consciousness sets us at odds with that most basic natural behaviour, the overriding will to survive, which we share with all living things. Liechty (1998) explains how human awareness of existence will come upon an inevitable and unavoidable realisation: “I am mortal…sooner or later, death will win out” (Liechty, 1998: p. 46).

According to Becker (1973), this is the deepest root of why we act the way we do. We are a species whose main strategy is in direct conflict with evolution. Liechty (1998) suggests evolution has created a self-contradictory animal: in our minds we are divine, transcendent and ethereal; yet these states are entirely dependent on a fragile physical body which will inevitably age and die. Liechty (1998) states that mortality is the ‘dark side of self-consciousness’ (Liechty, 1998: p. 46), of not being a dumb animal. As far as we know, we are the only species that knows and understands the reality of death before it happens.

This psychological anthropology is firmly rooted in both evolutionary biological science and in a transcultural constant, the universal fact of death. For Becker, a careful integration and synthesis of important insights gleaned from evolutionary biology, anthropology, psychology, sociology and the humanities yield a broad and powerful conceptual analysis of human motivation based on the notion that the awareness of death, and the consequent denial thereof, is a dynamic force that instigates and directs a substantial proportion of human activity (Becker, 1962, 1968, 1971, 1973, 1975).

What are the personal and social implications of the idea that haunting concerns about death pervade almost every aspect of human life? For the individual, Becker (1973) noted in ‘The Denial of Death’ that a sober examination of the motivational underpinnings of human behaviour leads ‘beyond psychology’ (Rank, 1958) and directly to religion – to find the 'courage to face the anxieties of meaninglessness' (Becker, 1973: p. 279). Because psychological equanimity requires a meaningful conception of reality and no such conception can ever be unambiguously confirmed, all such meanings are sustained by faith and are hence fundamentally religious. Human beings are thus by nature innately spiritual creatures, not in the psychopathological sense of religion advanced by Marx and Freud, but in the sense of religion as ultimate concern (Solomon et al., 1998).

Becker's Death Denial Theory includes three distinct areas of psychology that deserve consideration: the personal, the social, and the religious or spiritual.

(i) *The personal psychological*

In contrast to the Freudian view of socialisation, Becker understood personal psychological development in broadly post-Freudian terms. Thus Becker wrote not of a psychosexual oedipus complex but rather of a relational/existential oedipal transition in children of both genders. During childhood, the dualism of body and self begins to emerge. The need to create separate spheres for the physical and the psychological is necessitated by the realisation that occurs in confrontation with the fact of mortality. Quite early, the child learns that continued existence on the physical level is doomed to fail; this will push the human individual towards attempts at a psychological, symbolic (not physical) conquest of death.

Chronologically, the first anxiety is to do with physical separation from the caregiver. As the child's ability to abstract and symbolise develops, this first anxiety is displaced by the existential anxiety of mortality awareness. From that point at which the child is able to understand that caregiver separation (object loss) = inability to thrive = death, it can be assumed that death anxiety has established itself as basic to the anxieties of abandonment.

The experienced dualism of the physical arena and the arena of the symbolic self and the urge to conquer death, albeit symbolically, which emerges during what Becker describes as the oedipal transition, tends to define the problem of living itself. The child encounters this first as it moves to gain entrance into the adult world of symbolic meaning, but it is a life project. The oedipal transition leads into the lifelong oedipal project. It is characterised by ego expansion on the one hand and anxiety avoidance on the other.

(ii) The social psychological

Becker (1973) asserted that humans would be riddled with abject terror if they were constantly plagued by the ongoing awareness of their vulnerability and mortality. Therefore, human beings spend most of their psychic energy in the creation of symbols of immortality that promote an immediate suppression from consciousness of the terror that arises from awareness of mortality, proposed as the Terror Management Theory (TMT) by Greenberg, Pyszczynski and Solomon (1986) and Solomon, Greenberg and Pyszczynski (1997, 1998). The mechanism for taming the terror of finitude is the creation of cultural symbols of immortality with which people can identify and through which people vicariously participate in immortality. All people want to endure and prosper and in some sense gain immortality (Liechty, 1998). But knowledge of mortality condemns them to mask this fact and suppress awareness of it from consciousness. A viable culture provides what Becker called an 'immortality ideology' in which people find security and protection. By giving allegiance to some external source of symbolic power, whether in the form of a particular person, a political group or movement, or abject idol worship, the anxieties of personal finitude are calmed and subdued.

Cultural worldviews facilitate effective terror management by providing individuals with a vision of reality that supplies answers to universal questions such as: What will happen to me when I die? Accordingly, all cultures provide their members with precise information regarding death that affords opportunities for individuals to live forever – either symbolically (e.g. a physical testament to a person's existence), or through religious beliefs that promise immortality in a variety of ways, from the (predominantly) Eastern conceptions of reincarnation to the (predominantly) Western conceptions of 'heaven' (Solomon et al., 1998). However, eligibility for immortality is limited to those who 'do the right thing' (Solomon et al., 1998: p. 13).

Becker's concept of transference describes how as humans we are finite, mortal, weak animals. Given the choice between accepting this reality or giving themselves over to illusions of greatness and importance, which a leader imparts to followers, the mass of human beings will choose illusion over reality, lies over truth, fiction over fact. The most prominent features of social life can be understood as public striving for symbolic immortality. They are attempts to symbolically establish human worth, dignity, meaning and significance, thus to allay the anxious, gnawing, unconscious suspicion that, in fact, in the face of reality of mortality, human life is but fleeting, perishable, transient, insignificant, and meaningless (Liechty, 1998).

(iii) The religious or spiritual

Becker states that all personal, cultural, and ideological functions to allay the terror of mortality are fundamentally 'religious' to the core. He suggests that these are directly employed to help us confront the mysteries of life and death, of mortality and immortality, and that any such strategy is, in the broadest sense of the term, deeply religious in character. We may speak of a distinction between secular and religious strategies on the social level, but on the psychological level, all strategies are deeply religious. Religious faith is the strong and inevitable human response to mortality awareness and is manifested as containing individual, communal, and cultural aspects.

In relation to the nature of the spiritual and sacred, Becker suggests that the concept of a Creator God is obviously our ultimate transference object. It is only in this Creator God that we have real hope of transcendence over the terror of mortality. It is only by living for this Creator God that our lives gain significance, meaning, and value in a world of suffering and pain, a world in which death finally rules. In this world, any sense of significance – meaning and value – of transcendence over the terror of mortality must be received only as a gift from the Creator God. Our salvation can come only by the free graciousness of the Creator God and can only be accepted as our part as an act of total faith (Liechty, 1998).

Liechty (1998) states that here we see that, wittingly or unwittingly, by speaking the voice of the prophet, Becker stepped directly into the thicket of post-modern theological debate. For the very Creator God is an ideal aesthetic construction. This is a God who cannot be disproved or 'pinned down' (Liechty, 1998: p. 56) in terms of accountability or ever be known exhaustively. Because in all cultural immortality ideologies people seek protection from their own mortality, humanity has always been drawn to figures and ideologies that offer power, for power suggests the possibility of victory over ultimate powerlessness (Liechty, 1998).

1.3 Mortality

In the few studies on delivering RE for children with severe ID (i.e. Brown, 1996; Longhorn, 1993; Webster, 2004; Stern, 2004; O'Brien, 2004), spirituality is inextricably linked with religion. For Christians whose lives are guided by the Bible, the reality of death is acknowledged as part of the current human condition, affected by sin (Genesis 2:17; Romans 5; Hebrews 9:27): there is 'a time to be born, and a time to die' (Ecclesiastes 3:2). However, despite recognition of the difficulties of the concepts involved (Webster, 2004), there is hardly a mention of the understanding of mortality of children with disabilities.

To discuss issues such as mortality, spirituality and religion, the individual and collective circumstances of my study's participants need to be contextualized within the study itself. Such realities relate to the participants' vulnerability, stretching from their foetal status to their increased risk of earlier mortality. While my predominant ethical behaviour is to ensure that no physical or psychological damage comes to anyone as a result of my study, I conduct my work knowing that particular information is withheld from the participants. For example, the Down's syndrome (DS) children I interviewed represented the small minority not legally aborted (Gillon, 1998; Fletcher, 1998). As a result, certain topics explored in this review are intentionally withheld from the participants.

There are three main categories of rationale for withholding information: if overwhelming harm can only be averted through deceit; complete triviality such that it is irrelevant whether the truth is told; and a duty to protect the interests of others (Shickle, 2000). Therefore, society takes moral and ethical decisions to withhold certain information from some of its members. In my research scenario, I agree that this is appropriate to prevent emotional harm. However, it is necessary to acknowledge that society, similarly to a large hierarchical family, has its secrets. The next section of this literature review represents a moral prerequisite for the study, though not for obedience to principles, but as an individual expression of conscience.

1.3.1 Personhood

Personhood is generally the first criterion of a claim for rights and is both a legal and moral concept. Legal personhood uses statute or judicial fiat to confer recognition on certain members of society thereby protecting and guaranteeing a wide range of rights. Moral personhood is distinct from its legal counterpart, suggesting that some criteria independent of the law and its machinery afford a measure of respect for one's life and interest (Gross, 2002). In the developed countries (excluding Israel which offers no legal or moral status to a foetus), there is a large measure of consensus that the late-term foetus enjoys some measure of moral personhood. Moral personhood confers a measure of moral rights, most often the understanding that the late-term foetus has an interest and moral right to live that can only be overridden if the foetus poses a severe threat to the mother's health or is faced with a life full of chronic pain and suffering (Gross, 2002). Moral personhood is conferred relatively late in a pregnancy as the developing foetus achieves a measure of viability, sentience, and human cognitive developmental capacity, thereby affording limited rights and protection (Chervenak et al., 1995).

Alternative positions remain problematic. The Catholic Church, for example, confers personhood at conception. However, with Ireland being the exception, this is not the basis for policy in any Western nation, where early-term foetal interests are rarely recognised, or remain subordinate to maternal self-determination. At the other extreme, minority opinions conferring personhood with self-awareness attained in early childhood (Tooley, 1972; Singer, 1994) have prompted sustained philosophical debate. However, policy makers or legislators have never seriously considered these viewpoints for reasons that are both moral and practical. To push the criteria for moral personhood beyond birth ignores emerging features of human cognitive capacity and the emotional bonding that usually accompanies a child's birth (Warren, 1997).

Therefore, one cannot ignore the momentous impact of birth. With birth, the physically independent newborn becomes the undisputed master of his/her body and gains a right of 'self-ownership of the body' (Mason & McCall Smith, 1994: p. 148). Birth thereby affords an unambiguous moment to either grant or significantly enhance the newborn's legal status.

1.3.2 Abortion

The abortion of a foetus when abnormality is strongly suspected has become increasingly contentious (Daniel, 1996; Jackson, 2000). In 1967, when abortion was made legal in the UK, foetal abnormality was construed as a legitimate reason for abortion. However, this rationale is now considered at best ethically difficult and at worst eugenic (Furedi & Lee, 2001). The problemisation of abortion for abnormality can be discussed with reference to two groups whose views have helped shape the debate.

i. The medical profession

Under British law, one exception to the general prohibition of abortion after 24 weeks' gestation is where it is agreed that there is a 'substantial risk' that if the child were born it would suffer from such physical or mental abnormalities as to be 'seriously handicapped (sic)' (Abortion Act, 1967). The terms of this clause of the Abortion Act are in line with the way medical judgement is generally privileged in British abortion law. The clause that caters for abortion for abnormality is worded in an imprecise way (Furedi & Lee, 2001). There is no specification of what a 'substantial risk' actually is or what it is to be 'seriously handicapped '. This vagueness reflects the outlook of the medical profession, which was reluctant to allow parliamentarians to interfere with matters of clinical judgement (Furedi & Lee, 2001), at the time the Act was passed.

Today, by contrast, many doctors are uncomfortable with the onus placed upon them under the law and are reluctant to 'play God' (Furedi & Lee, 2001). Many doctors would prefer more specific guidelines when considering the request for abortion on the grounds of foetal abnormality (Chervenak et al., 1995; Green, 1993). This has led to calls for the creation of lists specifying which conditions are 'serious' and which are not. For example, there is an argument that abortion in the third trimester should be deemed ethically impermissible unless the foetus has an abnormality that can be diagnosed with certainty as leading to an early death or cognitive developmental capacity, ruling out for example DS as a condition warranting legal abortion (Furedi & Lee, 2001).

However, if only those conditions on a designated list are deemed sufficiently 'serious' to enable a woman to have an abortion, then other reasons, not included on such a list, are presumably deemed trivial in comparison. Furedi & Lee (2001) suggest we have to be careful about suggesting that a woman's reasons for abortion are ever 'trivial'.

ii The disability rights movement

The movement for the rights of disabled people has become increasingly influential in recent years. With the completion of the mapping of the human genome, the prospect of the detection of an increasing number of genetic markers has generated a great deal of debate, which centres on the notion that 'eugenic' abortion may result (SPUC, 2004). Many disability rights activists suggest that as knowledge increases about the human genome, it will bring with it attempts to 'screen out' embryos and foetuses whose genes are not perfect (Shakespeare, 1998; Cunningham-Burley, 1998). Certainly, it is reported from the Office for National Statistics that between 1996 and 2004, more than 20 foetuses were aborted in the UK because they had club feet, a deformity readily corrected by surgery and physiotherapy: an action difficult to view as anything other than the manipulation of the definition 'serious handicap' (Rogers, 2006).

Furedi and Lee (2001) suggest that the term eugenics is used very loosely, and perhaps often wrongly, in discussions of abortion and ante-natal screening today.

Defined properly, eugenics is the view that society can be improved through the manipulation of genetic inheritance, and that social problems can be resolved biologically, largely through the control and shaping of human reproduction. It could be argued that the abortion law in Britain, when first introduced, was motivated to some degree by a eugenic outlook. Some clauses in the Abortion Act were possibly motivated by a desire to tackle the social problems caused by poverty, deprivation and hardship by shaping people's reproductive patterns rather than by making greater social resources available to them (Furedi & Lee, 2001).

However, this was not the case with regard to the clause in the law about abortion for foetal abnormality, which was largely a response to the thalidomide tragedy in the early 1960s, where the thalidomide drug was legally prescribed to alleviate the symptoms of morning sickness but led to the birth of severely disabled children. The clause, therefore, was a response to women who feared they were to give birth to a severely disabled child and were unable to prevent it (Furedi & Lee, 2001).

The overwhelming majority of women who discover that they are carrying a foetus affected by DS currently choose to have an abortion (Alberman et al., 1998). A study by ante-natal screening expert Professor Eva Alberman shows that just eight per cent of women who discover they are carrying a foetus affected by DS decide to continue the pregnancy (Alberman et al., 1998). However, it should be acknowledged that Furedi and Lee (2001) suggest that a woman whose attitude to her pregnancy changes when she finds it is affected by an abnormality is not making a political or social statement about the abnormality, or about born people with a disability, but making a statement about herself: her ability to cope. Furedi and Lee (2001) state that to accept the notion that the views of some disability rights activists should be able to influence abortion law or policy is to privilege the views of those who experience a condition over women who carry foetuses affected by it.

It should be made clear that bioethical decisions on 'right to life' issues often include a very different agenda to other ethical discourse contained in this thesis. A DHSS document reads: "because caring for the handicapped (sic) can impose great burdens on our society....The costs of providing amniocentesis for all expectant mothers over the age of 40 years...would be more than offset by the economic benefits in terms of savings of expenditure on children and adults with Down's syndrome and spina bifida" (DHSS, 1977). There is little to suggest this view has changed, as the NHS National Screening Committee recommends that all pregnant women, irrespective of age, should be offered second trimester serum screening for DS. Aksoy (1998) asks, what will become *too* expensive if the economic climate becomes gloomier? Whether, and how far, it is right to accommodate cost-benefit analysis in the medical field has always been problematical, as has the question of whether economical considerations should affect clinical decisions.

1.3.3 Infanticide (selective non-treatment)

Early rulings in British case law allowed parents to refuse routine treatment to DS babies. However, this issue was not addressed by statute, and the courts were allowed to set policy instead. Although later court rulings took a dim view of withholding routine treatment from DS babies, the practice was never strictly regulated. Mason and McCall Smith (1994) note with some dismay that the courts demonstrated that there is no such thing as an absolute obligation to preserve the life of a physically abnormal baby. In light of these court rulings, the British interpretation of selective non-treatment makes room for quality of life decisions as well as considerations of family and societal interests.

Although a contentious ethical issue, the option of foregoing treatment is limited to a relatively small class of newborns whose treatment falls between the extremes of clearly beneficial and clearly futile care. A treatment is beneficial when it will most likely lead to a significant improvement in the newborn's condition. A treatment is futile if the likelihood of benefit is 'extremely small' (<1%) or 'the quality of the outcome of the intervention is extremely poor' (Jecker & Pagon, 1995: p. 49).

Between futility and beneficence lies a grey area of various degrees of suspected disability. Given the high probability of disability and the not inconsiderable costs associated with caring for these infants, there are grounds for withholding treatment from an entire class of premature newborns subject to parental approval. The Danish Council of Ethics terms this a 'modified threshold approach' (Danish Council of Ethics, 1995: p. 28). Decision-making calculus is dictated by utilitarian rules of social choice that leave only limited room for individual discretion (Gross, 2002). Therefore, an entire class of newborns will not be treated, under the assumption that a significant number, though not necessarily a majority, will either die or survive with severe disabilities (Danish Council of Ethics, 1995).

Selective non-treatment is an action that either directly or indirectly facilitates death. Whether permissible or not depends upon its affinity to homicide and murder, and upon the distinction, if any, between killing and letting die (Gross, 2002).

1.3.4 Ethics of life expectancy

Life expectancy is not, on the face of it, what one would call a moral or ethical concept. Yet its significance becomes an ethical issue when it enters into practical deliberation: that is, when differences in the life experiences of individuals or groups of persons are taken to be factors which contribute to determining choices that affect their lives in important ways (Small, 2002).

Some of the ethical problems surrounding life expectancies refer to individual persons, others to groups or populations. In both cases, there are questions over preference according to age in the allocation of scarce resources. Should scientific research into different illnesses be given priority according to the age groups they affect most? Consider the proposition that the rest of one person's life is worth as much as the rest of another person's life. John Harris (Harris, 1985) suggests:

> All of us who wish to go on living have something that each of us values equally although for each it is different in character, for some a much richer prize than for others, and we none of us know its true extent. This thing is of course 'the rest of our lives'.
>
> (Harris, 1985: p. 22)

The point being made is not simply that we do not each know the true extent of the rest of our life, but that the value we attach to it is not determined by the sorts of comparisons with other lives for which a quantitative approach is appropriate (Small, 2002).

1.3.5 Health status of the intellectually disabled.

In the first White Paper in 30 years on ID, the Department of Health (2001) reported that there are 210,000 people with severe ID in England and about 1.2 million with a mild or moderate disability. ID is described as a condition of arrested or incomplete development of the mind, which is especially characterised by impairment of skills manifesting during the development period that contribute to the overall level of intelligence, i.e. cognitive, language, motor and social abilities (The World Health Organisation, 1992).

Within the Disability Discrimination Act (1995), the meaning of 'disability' and 'disabled person' is defined as:

> a person has a disability for the purposes of this Act if he (sic) has a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities....In this Act 'disabled person' means a person who has a disability.
>
> (http://www.disability.gov.uk/dda/)

Intelligence is not a unitary characteristic but is assessed on the basis of a large number of different, more-or-less specific skills. Although the general tendency is for all these skills to develop to a similar level in each individual, there can be large discrepancies, especially in the person who has an ID. However, the assessment of an intellectual level is based on whatever information is available, including clinical findings, adaptive behaviour (judged in relation to the individual's cultural background), and psychometric test performance. The diagnostic category chosen should therefore be based on global assessments of ability and not on any single area of specific impairment (World Health Organisation, 1992).

Indicators of change in longevity and health status among adults with ID suggest that, as in the general population, lifespan among adults has increased considerably since the 1930s (Record and Smith 1955; Carter 1958; Collman and Stoller 1963; Fabia & Drolette, 1970: Balakrishnan & Wolf, 1976; Freyers & MacKay, 1979; Elwood & Darragh, 1981; Masaki, 1981; Baird & Sadovnic, 1987; Malone, 1988; Eyman et al., 1990; McGrother & Marshall, 1990; Eyman et al., 1991; Eyman et al., 1993; Kastner et al., 1993; McGuigan et al., 1995; Puri et al, 1995; Hayden, 1998; Hollins et al., 1998; Jagger et al., 1998; Janicki et al., 1999; Patja et al., 2000). Carter & Jancker (1983) noted that during the years 1931–1935 the average age of death for males with ID was 14.9 years and for females 22.0 years. More recent reports show that mean age at death for people with ID ranges from the late 50s to the mid-60s (Wolf & Wright, 1987; Carter & Jancar, 1983; Maaskant et al., 1995; Graves, 1996; Strauss & Kastner, 1996; Visser et al., 1997). Much of this change in life expectancy may be attributed to overall improved health status in the general population, greater access to the benefits of community living, and access to medical interventions (Fryers, 1986; Malone, 1988), especially preventative health care in paediatrics.

Some studies have demonstrated that proxy measures of severity of ID (i.e. impaired mobility and incontinence) were predictors of early death (Hollins et al., 1998). In general, the healthier and less neurologically or physically impaired the individual, the greater the probability of living longer (Scholl et al., 1982; Eyman & Borthwick-Duffy, 1995). Eyman, Call and White (1991) and Raitasuo et al. (1997) noted that individuals with major medical problems or profoundly impaired self-care skills had higher mortality rates when compared to those with no significant impediments other than ID. It is therefore suggested that the probability of survival decreases as the severity of ID increases (Herbst & Baird, 1984).

Although Evenhuis (1997) cites cancer as a more prominent cause of death for older people with ID, deaths are generally caused by cardiovascular diseases, bronchopneumonia or other respiratory infections, carcinomas, seizures, and to a lesser degree asphyxia due to aspiration, pulmonary embolisms, or gastrointestinal diseases (Evenhuis, 1997; Molsa, 1994; Beange et al., 1995; Graves, 1996; Puri et al., 1995; Malone, 1988; Eyman & Borthwick-Duffy, 1995; Eyman et al., 1991; Raitasuo et al., 1997; O'Brien et al., 1991). People with ID generally have more limited exposure to environmental factors: deaths due to accident (children with ID, especially boys, are less exposed to domestic accidents than their peers with normal intelligence, being more protected by their parents and caregivers (Patja et al., 2000)), murder, suicide (Strauss et al., 1998) or addictive practices (e.g. smoking and alcohol consumption) are rarely reported as causes among adults with ID (Evenhuis, 1997; Raitasuo et al., 1997; Kastner et al., 1993). In addition, dementia among older adults with ID, particularly those with DS (Janicki & Wisniewski, 1985; Sinex, 1986; Dalton, 1995; Duggan, 1996; Aylward et al. 1997; Wilkinson & Janicki, 2001), is gradually being recognised as an associate cause of death, since pneumonia and congestive heart failure, the primary causes of death among adults with Alzheimer's disease (Burns, 1992; Bowen et al., 1996), are often found in older adults with ID (Janicki et al., 1999).

Differences in longevity attributed to aetiology are particularly pertinent to those with DS and those with epilepsy. DS is the most common form of ID. The syndrome is characterised by congenital malformations, especially of the heart and gastrointestinal tract, which can result in high mortality rates in the affected population (Frid et al., 1999). It has been shown that there is a 40–50 per cent risk of congenital heart defects among children with DS, whereas this risk is less than 1 per cent for the total population (Frid et al., 1999). Reports on DS from the earlier part of the century generally indicated an average age of death ranging from age 9 years to the 20s (Penrose, 1949; Deaton, 1973). Although life expectancy of adults with DS has increased considerably since then (Benda, 1969; Janicki & Dalton, 1997), it still does not match that of the general population or that of persons with certain other aetiologies of intellectual disabilities (Haveman et al., 1989; Fryers, 1986; Dupont et al., 1986; Eyman et al., 1991; Janicki et al., 1996). Carter and Jancar (1983) observed that the mean age of persons with DS who died in 1976–1980 was 54.0 years, but that the mean age at death was still 5.1 years less than other people with ID.

Furthermore, people with epilepsy are known to have an increased risk of earlier mortality over the population in general (Hauser et al., 1980; Cockerell et al., 1994). This risk is increased for people with ID and coexisting epilepsy (Forssman & Akesson, 1970; Brorson & Wranne, 1987; Wieseler et al., 1995; Forsgren et al., 1996). This is significant, as epidemiological studies have suggested that as many as one-fifth of the population of people with intellectual disabilities have epilepsy (Welsh Office, 1995).

1.4 **Religiosity**

Religious organisations have long been associated with care. Indeed, the delivery of what we now call human services was at one time 'the sole province of churches and synagogues' (Levin & Vanderpool, 1991: p. 59). Religion continues to play an important role in the lives of millions of people worldwide (Selway & Ashman, 1998) as eighty per cent of the world's population identify as adherents of one of the major or minor world religious traditions (Bernstein et al., 1995). In the USA, Scuccimarra (1990) found that after television and movie viewing, attendance at church ranked as one of the most favoured activities of young persons with disabilities. Similarly Schalock et al. (1981) revealed that churches were the most frequently accessed community facilities, coming before restaurants and shopping.

Although multiple factors influence how people cope with disability, little is known about how people use religious beliefs to establish meaning for, and respond to, life with disability (Treloar, 2002). Even less is known about how people with a particular set of shared spiritual beliefs (e.g. Bible-based Christians) make meaning for lived experience with disability (Treloar, 2002).

1.4.1 Superstition and myth: a brief historical overview

People with disabilities have been directly or indirectly influenced by religion throughout history. Western religious views on disability were influenced by early pagan attitudes towards physical or psychological difference. As Kiev (1964) notes in his examination of primal religious thought, non-normative states of being such as disability or disease were seen as intrusions into the soul or loss of spirit, induced by witchcraft or violation of taboos. It is likely that later biblical sources took these attitudes and modified them in a monotheistic context, utilising them as a means to ensure adherence to law and maintenance of fear and loyalty to an unseen deity (Rose, 1997).

Eiesland (1994) suggests that uncritical use of the Bible to address the concerns of people with disabilities 'perpetuates marginalisation and discrimination in the name of religion' (Eiesland, 1994: p. 74). As an example of an inherently negative biblical depiction of people with a disability, Kokaska et al. (1984) illustrate how Leviticus (21:18) not only presents people with a disability in a negative light, but also effectively bans them from approaching the altar. Such depictions of disability in the Bible are presented in a short article by Kokaska et al. (1984) [3]. This study catalogued "180 incidents of disabilities using the descriptors, blind, deaf, diseased, dumb, mute, sickness, crippled, maimed, and lame" (Kokaska et al., 1984: p. 20). Kokaska found 46 incidents that depicted people with a disability in a negative light according to modern standards. The incidents were either inherently negative (i.e. the person was clearly placed in an inferior role) or a negative image was imposed by the way in which people with a disability were described. However, they concluded that if language changes could be made to reduce the stereotypes, the subtle and overt expressions of rejection of persons with a disability in Biblical text could be altered.

1.4.2 Family dynamics

As thinking, feeling, spiritual beings, humans seek to understand the reason and purpose for disability (Treloar, 2002). Spiritual questions include, "How has God allowed this to occur?" A variety of spiritual coping strategies, religious and nonreligious, may be utilised (Baldacchino & Draper, 2001). However, very few studies exist which examine disabled people's religious orientation and its effects on their acceptance of disability. Recognition is growing that the disability of a child affects the entire family. Some investigators have examined the role of religion in the lives of parents and caregivers of people with a disability, and it is through these studies we gain insight into the potential for 'informal' RE. Such studies have provided consistent evidence that religious orientation can play an important role as a coping strategy in the lives of these people (Bennett et al., 1995; Gnagy et al., 1977; Schmitt, 1978; Weisner et al., 1991; Wright et al., 1985; Zuk, 1959, 1962; Zuk et al., 1961).

Marshall et al. (2003) suggest that because families reside within complex contexts of personal experiences, religion often plays a powerful role as belief shapes meaning (Wright, Watson and Bell, 1996; Bennet et al., 1995; Haworth et al., 1996; Rutledge et al., 1995; Schmitt, 1978). Religious belief and devotion are increasingly reported as a resource for coping (Abbott & Meredith, 1986; Erin, Rudin & Njoroge, 1991) and can provide a way for families to 'grapple with the ultimate problem of meaning' (Bellah et al., 1991: p. 218; Patterson, 1993). Religion is suggested to also provide a spiritual foundation that is needed to understand suffering or loss (Wright, 2000).

Most theories centred on religion do not include the complexity of a shared family viewpoint, and most coping or adaptation theories or theories of family structure and function do not include religion as an essential concept (Marshall et al., 2003). Theories that specifically address religion and family responses to crisis or challenge typically conceptualise religion as a resource for problem solving, coping, or social support (Pargament, 1997). However, the conceptualisation of religion and meaning in families who deal with the multiple challenges related to chronic illness or disability is more profound than that portrayed in a theoretical frame that presents religion simply as a resource for individual needs (Marshall et al., 2003).

Although many studies of families with children with disabilities or chronic illness have emphasised the associated stress, crisis, or chronic sorrow (Kazak & Marvin, 1984; Leyser & Dekel, 1991; Noa et al., 1989; Singer & Farkas, 1989; Wikler et al., 1981), researchers have also begun to examine strengths, health, and resilience among such families (Dyson, 1991; Friedrich & Friedrich, 1981; Garland, 1993; McCubbin & Huang, 1989). Religion may be an important variable in this conceptual shift.

However, Sorensen (1989) noted two major limitations of past research on religion in the social sciences. First, 'religion' was predominantly defined as organisational affiliation or church attendance rather than factors of personal belief, faith, hope, or meaning of religion. Second, among disciplines in health care, religion has been most predominantly described as a characteristic of the individual and not considered in a family context (Grant, 1986, Hackett, 1986; Pruyser, 1984; Schnorr, 1983; Sevensky, 1984).

Religious belief systems, apart from formalised religious practice, may promote acceptance and assist families to give meaning to the disability (Paterson, 1975b; Weisner et al., 1991; Wrigley & LaGory, 1994; Bennet et al., 1995; Rehm, 1999). However, while there are more positive than negative functions of religiousness in families with disabled members (Rogers-Dulan & Blacher, 1995), parents may experience increased stress, including the perception of religious failure or punishment for wrongdoing. Few attempts have been made to determine if different spiritual belief systems ascribe meaning differently to disability (Treloar, 2002). Although some early studies suggest possible religious denominational differences with family adjustments to a child with disability (Zuk et al., 1961), more recent studies have not supported this (Weisner et al., 1991; Rogers-Dulan & Blacher, 1995).

Social scientists have provoked new dialogue regarding the role of religion or spirituality in individual healing, health, and positive human relationships (Byrd, 1998; Dossey, 1998, 1999; Ellison & Sherkat, 1993; Heaton & Pratt, 1990; Jarvis & Northcutt, 1987; King & Bushwick, 1994, Levin, 1994, 1996; Levin et al., 1997; Levin & Schiller, 1987; Levin & Vanderpool, 1989; Maugans & Wadland, 1991; Sloan et al., 1999; Sorensen, 1989; Wilson & Filsinger, 1986; Witter et al., 1985). Some investigators have found religious organisations to provide helpful sources of family support (Erin et al., 1991; Maton & Wells, 1995; Taylor & Chatters, 1988), whereas others have demonstrated family dissatisfaction with support offered by church organisations or clergy (Ferguson & Heifetz, 1983; Fewell, 1986; Sonuga-Barker et al., 1993).

Some researchers have studied religion as a component of therapeutic interventions for individuals and families with chronic illness, disability, or mental illness. Such interventions include scripture reading (Byrd & Byrd, 1993), use of religious stories and narratives (Webb-Mitchell, 1993), recruitment of people with disabilities into participation in activities of religious organisations (Riordan & Vasa, 1991), and use of specific religious practices, such as blessings and prayer (Byrd, 1998; Dossey, 1998; Richards & Potts, 1995).

However, it should be noted that parents of children with disabilities may reject religious interpretations. Peter Nichols (2000) records in his diaries (1969–1977) how, at his disabled 10-year-old daughter's funeral, he refused to pray to a God whom he describes as "some far fetched sadist who could have allowed cruelty like this" (Nichols, 2000: http://books.guardian.co.uk/extracts/story/0,,375296,00.html).

1.5 Education

In the UK each year, approximately 165,000 children under the age of 16 years lose a parent, and many others are affected by the death of another relative or friend (BBC, 2005). Additionally, children attending special schools may be more likely to experience the death of a peer due to the increased mortality rate of those with disabilities [4]. Holland's (2003) study showed that many children had adverse experiences on returning to school after the death of a parent, and that they often felt that schools offered them little effective help or understanding on their return. Teachers have rated the area of bereavement as important (Holland, 1993; Holland & Ludford, 1995) so the children's perceptions were surprising. Holland (2003) suggests it may be that teachers were wary and unsure about broaching the subject of death, either because they found the subject too difficult, or for fear of causing upset.

Yanok and Beifus (1993) recommend that the following points should be included in any educational curriculum designed for people with ID: (i) discussion on how death can occur; (ii) introduction of a new vocabulary – to replace euphemisms like 'gone to sleep' which may confuse and cause them to be fearful of sleeping – especially those likely to take such an expression literally, i.e. those with autism; (iii) teaching community standards of behaviour including socially acceptable displays of grief; and (iv) trips to cemeteries and churches.

1.5.1 Loss awareness

Much of the literature suggests that children are in general poorly informed about death, and even illness (Eiser, 1990; Nelson et al., 1994). Based on this evidence, there are clear implications for practice in education and palliative care, where families are required to learn rapidly about the nature of illness and a whole new vocabulary that accompanies this trajectory. Thompson & Payne (2000) suggest that age has been found to be the principal factor associated with qualitative differences in children's death-related concepts. Other researchers have suggested a Piagetian stage-based progression, as highlighted in Judd's (1989) review, where the general agreement can be summarised as follows. Very young children either have no comprehension of death or understand it as a temporary separation. Children of about 3–5 years of age have a basic realisation of death, but see this as being caused by external violent or accidental causes. By the middle childhood years, children have acquired an understanding of the irreversibility of death as well as understanding its universality. Understanding of internal causes may be added to understanding of external ones. The alteration of the appearance of the dead is the last, and most difficult, concept for children to grasp. By adolescence, the understanding is that death is irreversible, universal and personal.

Many studies demonstrate positive outcomes when families with a dying or deceased member can communicate openly and express the way they feel (Harris, 1991; Silverman & Worden, 1992; Breyer et al., 1993; Lauer et al., 1985). Harris (1991) demonstrated that, where the cause of death remained unclear, adolescents often felt responsible either for causing or being unable to prevent their parent's death, which potentially complicated their grief.

In her landmark work beginning in the 1980s, Maureen Oswin began to discuss the normality of the death experience, arguing that people with ID have the same right to grieve as anyone else, and proposed some guidelines for facilitating this (Oswin, 1981, 1991). It is only in recent decades that the implications of loss for people with ID have been acknowledged. Conboy-Hill (1992) argues there are two major explanations for this. Firstly, she proposes that western attitudes to death and dying render open discussions about what it means and how it feels when someone dies very difficult. Secondly, society's attitudes towards ID allow us to deny people's level of understanding or emotional functioning. Therefore, people with ID face a 'double jeopardy' (Summers & Witts, 2003) when it comes to grief and loss.

Thompson and Payne's (2000) study suggests that the questions posed by bereaved children were "predominantly seeking reasons and causes of death, a study which confirms young persons' desires to increase their understanding" (Thompson & Payne, 2000: p. 92). From a Piagetian stance, it would seem that any attempts to question, show or explain would only foster development if the child was 'mentally ready' (Thompson & Payne, 2000: p. 94). Vygotsky's (1962, 1978) theory, although acknowledging the significance of age in learning, entails a far greater emphasis on the role of communication, social interaction and instruction in determining the path of development.

However, the child's individual experience outside the classroom makes tackling this subject more difficult as they may have already formulated thoughts and beliefs. Piaget and many contemporary theorists of child development share the view that children actively 'construct' their knowledge of the world. Thompson and Payne (2000) suggest:

> Learning is not synonymous with schooling – a great deal of what children learn occurs spontaneously outside the school walls as they play, observe, ask questions, experiment and make sense of the world around them.
>
> (Thompson & Payne, 2000: p.75)

Therefore, and similarly perhaps to sex education, children may have very different entry levels to the subject: experiential, anecdotal, informed and misinformed.

1.5.2 Attitudes

While the concept of death is central to religious faith, many people in contemporary society avoid talking about death until it affects them personally. The topic of death is considered 'morbid' and 'depressing' to talk about despite it being one of life's certainties (Bowie, 2000: p. 22). This avoidance seems at its greatest where children are concerned. Many adults do not feel it is an appropriate subject to discuss with them. However, in a natural effort to 'protect' children from death, adults may only succeed in heightening the fears and misconceptions that children have (Bowie, 2000: p. 22).

Almost 73 per cent of the child participants in Bowie's (2000) study indicated death and dying as a topic that they think about to some extent, illustrating a marked curiosity regarding this subject. The results contrast with the class teachers' views, as they believed it was only when pupils were directly affected that they thought about death. This opinion contradicts many theorists' belief (Chadwick 1994; Holland 1997; Leaman 1995) that children already have a 'second-hand' experience of death through the media, as Grollman (cited in Ward et al. 1989: p. 2) emphasised, stating that children are all too aware of the reality of death as "TV nightly bombards us with death in many forms in glorious colour".

Doyle (1989) and Wells (1988) noted that there were many benefits to be gleaned from addressing death as a natural part of life – that is, before bereavement occurs. Perhaps the most significant of these is in helping to allay children's fears (Bowie, 2000). Holland (1997) believes an additional advantage is that death can be incorporated into a diversity of topics, such as life cycles. Holland describes this pro-active approach to help children to "reach a greater understanding of death and loss (and) to achieve better coping mechanisms in preparation for their own inevitable losses later on in life" (Holland, 1997: p. 45). However, death hardly features in most schools' resource planning, pointing to a lack of understanding of the possible benefits of addressing death naturally within the curriculum.

It is evident that teachers may require some form of training to teach and cope with death and bereavement, in order to raise awareness, knowledge and understanding of support agencies, resources and literature on this area (Eiser, Havermans, Rolph &

Rolph, 1995). However, teachers may need to first address their own fears and feel totally comfortable about this subject before they broach the subject in the classroom, as Gunn (1990) explains:

> How we confront death can be a constructive or destructive experience and the way in which we, as...teachers, present the circumstances of death to the children in our care will be of great importance for their whole future attitude to death and dying. The person who attempts to deal with a child's feelings about loss has...to be comfortable within himself (sic) about death.
>
> (Gunn, 1990: p.5)

Stevenson (1995) stressed the impact which grief has on a classroom atmosphere, in terms of academic, behavioural and emotional implications. Therefore, it is clearly evident that 'teachers need to have an understanding of the grief process before they can monitor any changes' (Bowie, 2000: p. 25).

1.5.3 'Death' in the classroom

In the first part of the twentieth century there was a considerable body of work carried out into the attitudes of children towards death. However, after the First World War, talking about death to children appears to have become prohibited (Jackson & Colwell, 2001a). In the UK, the death of Diana, the Princess of Wales, in 1997 happened only a few days before the beginning of a new school term and was an event which brought the subject of death back into the classroom. Many teachers were aware that they might have to talk about this event with the children they were teaching but were unsure how to do this (Jackson & Colwell, 2001a). Jackson and

Colwell (2001a) suggest that many teachers expressed adult anxieties about death. The fear of discussing this concept with children was partly to do with the opinion that talking about death openly was morbid and might cause the children to worry that those close to them might die. There is a common belief that perhaps the subject of death should be discussed as the need arises. However, this view starkly contrasts with the belief held by many theorists, such as Doyle (1989) and Wells (1988), who advocate the pro-active approach, as they argue that death cannot be discussed objectively while children are grieving.

1.5.4 Pedagogy

In 1985 an official British inquiry into the Education of Children from Ethnic Minority Groups, chaired by Lord Swann, published its findings under the title 'Education for All.' The Swann Report included a substantial section on the role of religion in schools and came down decisively in favour of a non-dogmatic, non-denominational, phenomenological approach to RE. Such an approach, the report believed, provided the "best and only means of enabling all pupils, from whatever religious background, to understand the nature of religious belief, the religious dimension of human experience, and the plurality of faiths in contemporary Britain" (Swann, 1985: p. 518). This unqualified endorsement of the phenomenological approach came as no surprise as it was viewed as best suited to education in a multicultural society (Barnes, 2001). This approach sought to 'inform rather than convert pupils' (Swann, 1985: p. 498).

The government White Paper of 1985, entitled 'Better Schools', focused on the notion of a national curriculum and reforms in the administration of education, and, for the most part, simply ignored the subject of RE, including Swann's recommendations (Robson, 1996). However, this was to change when the Education Reform Bill that followed the White Paper passed to the House of Lords for discussion. A strongly vocal Christian lobby was successful in amending the legislation to require agreed syllabuses of RE "to reflect the fact that the religious traditions of Great Britain are in the main Christian whilst taking account of the teachings and practices of the other principal religions represented in Great Britain" (Her Majesty's Government, 1988: p. 6). Barnes (2001) suggests that there is little doubt that the political climate changed to become more openly hostile to the phenomenological approach to RE.

Bates (1994) suggested that, instead of methodologies involving the study of the major religions in a framework focusing upon shared concepts and common features, "there is now the requirement for separate treatment of religions, stressing their integrity and difference" (Bates, 1994: p. 5). Bowie's (2000) research reveals support for the inclusion of death education in the primary curriculum, as it is a natural part of life. However, this would require careful planning, as difficulties may arise due to the diversity of faiths in today's society. Furthermore, if it is exclusive to the curricula of religion, this may convey the message to pupils that death is perhaps only related to religion (Bowie, 2000).

Jackson and Colwell (2001a) considered the way in which it might be possible to introduce death and dying into the British school curriculum. One of the problems involved how to develop a language that would give children the tools to talk about death (Thompson & Payne, 2000). By extending the scope of much of the typical education and by incorporating talk of death into every subject taught, Jackson and

Colwell (2001a) suggest we might: "introduce notions of death as normal and non-frightening and thus give children and adults a common language within which to address the more problematic issues caused by bereavement and loss" (p. 321).

Jackson and Colwell (2001a) considered the UK curricula to establish where talk of death would fit naturally. This, they propose, would therefore not be a topic seen as being 'additional' to the existing curriculum (Jackson & Colwell, 2001b). One obvious example of how this can happen is at Key Stage 2 (1) (8 years), with the topic of the Ancient Egyptians. The Department for Employment and Education curriculum materials (DfEE, 1999) suggested that children look at the process of mummification in quite graphic detail. Jackson and Colwell (2001a) suggest that it is a short step from this to ask the question: "Is this what we do with people that die nowadays?" They also suggest that mathematics lessons are also times when the concept of death could be introduced. They give an example of a trip to a local cemetery for calculating the average age of death, life span, and so on. They suggest this information could be transferred to a history lesson to consider why the lifespan may have been shorter. Death would thus be talked about as a feature of life and of our daily routines.

Jackson and Colwell's (2001a) research showed how the majority of 14–15 year old children in their study expressed a positive attitude towards the notion of introducing death studies at an early age. This study suggested that children are not as worried about talking about death as adults may believe. However, if the 'Loss and Death' module of the personal, social, and health education (PSHE) syllabus for year 9 pupils (aged 14–15) is the first explicit encounter with death within the curriculum, how is this addressed for SEN children who many never reach the IQ norms of this chronological stage?

RE is a curriculum area that has traditionally neglected the child with ID (Swinton 2001; Webster, 2004). Historically, the subject has been dogged (from both within and outside the profession) by feelings of ambivalence regarding the appropriateness of RE for such children, particularly those whose difficulties are of a severe and complex nature. Webster (2004) suggests this has been chiefly due to perceptions, perhaps misplaced, regarding the difficulties of the concepts involved, and perhaps the controversial nature of religion itself. This situation became more acute with the implementation of the National Curriculum, introducing academic subjects into the Special School curriculum, which was previously more concerned with developmental and functional activities [5].

Non-RE specialists, called upon to teach RE in the Special School, may have felt tempted to give the subject a lower priority than some other curricular subjects, particularly when the timetable still had to accommodate the range of specialist therapies required by their pupils (Webster, 2004). For a short intense period of time in 2004, RE was talked about (Krisman, 2004). The draft national framework, published for consultation by the Qualifications and Curriculum Authority in April 2004, sparked a media explosion of articles, most focusing on atheism and secular world views and the point of teaching minority religions. The key themes in the consultative document, including the vital role the subject plays in the inclusion agenda such as deepening respect, heightening sensitivity and combating prejudice, were sidelined (Krisman, 2004).

The development of RE in Special Education continues to be informed by professionals with a particular expertise in the area, including Erica Brown (1996) and Flo Longhorn (1993). The sensory approach has been explored by authors such as O'Brien (2004) and Webster (2004) and has enabled many teachers to find ways of promoting access to the subject that do not rely solely on cognitive and communicative competence.

1.5.5 Standing Advisory Councils for Religious Education

Although RE is part of the basic school curriculum, it is not part of the English National Curriculum, and its content and management are determined locally. Standing Advisory Councils for Religious Education (SACRE) are the local committees that advise Local Education Authorities (LEA) on matters connected with RE and religious worship; Agreed Syllabus Conferences (ASC) are the SACRE sub-committees responsible for drawing up local RE syllabuses.

SACREs advise LEAs on matters connected with RE and religious worship. These include matters related to the quality of teaching; advising on teacher training; reviewing teaching methods and materials; discussing OFSTED reports on RE, collective worship; and spiritual, moral, social and cultural education. SACREs also consider questions relating to worship in schools, including requests from head teachers to hold collective worship that is not of a broadly Christian character.

However, a small survey carried out by the British Humanist Association (BHA) in 2000 suggested that many councils were not representative (BHA, 2006). Of the six faiths usually studied in RE, only 24 per cent included all six, with Buddhists being the most frequently absent.

Endnotes

[1] In organisations today, including education, there appears to be a tendency to reinforce an individual deficit view of needs to individual pathology (Brownlee & Carrington, 2000). This application of a medical model of disability suggests the disabled person is flexible and 'alterable' while education is fixed and unalterable. Disability is, thus, a 'personal tragedy' rather than anything to do with society (Darke, 1999: p. 4).

[2] Despite similarities between New Age ideas and the modern hospice, it has to be said that many of the authorities on the care of the dying referred to by New Agers turn out, on closer inspection, to be Buddhist (Levine, 1992).

[3] Interestingly, only one writer was found to make direct reference to disability in the Koran. Haj (1970) noted that special consideration was given to the blind, and gave examples of passages XLVIII, 17, and XXIV, 61. In those passages, special compensation is granted to the blind, lame and ill in regards to their civic responsibility (i.e. fighting in a war) and their social responsibility (i.e. sharing a meal; see Ali, 1975, pp. 501-502).

[4] During the study, three children died from disability-related causes at the school from which the majority of the participants were drawn.

[5] Throughout key stage 1, pupils explore Christianity and at least one other principal religion. They learn about different beliefs about God and the world around them. They encounter and respond to a range of stories, artefacts and other religious materials. They learn to recognise that beliefs are expressed in a variety of ways, and begin to use specialist vocabulary. They begin to understand the importance and value of religion and belief, especially for other children and their families. Pupils ask relevant questions and develop a sense of wonder about the world, using their imaginations. They talk about what is important to them and others, valuing themselves, reflecting on their own feelings and experiences and developing a sense of belonging.

Throughout key stage 2, pupils learn about Christianity and at least two of the other principal religions, recognising the impact of religion and belief locally, nationally and globally. They make connections between differing aspects of religion and consider the different forms of religious expression. They consider the beliefs, teachings, practices and ways of life central to religion. They learn about sacred texts and other sources and consider their meanings. They begin to recognise diversity in religion, learning about similarities and differences both within and between religions and beliefs and the importance of dialogue between them. They extend the range and use of specialist vocabulary. They recognise the challenges involved in distinguishing between ideas of right and wrong, and valuing what is good and true. They communicate their ideas, recognising other people's viewpoints. They consider their own beliefs and values and those of others in the light of their learning in religious education.

Throughout key stage 3, pupils extend their understanding of Christianity and at least two of the other principal religions in a local, national and global context. They deepen their understanding of important beliefs, concepts and issues of truth and authority in religion. They apply their understanding of religious and philosophical beliefs, teachings and practices to a range of ultimate questions and ethical issues, with a focus on self-awareness, relationships, rights and responsibilities. They enquire into and explain some personal, philosophical, theological and cultural reasons for similarities and differences in religious beliefs and values, both within and between religions. They interpret religious texts and other sources, recognising both the power and limitations of language and other forms of communication in expressing ideas and beliefs. They reflect on the impact of religion and belief in the world, considering both the importance of interfaith dialogue and the tensions that exist within and between religions and beliefs. They develop their evaluative skills, showing reasoned and balanced viewpoints when considering their own and others' responses to religious, philosophical and spiritual issues.

Chapter 2 Epistemological and philosophical foundations

2.1 Introduction

The aim of this chapter is to articulate an appropriate process or method to determine and justify the epistemological and philosophical influences on this study and to locate them within the 'abundant and conflicting literature' (Caelli, 2001: p. 275).

Traditional methods of research in ID contexts are considered by some commentators to be anachronistic. These authors suggest that the current climate causes the non-disabled researcher to feel somewhat 'uncomfortable and certainly vulnerable' (Kellet & Nind, 2001: p. 51). They suggest one option to consider prior to engaging in disability studies, is to 'give up and go home!' (Kellet & Nind, 2001: p. 51). Although this comment's flippancy is acknowledged, its message is not as light-hearted as it first appears. The non-disabled researcher's role is challenged at the outset by authors such as Branfield (1998) who calls for positive discrimination against the non-disabled and warns her fellow disabled academics to be on their guard against disability studies being 'hijacked' (p. 144). Bury (1996) considers that some disabled people feel so strongly about the 'oppression' inherent in traditional research that they employ language such as 'voyeurism' or even 'rape' (Bury, 1996: pp. 110–112). When confronted with such vitriolic hostility, it is not unlikely that non-disabled researchers may choose to avoid disability studies altogether.

Some compromise is suggested by (predominantly) disabled researchers, to select either an emancipatory or participatory paradigm. The problem with such a proposition is twofold. Firstly, there is the suggestion that obedience enables the non-disabled researcher to be granted a 'temporary visa' (Humphrey, 2000: p. 75) to pursue their research interest; representing a *psychological moment* to effect compliance. Secondly, I concur with Mitchell (1996) that in fact the terms 'emancipatory' and 'participatory' are used so inconsistently in the literature (although both are considered consistent within the principles of the social model [1] of disability) that they appear to have the same meaning.

2.2 Who are the 'disabled?' Terminology and definitions

The more common term in the UK of *learning disability* is a label predominantly used as a convenience in discussion for planning services (BILD, 2001). However, the field continues to be plagued with inconsistent, uncritical and unscientific phraseology (Fryers, 1997), e.g. mental handicap, mental retardation, developmental disability. In any discussion of disability, terminology and definitions are key factors in determining how it is interpreted (Darke, 1999). The labels that society gives disabled people affect not only the way disabled people are perceived, but also how they perceive themselves (Zola, 1993). Linton (1998) and Morris (1997) both emphasise that it is the meaning that is ascribed to the word that is significant. However, it appears the more politically correct we become, the more our language becomes ambiguous. This study acknowledges many of the contributions to this subject: Corker's (1993) suggestion that the disability 'experience' is unstable; Oliver's (1990) preference for the linguistic conveyance of the *person* before the *disability*; Goodley's (2001) proposal for dialogue into the 'exaggerated' social origins of the label; Dumbleton's (1998) observations on how only the deficiencies and failings of people are emphasised; and the People First organisation's chosen terminology of 'learning difficulty.'

However, my decision to use the term *intellectual* disabilities in this thesis, rather than 'learning' disabilities, has been influenced by the rationale presented by Bob Gates, editor of the UK *Journal of Intellectual Disabilities*, which changed its name from the *Journal of Learning Disabilities* in 2005. Usage of the term *learning* disabilities remains in my 'Invitation to Participate' (Appendix i) to present a consistency of language used within the participants' school. However, my intention was to select a term that had global meaning and universal consensus without imposing yet another name. Therefore, *intellectual* disability is used throughout this thesis to present clear and precise usage without intending to cause offence.

2.3 Vulnerability, dependence, and the human condition

Some elements of the disabled community see research, particularly that conducted by non-disabled researchers, as something that increases discrimination, essentially being part of the problem, rather than being helpful (Oliver, 1992). Moore et al. (1998), for example, go as far as to query whether non-disabled researchers actually contribute to the disempowerment of disabled people. Researchers, like society, are broadly separated into two camps: the non-disabled 'oppressors' and the disabled 'oppressed' (Barnes, 1996a: p. 110). Branfield (1998) speaks for her disabled peers to describe the disability movement as a socio-political reality. She claims that no matter how 'sincere, sympathetic, or whatever' (p. 143) non-disabled people are, they are always in a position of domination. Branfield's view is that "non-disabled people are not where we (the disabled) are and can never be" (p. 143). She continues to suggest that non-disabled people's experience, history, and culture manifests as oppression: an oppression that is the responsibility of the non-disabled. Branfield claims that to deny this is to ignore what the disability movement is all about. Such demarcation between disabled and non-disabled academics is made tangible by Barnes (1992), who suggests "logic dictates that if a researcher is to empathise with those being researched then it follows that their life history must be as near as possible to that of the people being studied…." (Barnes, 1992: p. 117). However, if this contentious view is valid, is it true that the non-disabled experience is so far removed from the disabled one in the first place? Perhaps the first mistake authors such as Branfield make is to assume that the experience of dependence is one unique to the chronically disabled.

MacIntyre (1999) suggests that we human beings are vulnerable to many kinds of affliction, with how we cope being only in small part up to the individual. He illustrates childhood and old age as being obvious stages of our lives characteristically marked by dependence on others for protection and sustenance. MacIntyre adds that between these first and last stages of our lives there may be shorter or longer periods of injury and illness; additionally, some among us will be disabled for their entire lives. However, the history of western philosophy, with some 'rare exceptions' (MacIntyre, 1999: p. 1), makes only passing reference to human vulnerability and affliction and the connection with dependence on others. Additionally, what of the ex-disabled person who may be a survivor of an illness but not of the cure, e.g. treatment such as psychiatry?

Considering these issues, MacIntyre (1999) poses the question: What difference to moral philosophy would it make, if we were to treat the facts of vulnerability and affliction and the related facts of dependence as central to the human condition? MacIntyre (1999) suggests that in modern, sophisticated Western cultures we have been distracted from just how much we share with certain other animal species, which puts us at odds with both older Aristotelian modes of thought and with modern post-Darwinian evolutionary naturalism. The failure to recognise the relationship between our animal condition and our vulnerability is cited by MacIntyre as an obstacle to acknowledging the facts of affliction and dependence. Such failure or refusal is either rooted in and/or reinforced by the extent to which we imagine ourselves as other than animal.

2.4 Deconstructing disability

2.4.1 Identity

The disabled community has made enormous efforts in recognising its own heterogeneity and in accommodating those with multiple identities e.g. sub-groups for disabled ethnic people (Priestley, 1995) and for disabled gay or lesbian people (Shakespeare, Gillespie-Sells, et al., 1996). This is a positive development in terms of understanding the multifaceted nature of identities (Vernon, 1999), and the variegated impacts of policies and practices (Drake, 1999).

However, Humphrey (2000) suggests how it may become problematic if such sub-groups splinter apart from the main movement(s) that gave birth to them, or if they prioritise one aspect of their identity or oppression above another, as indicated by Vernon (1999).

A further boundary problem is arguably more germane to the disability community, since it pertains to the boundaries of disability itself. From the 'inside', there are deaf people who are classified as disabled in legislation and by society, but who repudiate the disability identity on the grounds that they constitute a distinct and cultural minority (Harris, 1995) with their own language. Furthermore, there are many disabled sub-groups that have not contributed to the prevailing orthodoxy of the social model of disability: groups such as the participants in this study.

The 'policing' of the disability identity is cited by Humphrey (2000: p. 68), when he illustrates an example of how a disabled person experiences problems with the social model:

> It's very convenient for people with apparent (observable) disabilities or impairments to operate a social model which says: "We don't want to discuss things in terms of 'impairments'". The trouble with it (social model) is that it's very difficult...for people with learning difficulties or other conditions...which are not catered for...to raise their concerns as things which need dealing with on a service level, without feeling that they're breaking the law and talking about impairments.
>
> (Humphrey, 2000: p. 67)

Humphrey (2000) suggests that the social model (as operationalised within her disabled group research) has reduced the disability identity to different kinds of impairments in a way that can deter many people from adopting a disabled identity and participating in a disabled community. Humphrey states that, paradoxically, some disabled people's organisations may have expended more energy in reaching out to black/Asian and gay/lesbian people, for example, who harbour specific impairments, than in reaching out to differently disabled people whatever their other oppressions. Therefore the question "Who is to count as a member of the disability community?" is not as strange as it may sound and may even be the Achilles' heel of disability politics to date (Humphrey, 2000).

2.4.2 Politics

Whilst such an over-simplified schema as the social model of disability has been stamped upon the psyches of activists, rather than the texts of academics, it does create tensions in the writings of some academic-activists. No doubt some follow Tom Shakespeare's (1993, 1996a) valiant attempts to bury the disabled/non-disabled dualism by reminding us of the multi-faceted oppression matrix. No doubt others follow Fran Branfield's (1998, 1999) attempts to resurrect such dualisms for the sake of separatism, which co-exists uneasily with an acknowledgement of complexity.

The dualism between disabled and non-disabled people remains intact in a way which can militate against a recognition that many currently non-disabled people have been and/or will become disabled in their lifetimes, that many carers and some professional service-providers are also disabled people, and that the disability identity may have been constructed in a way which limits its inclusiveness (Humphrey, 2000: p. 70). Additionally, there is no practical-political space that encourages supporters to organise themselves so that disabled people can call upon them if required for mass meetings, civil disobedience, etc.

The politics of experience, which states that a lived experience of a given oppression is a necessary, if not sufficient, prerequisite for understanding that oppression and becoming part of the solution rather than part of the problem, is not entirely tenable. It cannot be pursued too far without lapsing into self-contradiction – taken literally, it entails that, for example, those with a mental health disability cannot understand those with a physical disability and so on, leaving each group in isolation and deprived of the chance to elaborate a more inclusive civil rights agenda or a more overarching theory of disability. The question is whether it is helpful to call someone 'disablist' if they have assumed responsibilities in bringing about a non-disabling society by (re)educating themselves and others, and by altering their social practices and institutional policies, and if they are indeed doing this on a daily basis and over a lifetime's labour. Ironically, it may be those labouring under other oppressions who are more 'in tune' with the disability movement than those who command power and resources, suggesting that some diatribes against non-disabled would-be allies may be misdirected (Scott, 1994).

Humphrey (2000) suggests an 'ideology' route through disability politics when we embark on a political journey only with those who share our critiques of the *status quo* and our visions of a better world, regardless of whether they share disabled identities. This might mean that those such as the non-disabled take the same journey without suffering direct oppression as such, although they will, nevertheless, experience the world we all inhabit as oppressive on account of their observations and convictions. In other words, the politics of experience may need to be reworked.

2.4.3 Hierarchy

As Goodley (2001) identifies, writers in disability studies more commonly locate impairment at the forefront of such research and critically examine the assumptions that underpin the social model of disability. By exploring *attitudes* towards impairment, from both disabled and non-disabled persons' perspectives, it may be possible to determine whether, as Watson (2002) suggests, it is possible that disabled people do not have a common group identity, or whether the group identity only exists within impairment groups and not as a collective whole.

An attitude can be defined as 'a state of readiness, a tendency to respond in a certain manner when confronted with certain stimuli' (Oppenheim, 1992: p. 174). Attitudes towards disabled people have been predominantly negative in direction, with behaviour towards this group in society ranging over time from denial of goods and services (Disability Rights Commission, 2002: p. 22), to incarceration (Stalker & Hunter, 1999), to elimination as a consequence of eugenic policies in the twentieth century (Hubbard, 1997). Tringo (1970) argues that, if a general prejudice exists toward disabled people, then a hierarchy toward specific groups should also be present, suggesting that those ranked as least preferred will have the most difficulty in being accepted by society. It was found that ID, alcoholism and mental illness were the least preferred by the non-disabled subjects, with ulcer, arthritis and asthma ranked as most accepted. Tringo's hierarchy has been found to be relatively stable 30 years later, with only people with cancer showing a change in position (Thomas, 2000).

Watson (2002) concludes that, whilst disabled people share the common characteristic of having an impairment, this is not enough to sustain the notion of a common identity. Deal (2003) suggests that it is not uncommon for 'disassociation' (p. 898) between impairment groups. An important series of questions in relation to the field of disability studies must therefore ask: Do disabled people regard themselves as part of an in-group of disabled people, as part of an in-group of those with the same impairment, or as part of an out-group (i.e. not associated with disability)? Linton (1998) comments that people tend to perceive a greater number of 'subtypes' within their in-group than within an out-group. It may be possible, therefore, that whilst disabled people view other disabled people as part of their in-group, due to the heterogeneity of impairment, the disabled person may view each impairment group as a subtype and thus different from them as individuals. Haslam et al. (1995: p. 139) add to this discussion by giving an example of meta-contrast. Meta-contrast is defined thus: "a given set of stimuli is more likely to be categorised as a single entity to the extent that the intra-class differences between those items are smaller than the inter-class differences between those items and others that are salient in a given comparative context." Thus Haslam et al. suggest that various pieces of fruit will be perceived *as* fruit rather than as apples or pears when in a collection of other food products. However, when only fruit are present, the perceiver is more likely to identify greater differentiation and categorise more fully. Thus, in the first instance, stereotype traits are likely to be used to self-categorise between one group or another (in-group or out-group). Building on this model, disabled people, when in a group of non-disabled people, are therefore more likely to view themselves as a disabled group than when they are only with disabled people. When only with disabled people, according to meta-contrast, disabled people should self-categorise on other traits, which may include impairment, amongst other things such as race, gender, sexual orientation, class, and educational background. Shakespeare (1996b) warns of the danger of viewing disability as the 'sole and significant identity' (p. 110), preferring the notion of simultaneous oppression, with each group being viewed uniquely rather than additively.

Davis (2002) adds to this debate by arguing that the unifying theory of the social model of disability is now moving to a second phase (as did race and gender) whereby the group no longer seeks group solidarity, but feels confident in 'finding diversity within the group' (p. 11). Within the field of disability studies, Davis contends, different impairment groups are recognising that they have little in common with other impairment groups. Although there are common experiences linked to impairment and disability, other facets of identity make their experiences and, therefore, perspectives unique (p. 903).

2.4.4 Agendas

Consider the 'through the looking glass' issues of agenda in relation to the *disabled* researcher. It is first necessary to acknowledge the basic desire for a person to obtain or maintain a positive self-concept (ego-defence). Meeres and Grant (1999) note that this may occur via the process of differentiation, whereby an individual portrays his or her own group (the in-group) as superior to a relevant other group (the out-group). This could, in part, help to explain the possibility that a hierarchy of impairments exists between other disabled people, whereby some sub-groups of disabled people, based upon their impairments, view other sub-groups as 'inferior', or even 'superior' (Deal, 2003: p. 903). Deal (2003) suggests that ownership of a disability identity may be stimulated by two main motivators: first, pride in identifying as a member of a minority group in a manner similar to other oppressed groups; and, second, 'to restrict the number of competing groups for limited financial resources' (Deal, 2003: p. 903). If each impairment group regards other impairment groups as out-group members, then Fiske and Ruscher's (1993) assertion that out-group members hinder in-group goals also needs to be considered. Fiske and Ruscher (1993) hypothesise that out-group members will be assumed by in-group members to either passively or actively hinder long-term goals or short-term daily functioning. Putting this into a disability context, persons with certain impairments may thus view people, for instance those with ID, as blocking their goals by competing for the same resources (Deal, 2003: p. 904). In this scenario, the more articulate disabled individuals are advantaged as they can express their views and advocate for themselves.

Hence, individuals distance themselves from the 'out-group' others, effectively placing each distinct 'out-group' into a hierarchy of acceptance in relation to the 'in-group'. Dovidio et al. (2000) note, in relation to the concept of stigma, that the process of stigmatising others can produce an enhancement of the stigmatiser's own self-esteem through a 'downward-comparison' process (Deal, 2003: p. 904). Thus, a member of a stigmatised group (such as a person with a particular impairment) may find that by comparing themselves to others perceived to be less 'fortunate' than themselves (for instance, a person with a different impairment), their self-esteem is enhanced. Finkelstein (1993) adds that disabled people may falsely believe that by distancing themselves from other groups (viewed as lower in the hierarchy), the individual or subgroup can 'consider themselves as only a variation in the pattern of normality while the others, lower down the scale, can be regarded as '*really* disabled' (Finkelstein, 1993: p.13. My emphasis).

Deal (2003) states that it is vital that disabled people consider their own beliefs towards other impairment groups, to ensure that prejudice and discrimination do not hinder the progress of the disability movement in seeking its goal of true social inclusion for all citizens. The importance of such a warning is highlighted by Wolbring (2001) in his discussion of eugenics when he argues:

> Deaf people, blind people and dwarves may denounce eugenic practices for their own impairment characteristics but not for others. In resisting the tide of eugenic practices, it is tempting for different groups to see their only salvation in distancing themselves from others.
>
> (Wolbring, 2001: p. 46).

Hence, those ranked lowest in the hierarchy become even more vulnerable to the vagaries of social policy without the support of those who should be their comrades and defenders (Deal, 2003: p. 907). Thus, Deal (2003) suggests that disabled people (such as himself), and I would include Branfield and Davis at this juncture, need to acknowledge their own prejudices before they can truly demand a wholly inclusive society.

2.5 Theory of action

Traditional social relations of research have cast the researcher as the holder of specialised knowledge and skills who decides on research topics and controls the research project (Oliver, 1992). It is suggested that both qualitative and quantitative research is frequently carried out by powerful experts on powerless subjects (Oliver, 1992; Felske, 1994; Ward & Flynn, 1994). While an interpretive paradigm has tried to look at the meanings for people with disabilities, it is suggested the resultant research has had little effect on quality of life (Oliver, 1992). Oliver suggests that one reason for this is that having made an exposé, researchers move on without altering things for their subjects. There is a strong perception that while research may have improved the career and status of the researcher, it has not contributed to improving the lot of disabled people (Oliver, 1990, 1993, 1999; Stone & Priestley, 1996). Oliver

(1992) explained that such research was viewed by disabled people 'as a violation of their experience, as irrelevant to their needs and as failing to improve their material circumstances or quality of life' (Oliver, 1992: p. 105).

Such criticism is fundamentally a challenge to the non-disabled researcher's agenda and integrity. However, the disabled person's accusations and assumptions towards non-disabled researchers may be a superficial comment of the 'simple component' (MacIntyre, 1993) of the non-disabled researcher's perceived aims and gains. MacIntyre suggests there is no such thing as 'behavior independent of intentions, beliefs and settings' (p. 208). As non-disabled researchers are openly criticised for their motivation, it is appropriate to scrutinise some of our most taken-for-granted insights about human actions.

2.6 The representation of others

If 'academics and researchers can only be with the oppressors or with the oppressed' (Barnes, 1996a: p. 110), it is unclear how to differentiate between them. Barnes and Mercer (1997b: p. 6), suggest that "For some (non-disabled researchers), their lack of personal experience of disabling barriers means that their contribution lacks authenticity; for others, disabled and non-disabled researchers live in a disablist society and both can contribute to disability theory and research." This is probably true, but it still leaves the non-disabled researcher located between 'both ally and enemy camps' (Humphrey, 2000: p. 75).

There can be no doubt that disabled people have rights to represent themselves, especially as they suggest they are often misrepresented by non-disabled people

(Morris, 1991; Barnes, 1996b). There can also be no doubt that self-organised groups of disabled people and service-users are often marginalized in all kinds of research projects (Oliver, 1997). Even when disabled people acquire the academic credentials for researching in disability studies and elsewhere, their employment prospects will be limited, and neither funding nor employing organisations have usually thought through the resource implications of assisting someone with physical or sensory impairments to undertake fieldwork in terms of travelling, interviewing, transcribing, etc. (Oliver & Barnes, 1997a).

In spite of all of this, the reasoning behind the claim that non-disabled researchers have no right to represent disabled people is flawed. Humphrey (2000) suggests there is a danger that activists conflate political and intellectual representations – for example, an accurate theoretical representation of the participants' narratives in this study is not *also* seeking to 'represent' any group in any political, or any other, way. Indeed, some disabled people have insisted upon retaining a distinction between their roles as activists and academics in the service of integrity and independence (Shakespeare, 1996b). There is also a danger of demarcating sameness from 'otherness' in such a way that everyone is misrepresented. For example, obviously ID people are simply not the same as (any) other disabled people, nor their barriers, and indeed otherness-qua-uniqueness is written into their personalities and biographies (Humphrey, 2000). Even if a researcher experiences the same impairment as his or her research subjects, he or she would need to be attuned to the 'otherness' of the other, and any presumptions of sameness in experiences may challenge the validity of the research (Kitzinger & Wilkinson, 1996). Additionally, the essentialist paradigm, which insists upon the ethical and epistemological superiority of like-researching-like, is being criticised, as the deployment of researchers with different identities will open up more possibilities for understanding (Humphrey, 2000: p. 79).

2.7 The pleasure principle

Despite hostility from some disabled authors, the role of the non-disabled researcher, who empathises with people with ID and uses his or her academic position to tell people's stories to the outside world, often in psychology-based journals, argues for improved services (Chappell, 1998; Goodley & Moore, 2000).

There is a perception in disability literature that there is a *disabled* experience and there is a polar opposite *non-disabled* experience. What I have set about to do is twofold: firstly to peel away the layers of disability rhetoric to expose the core realities of vulnerability, affliction and dependence of both groups, and secondly to expose the heterogeneous reality of impairment. In doing so, I do not fail to recognise the opportunities for participatory research in which people with ID could themselves be involved in the research processes – particularly the work in oral history approaches (Chappell, 2000). However, there are a number of studies such as those of Tregaskis (2000), Atkinson (1988) and Stalker (1998) who distract criticism by adopting participatory approaches, with lip-service regard to consent, which leaves me uncomfortable with how such methods are employed. While I cast no doubt upon Tregaskis' claim that researcher and researched 'enjoy each other's company (p. 10)', I remain rather concerned about such an approach, as the fostering or nurturing of cosmetic friendships may be exploitative. Stalker herself (1998) later warns of the dangers of 'parachuting in and out of people's lives' (Stalker, 1998: p. 17), which we do, however well intended.

Disappointingly, some disabled academics accuse their non-disabled peers of being 'professional disability parasites' who are perhaps 'in it for the money or the power over others – albeit disguised as benevolence' (Davis, 1993: p. 199). Oliver (1996: p. 196) suggests that non-disabled researchers are less likely to be 'committed' to the movement and more prone to 'distortions'. Such reprehensible views appear ignorant of any ethical or moral inference or thinking, and perhaps illustrate the root of the problem.

The work that has been done on virtue theory and virtue ethics has opened up many new areas of debate in modern moral philosophy (Crisp, 1996). One reason for this is the fact that virtues are primarily qualities of *persons* and not *acts,* and this is an important point. It might be more helpful to follow Connolley's (1996) argument that what matters is not so much 'who' is doing the research in terms of their ascribed characteristics, but rather 'who' they are in terms of their own integrity, 'what' kind of research they are undertaking in terms of their epistemological and methodological orientations, and 'why' they are doing it in terms of their biographical and political profiles.

If the chief pleasure I gain out of being morally virtuous comes from me *thinking* I am, then I might be better off not actually *being* morally virtuous but merely *believing* falsely that I am, or deceiving someone into thinking I am – because actually being morally virtuous can carry considerable costs (Hooker, 1996). However, the potential for the recommendations of this thesis having influence to bring about change is more difficult to classify as being either egotistic or hedonistic.

To conclude this section, I relate to Shakespeare's (1997) description of himself as being a pluralist (tolerant to a variety of groups in society), following his own intellectual and ethical standards rather than conforming to an orthodoxy to tackle the myriad 'dilemmas and compromises' (Kellett & Nind, 2001: p. 51) of disability studies.

2.8 Philosophy

2.8.1 Initial engagement with the research

There exists, within each researcher, a problem or question. The starting point for my research was the task of initial engagement: one of discovering an area of intense interest, a passionate concern, which holds important social meaning and personally compelling implications for the researcher (Moustakas, 1990).

For a study to successfully address or generate its research questions, it must be firmly grounded within a methodological approach (Allen et al., 1986). A strong rationale existed for choosing a qualitative approach for a number of reasons. First, a qualitative study needed to be congruent with my research question (Wimpenny & Gass, 2000); an initial foray into the exploration of a 'lived experience' enables such a phenomenon to be described through narration. This is in contrast to the traditional quantitative research methodologies, which are questionable as adequate approaches for the study of human life experiences (Van der Zalm & Bergum, 2000). Secondly, as the research included subjects that were extremely emotive for me on a personal level, I wanted to use a literary style that brought myself into the study by the use of the personal pronoun or the storytelling form of narration (Cresswell, 1998) which is better situated within a qualitative methodology.

2.8.2 Adopting a paradigm

The adoption of a naturalistic paradigm, which is expounded by qualitative research, rests on a particular set of assumptions about the appropriate study of social life (Guba & Lincoln, 1982). Firstly, what is considered to be 'knowledge', 'truth' or 'reality' is seen as dynamic, subjective and multi-faceted – a difficult concept for the qualitative researcher to define (Dyer, 2000). Indeed, there is no static explanation of phenomena in the naturalist paradigm. Reality is seen as being socially constructed (Guba & Lincoln, 1982) and the role of the researcher in the generation and representation of knowledge is not so much one of explaining and predicting social events, as one of understanding what meanings and significances the social world has for the people who live in it (Gilbert, 1986). The naturalist stance, therefore, is committed to seeing the world from the perspective of its participants, which is termed the emic perspective, as distinct from, and opposed to, the etic perspective of the imposition of an external frame of reference (Silverman, 1995: p. 24). Thus naturalistic enquiry uses descriptive and narrative data to understand the participants' viewpoint.

2.8.3 A 'notorious tradition'

In the 1990s, there were a number of salient and sometimes damning critiques of how phenomenological research methods (PRM) had been handled (see Crotty, 1995, 1996b; Paley, 1997, 1998). These critiques demanded greater rigour, both in the interpretation of the methodology and in the selection of methods to complete the research. Subsequently, new researchers have frequently been placed in an extraordinary indeterminate position. First, they must be sure that the studies by which they clarify their approach are judiciously informed by the philosophy that is held to guide them. They must then search for hints about how they might proceed, but this must be done amongst studies that have equally judiciously employed the particular philosophical approach they have chosen to pursue (Caelli, 2001).

In Sadala and Adorno's (2001) opinion, most phenomenologists neither define nor clearly describe their research method. Spiegelberg (1984: p. 1) chronicles the philosophical development of phenomenology and contends that
"The difficulties of stating point-blank what phenomenology is are almost notorious". Instead, ways to carry out phenomenological research can be found 'scattered amongst several authors' work' (Sadala & Adorno, 2001: p. 284). Caelli (2001) illustrates some of the problems faced by researchers when they attempt to engage with phenomenology for the first time. She suggests that problems still occur despite the guidance that is provided by phenomenological researchers such as van Manen (1990), Bergum (1991), Lynch-Sauer (1985) and others; an array of methods described by Field and Morse (1985); and discussions of various processes by phenomenological methodologists such as Crotty (1996b).

As with other qualitative research, the method that is chosen must be defensible from the philosophical positions that guide the study. However, "The lack of articulated methods for achieving phenomenological research, together with the even greater challenge of understanding the philosophical research, represent perhaps the two greatest challenges faced by the researcher wishing to follow the phenomenological path" (Caelli, 2001: p. 276). In recent years, several writers have added to the information contained in the foundational texts of phenomenology to try to assist new researchers in gaining the requisite knowledge about methodology to undertake phenomenological research (Benner, 1994; Crotty, 1996a, 1996b; Paley, 1997). However, there are surprisingly few sources of information that address the utilitarian aspects of how to actually carry out a phenomenological study. This lack of discussion about methods may leave new researchers floundering with regard to how a project might actually be achieved. It would seem that in attempting to be true to its philosophical beginnings, phenomenological researchers have been too reticent about how the research may be implemented (Caelli, 2001). As a result, outside of phenomenological dissertations, which are difficult to access in many cases (and may or may not be helpful), there is a surprising lack of description of the techniques used to facilitate the research process.

Despite these problems, phenomenological research has been adopted and deployed with varying degrees of enthusiasm by different academic disciplines (Dyer, 2000). However, the picture in respect of phenomenological research in areas such as education is not so healthy. Why this should be so is puzzling, especially since Moustakas (1994) has written of the application of PRM as ideal for exploring the nature and processes of learning. Moustakas (1994) argues that it may be that educational researchers, as pragmatists with an agenda for voice and publication, seek utility and application which PRM do not, per se, offer. For educational researchers to adopt PRM would require a long journey from qualitative research through humanistic psychology, with a distinct focus on the self, identity and development: a journey few would wish to seek or undertake (Dyer, 2000). I refer to Knafl (1994) to summarise this tradition with his assertion that 'this is tough stuff, very abstract, and very conceptual' (p. 134), and suggest that in recent years, the acknowledged difficulties appear to have grown rather than diminished.

2.8.4 The problems with phenomenology

Although there is no consistent definition of phenomenology, phenomenological research can be distinguished from other qualitative methods in that the phenomenological researcher aims to describe and/or understand the meaning of the participants' lived experiences (Omery, 1983; Cresswell, 1998). According to Koch (1995) it is imperative at the outset to contextualise phenomenological research with the different philosophical traditions that inform its methods. Martin Heidegger (1889–1976) developed a unique kind of phenomenological method of inquiry (Streubert & Carpenter, 1994; Walters, 1995). Since Heidegger was greatly influenced by Husserl (1859–1938), there are aspects of their philosophies that are inevitably shared. However, because Heidegger deviated from Husserl on several important points, there are aspects of their philosophies that are very distinct in important ways (Sheehan, 1998), particularly in relation to this study. These two 'schools' of phenomenology are interpretive (existential) and descriptive (transcendental). It is outside the scope and remit of this study to compare and contrast these philosophies in any great depth. However, references to Husserlian phenomenology are included to illustrate the key areas of dichotomy.

2.8.5 Origin of meaning, temporality, and being-in-the-world

Heidegger reminds the researcher that *meaning* is always in the context of something: one's humanity, one's culture, one's personal situation or the practices adopted by a particular group (Rescher, 1996), and meaning arises not from consciousness but from the essential finitude of being human. Therefore, if one assumes that as the methods the researcher uses are driven by the methodology, the stance the researcher takes in relation to the interview (i.e. the kinds of questions the researcher asks the participants and what the researcher listens for in the interview and how the researcher interprets the text of the interview) will vary depending on the philosophical underpinnings (Johnson, 2000).

For Heidegger, the standpoint of humans is to always be involved in the practical world of experience. Therefore, the world of human beings can never be a presuppositionless world wherein one's consciousness confers meaning on the objects one encounters. The world of human beings is always one of practical involvement where things take on meaning in relation to one's purposes (Nenon, 1997). More specifically, meaning emerges because of the unitary relation between human beings and other objects, which is possible only because of the unique structure of being human. Heidegger calls this structure *temporality,* and the way humans have of relating to others in the world *being-in-the-world.* Thus being-in is not a spatial relation, but rather indicates the way that human beings relate to other entities (both human and non-human) in a familiar world of involvement. Therefore, the things humans encounter in the world do not simply exist 'out there' in a detached manner, waiting to be investigated. They are all part of an *interconnected* world of human investment and interest (Johnson, 2000).

First, being-in-the-world, as temporality, reminds us that our lives are unified and connected within the whole of our significances and involvements. Because human involvement is the clearing that makes all meaning possible, the participants' experiences and the meaning of these experiences cannot be separated from the whole of that person's world. Therefore, a single experience is inseparable from its context of involvements. Moreover, the meaning of any experience is not presented to the researcher as a decontextualised entity that can be investigated and understood as an isolated object. Rather, both the experience and the meaning of that experience are embedded within a contextualised whole (Johnson, 2000).

Second, being-in-the-world, as temporality, reminds us that all of our experiences and understandings are related to a larger context of involvement. Although the culture and traditions we have inherited may remain implicit, we are embedded in and formed by these cultures and traditions. Thus, an understanding of the participant's experiences and/or practices cannot be separated from that person's culture, history and tradition (Johnson, 2000).

Third, and finally, being-in-the-world, as temporality, reminds us that all meaning and discovery are fraught with finitude. Although questions open up possibilities of meaning, questions also limit the boundaries of what is going to be talked about (Gadamer, 1989: p. 363). In other words, by virtue of asking one question one does not ask another question. Likewise, questions take the researcher in a particular direction. Therefore, the risk during both the interview and the analysis of the text is that the researcher will ask questions that are too leading or too narrow in focus, thus limiting the boundaries of what is being explored, and/or the researcher will impose his or her perspective, theoretical or otherwise, onto the interview and onto the text. Thus hermeneutical phenomenology (also known as hermeneutic phenomenology and interpretive phenomenology) reminds the researcher that *hiddenness* is intrinsic to this disclosure process (Nenon, 1997). In all aspects of research, there is inevitable hiddenness and incompleteness. Therefore, although the participant's meanings are coming out into the open, these meanings will never be completely revealed and the participants will never be completely understood. There will always be a part of the participant's world that remains hidden and concealed. Although the distance between the participants and the researcher narrows, that distance will never completely close. Neither the participants nor their experiences can be understood in their entirety. Therefore, being-in-the-world, as temporality, reminds the researcher that in addition to noticing what is coming into the open, he or she must notice what is not spoken, what is not revealed (Johnson, 2000).

For Heidegger, human understanding and our involvement in the world of significance is not a barrier that stands between the knower and the known. Nor is the 'the process of interpretive understanding...a process in which the thing is hidden from us' (Carr, 1987: p. 182). Rather, interpretive understanding is how the thing is revealed (Carr, 1987). Thus interpretive phenomenology is not an action taken only in relation to the text of an interview, because being-in-the-world reminds us that we are already interpreting our experiences; each step of the research process is interpretive.

Heidegger gives the phenomenological researcher a different understanding of how a human being is structured and of the origin of meaning than that provided by

Husserl's philosophy. Because humans are first and foremost temporal beings, they are also embedded in historical-cultural contexts and traditions that are shared with others in the community. Charles Taylor (1995) calls this historical understanding *background*, and credits both Heidegger (1962) and Wittgenstein (1968) with attempting to return to an understanding of the person as engaged in a cultural world of involvements and concerns (p. 62). Thus, the basic thesis of hermeneutic phenomenology is that all understanding, phenomenological and natural science, is interpretive (Kockelmans, 1997: p. 477). In other words, "our large scale research programs and theories are all very sophisticated interpretations of natural phenomena that rest on a limited number of assumptions, the validity of which cannot be justified on the basis of empirical grounds alone" (Kockelmans, 1997: p. 477).

2.9 Gadamerian Hermeneutics

It is hermeneutics, in this Heideggerian and phenomenological sense, that is taken up in Hans Georg Gadamer's work, and that leads him, in conjunction with certain other insights from Heidegger's thinking, to elaborate a philosophical hermeneutics that provides an account of the nature of understanding in its universality and, in the process, to develop a response to the earlier hermeneutic tradition's preoccupation with the problem of interpretive method (Malpas, 2003). In these respects, Gadamer's work, in conjunction with that of Heidegger, represents a radical reworking of the idea of hermeneutics that constitutes a break with the preceding hermeneutical tradition, and yet also reflects back on that tradition. Gadamer thus develops a philosophical hermeneutics that provides an account of the proper ground for understanding, while nevertheless rejecting the attempt, whether in relation to the human sciences or elsewhere, to found understanding on any method or set of rules.

Although Gadamer (1975) emphasised the continuities between his own work and that of Heidegger, he argues that Heidegger's attempts, in his later thinking, to find a 'non-metaphysical' path of thought led Heidegger into a situation in which he experienced a lack of (or need for) language. Gadamer's own work can thus be seen as an attempt to take up the path of Heidegger's later thought in a way that does not abandon, but rather attempts to work with our existing language. Gadamer recognised that language, understanding and interpretation are inextricably bound. Building on the notion that all understanding is hermeneutic, the focus is on the way of being in the social historical world, where the fundamental dimension of human consciousness is historical and socio-cultural and is expressed through language. Gadamer's text 'Truth and Method' (1975) identified the necessity of historical consciousness within hermeneutics. Gadamer asserted that understanding was always a historical, dialectical, and linguistic event. This understanding occurs from interpretations embedded within our linguistic and cultural traditions (Annells, 1996; Pascoe, 1996). Hermeneutics pertains to the process of exposing hidden meanings (Allen, 1995; Jones, 1998) embedded in the words of narratives (Maggs-Rapport, 2001), and is therefore an artful form of understanding (Wiehl, 1990).

Gadamer therefore places language at the core of understanding. Conversation assumes mutuality of question and answer (Gadamer, 1976; Wright, 1990). Gadamer proposed that through conversation with the text, or with one another, an event of understanding would occur that could not be predicted nor controlled.

2.10 Epoche (bracketing)

I now turn my attention to a key area of conflict between Gadamerian/Heideggerian and Husserlian philosophies: the concept of 'epoche' or 'bracketing'. However, before considering the distinctive features that justify a Heideggerian/Gadamerian approach, it is important to first clarify some of the confusion around the concept of epoche within current literature. Many researchers recognise that the pivotal move in Husserl's phenomenology is what he refers to as the phenomenological reduction, a procedure that is associated with the metaphor of 'bracketing'. Koch's (1995) account of this is an accurate one, in which he describes how Husserl insisted on an initial 'suspension of belief' in the 'outer world', either as it is naively seen by an individual in everyday life, or as it was interpreted by philosophers or scientists. The 'reality' of this world is neither confirmed nor denied; rather, it is 'bracketed' in an act of phenomenological reduction. It is worth pausing to assimilate the radical nature of this suggestion. In performing the reduction, *all* judgements about the external world must be suspended. Husserl's epoche (an alternative name for phenomenological reduction) is a philosophical device to put on hold assumptions that are normally made with the 'natural attitude', the habits of the mind that are characteristic of everyday understanding of the 'outer world' (Paley, 1997: p. 188).

However, what many researchers say about bracketing is very different from Husserl's epoche. For example, Baker et al. (1992) say only the preconceptions about a phenomenon *being investigated* are 'bracketed' by being identified and put aside. Elsewhere, it is claimed that bracketing involves the deliberate examination by researchers of their *own beliefs about the phenomenon* and the temporary suspension of them (Jasper, 1994). Cohen and Omery (1994) suggests that reduction is the *process of looking at the experience* naively, without preconceptions, prejudices and biases. Although these examples describe techniques that are no doubt valuable, it would seem that they make an incorrect use of Husserl's terminology (Paley, 1997). It may even be legitimate to label these techniques as 'bracketing', but it is clear that these procedures are not the same as phenomenological reduction, and when Husserl refers to 'bracketing', he has a different sort of operation in mind.

Gadamer did not agree with the putting aside of presuppositions as prescribed in Husserlian phenomenology. He claimed that in order to understand or interpret a phenomenon, the interpreter must both overcome the phenomenon's strangeness and transform it into something familiar. By doing so, the interpreter is able to unite his/her own horizon of understanding with that of the historical phenomenon. For Gadamer, prejudice not only gives the hermeneutic problem its real thrust, it is the only means by which the truth about a phenomenon is established (Gadamer, 1975). Thus the relationship between truth and prejudice is a positive one, and of integral importance to understanding.

Therefore prejudice, as defined by Gadamer (1976), was simply prejudgement. Prejudices are our preconceived notions of things, emanating from our past experience and socialisation. In the positivist/empirical and Husserlian views of truth, the way to eradicate prejudice was to maintain objectivity by 'bracketing' experiences. However, Heidegger and Gadamer did not believe this to be possible. To understand another we cannot shed our past experience, because it is this past experience that actually facilitates understanding another. Gadamer advocated continual striving to explicate our prejudices. The philosophers Grondin (1990) and Maguire (1991), in their writings on Gadamer, identified the importance of understanding our prejudices. Grondin stated:

> For whoever pronounces himself or herself free of prejudices is all the more blindly exposed to their power. Prejudices will exercise their underground domination all the more strongly, and potentially distortingly, when denied or repressed.
>
> (Grondin, 1990: p. 54)

Maguire (1991) adds:

> To be engaged in a conversation with a text is to bring one's prejudices into play. On the basis of one's prejudices one is able to understand the content of what the text says. The reader is engaged from a definite point of view and is only able to understand the content of the text from this perspective. The very fact that we question the text suggests that we are trying to transcend our own prejudices.
>
> (MaGuire, 1991: p. 40)

Therefore, I did not enter the research process with a blank slate. All interpretations and understandings – including the research questions, the interview and analysis of the text of the interview – were grounded in fore-having, fore-sight and fore-conception (Gadamer, 1989; Heidegger, 1962). Thus the researcher cannot completely separate from or set aside (bracket) his or her culture, tradition or point of view.

Johnson (2000) supports the notion that there can be no presuppositionless state from which we can approach the research process. Moreover, to think that there *is* such a presuppositionless state 'ignores the contextualised nature of human understanding' (Pollio et al., 1997: p. 47).

2.11 Practical phenomenology

Professional practitioners tend to be less interested in the philosophy of phenomenological method than its practice and application (Malpas, 2003). Therefore, when exploring the nature of phenomenological research, it is helpful to make an immediate distinction between phenomenological research performed by professional philosophers, and phenomenological research conducted by professional practitioners. The interest of the professional philosopher tends to lie with philosophical topics, themes, and issues emanating from the study of historical developments of philosophical systems. In contrast, professional practitioners tend to work within the applied domains of the human sciences such as education (Malpas, 2003).

Phenomenology illuminates the various ranges of human experiences that are possible, the context of these experiences, and how these experiences may be described (Spiegelberg, 1984; Burch, 1989; Hammond et al., 1991). Through language, the phenomenological text has power to disclose the world 'as we live in it'. The results of phenomenological inquiry are descriptive in nature, depicting multiple possible experiences. All phenomenological descriptions can be challenged by another phenomenological description, as the complex life-world does not always remain static, and so alternate descriptions may always exist, nor are sacrosanct (Paley, 1998). As a result, a full explanation of the world is not possible (Anderson, 1991) nor is it possible to obtain causal certainty and inference, or the production of law-like statements (Koch, 1995; van Manen 1997a).

Observation from a 'seasoned' (Yegdich, 1999: p. 30) Husserlian researcher, Jones-Porter, reveal that applied researchers, including herself, have tended to rely on methods, rather than on 'gleaning philosophic sources as methodologic guides' (Jones-Porter, 1998: p. 17). This may reflect a more pragmatic, or 'rolled-up shirtsleeve' approach to using phenomenology. However, by offering depth and breadth for my own philosophical rationale for this study, I intended to avoid the accusation that 'practical' phenomenology excused itself from its philosophical roots completely, resulting in 'having done phenomenology without knowing phenomenology', an accusation levelled by researchers such as Jones-Porter (1998: p. 18), and thereby simply adding to the confused landscape of phenomenological literature and discourse.

2.12 Autobiographical meaning

Moustakes (1990, 1994) has indicated that the discovery of a research topic and question is rooted in autobiographical meanings and values. Barrell (1986), therefore, proposes the starting point for research to be via a process of engagement with the self to describe personal experiences. It was this thinking that prompted a self-analysis of my own motivations, thoughts and feelings towards the study, which are briefly summarised in this section. This autobiographical narrative, or reflexive investigation, serves a dual purpose: to inform both the reader, and the self, as to why I may be asking a particular research question.

In 1987, my daughter was born with an ID. The search for a specific diagnosis to explicate the causation of her disability was an emotive and difficult time as she underwent various investigations, which included blood tests, Computerised Tomography (CT), and Magnetic Resonance Imaging (MRI) scans. Her mother and myself were also blood tested for any genetic causation, although none was found. As a parent of a child with an ID, her birth was monumental and entitled me automatic assumption of minority group status (Marshak et al., 1993), forcing me to confront my own beliefs and prejudices about disability.

This process was reawakened in 2000, when, during my own (Husserlian-informed) phenomenological research into maternal responses to the diagnosis of ID in children, I recognised within myself behaviour consistent with 'complicated grieving' (Herbert, 1996), in which the person exhibits emotions such as anger, blame and guilt (Hall & Hill, 1996; Partington, 2002), and despite recognising that there was no logical reason for feeling this way, this knowledge did not stop the experience (Kroon, 1998). Clore (1994) suggests that emotion and cognition are intertwined. Emotions have a biological component but are essentially part of a larger information processing system (Clore, 1994) and the endpoint of a cognitive appraisal (Carter, 2000: p. 6). This appraisal related to my daughter's prognosis in relation to health problems, especially as I was forced to confront issues relating to life expectancy. In relation to the 'right to life' debate I am not entrenched in either camp but agree with the concept of informed choice.

I reflected upon the world that had opened up to me as a result of my daughter's disability. The issue of my own spiritual beliefs was, of course, a significant factor in how I approached the subject of mortality and immortality. The analogy of looking at a window and choosing to gaze either at my reflection in the pane (my daughter's mortality?), or at the world outside (my own mortality?), as described in Jones' (1998) phenomenological study captures the scenario well.

If my research really does represent a 'desire to inform' the self, this motivation resides in my subconscious. My childhood Catholicism has been eroded by the rational logic of science more than any emotional incident, and I find myself within the 15.5 per cent of the UK population who claim to be non-religious (2001 Census). I would describe myself as agnostic: perhaps the ideal perspective for a study of this kind? After all, neither theologians, whose literary domain I have wandered into, nor atheists are likely to saw away at the branches they sit on.

Chanfrault-Duchet (1991) suggests that, whether implicitly or explicitly, a narrative explicates events into a social framework. This prompts me to reflect upon my humanistic beliefs, which I consider as being philosophical, political and social in nature. In my own modest 'autobiography' presented here, such a cultural context is apparent. Erben (2000: p. 383) suggests, 'Lives are lived through time but made intelligible through narrative'.

[1] The social model germinated from within the womb of the disability movement, and has been the source of the movement's consolidation and legitimisation. If the model is predicated upon the disabling effects of society, then the movement is predicated

upon the self-organisation of disabled people in combating this disabling society; since society has been arranged by and for non-disabled people, they are consigned to the 'enemy camp' (Humphrey, 2000: p. 70).

Chapter 3 Research design (methodology)

3.1 Communication and interaction.

The study was guided by the phenomenological method outlined in Pollio et al. (1997) and Thompson et al. (1989). This involved the various steps of:

i. Interviewing participants (participants as focus)
ii. Interview transcriptions (hermeneutic analysis: text as focus)
iii. Reading transcription for sense of whole/Reading for meaning units
iv. Clustering initial thematic meaning
v. Developing thematic structure

The UN Convention on the Rights of the Child acknowledges the right of children to express opinions about issues affecting them and the right to have these views heard (Davis, 1998). Further to this, Article 2 states, 'all rights on the Convention must apply without discrimination of any kind irrespective of...disability....' (Lewis & Lindsay, 2000: p. 26). In recent years there has been a growing body of literature that identifies the importance of including children as participants in research (Garth & Aroni, 2003). Despite there being very few studies that explore the perceptions of children with severe ID or communication difficulties (Mitchell & Sloper, 2001), researchers from the UK in particular have led the way with a number of informative studies (Garth & Aroni, 2003).

However, it has been suggested that research that includes children with disabilities as informants is perceived as being time consuming and labour intensive (Minkes et al., 1994; Case, 2001) and access to children may be seen as difficult. While it is hard to disagree with these perceptions, I shared Garth and Aroni's (2003) view that to exclude disabled children from being participants in research simply because it is 'too difficult' is questionable; such a view implies that disabled children are less important or worthy of our time and energy. If this stance continues to be adopted by researchers, those members of the community with ID will remain on the fringes of society.

My starting point was to consider my interviews as 'conversation with a purpose' (Kahn & Cannell, 1957: p. 149). Vygotsky (1962) suggests that the interrelation of thought and language is one of the most complex problems in psychology. Theories group themselves around two poles – either the behaviourist concept of thought as speech without sound, or the idealistic concept that thought can be 'pure', unrelated to language, and that it is distorted by words (Vygotsky, 1962: p. 152). As Vygotsky (1962: p. 158) suggests, "A word devoid of thought is a dead thing, and a thought unembodied in words remains a shadow."

Kellet and Nind (2001) explore the ethical issues of research involving individuals who are preverbal and those with ID. They suggest that such individuals may be left outside research efforts because they are perceived as being too difficult to include. This may well relate to the potentially rich but untapped data within Vygotsky's 'shadows'. It has been assumed in the past that difficulties experienced in communicating with people with a severe ID are largely the consequence of the disabled person's 'lack of skills' (Shaddock et al., 2000: p. 383). A range of factors appears to be involved in the attention now given to the functions of communication.

Research has demonstrated that the communicative intent of the behaviour of individuals with severe disabilities can be reliably inferred (Cirrin & Rowland, 1985; Dalton & Bedrosian, 1989; McLean & Snyder-McLean, 1987; Owens & Rogerson, 1988; Siegel-Causey & Guess, 1989). Research has drawn attention to a variety of contextual influences on communication, and it is acknowledged that narrow, clinical assessments of communication may place undue emphasis on 'within-person' cognitive and motor deficits. Focusing on the social bases for communication, Calculator (1988) and Morse (1988) proposed widening the approach to communication assessment by including observations in different settings, at different times, and under different circumstances. Therefore, comprehensive assessment of communication should not only deal with cognitive, motor, and sensory factors; it should also provide broadly based information about how the person interacts (Shaddock, 2000).

Although the 'theory of pragmatics' (Shaddock et al., 2000: p. 384) has stressed that communication is a two-way, functional process, it is only recently that detailed attention has been given to the implications for communication partners. Sack and McLean (1997) recommend that communication partners need to be taught how to 'expect, recognise, and respond to communication from individuals with severe disabilities' (Sack & McLean, 1997: p. 154). Butterfield et al. (1992, 1995) illustrate how profound the impact of the behaviour of others can be on the communication performance of people with an ID, and Knop-Biklen and Moseley (1988) have suggested that useful information can be provided by caregivers and close acquaintances, that is, by those who know the person well. In their review of the literature, Balandin (1992) and Zilber (1993) cite research that supports this contention (i.e. Browder, 1987; Cottam, 1986; Schuler & Goetz, 1981; Van der Gaag, 1988).

3.2 Levels of understanding.

Communication problems are prevalent in people with ID (Bott et al., 1997), although reports vary according to the methodology and definitions employed (Bradshaw, 2001). Communication mismatches can be discussed in terms of mode and complexity, and are influenced by the interviewer's perceptions of their own and the ID person's communication skills (Purcell et al., 1999), as illustrated in my introduction to this thesis. Ware (1997) suggests that to communicate effectively, there needs to be a full recognition of a range of communication events, including reflex responses, actions, sounds made and facial expression. Other authors have reflected on the need for considerable effort to check whether or not the person with an ID has actually been correctly understood in the first place (Sigelman et al., 1981; Simons et al., 1989).

Hearing loss is also prevalent, with studies showing that 40 per cent of adults with ID experienced a hearing loss that warranted amplification (Yeats, 1992, 1995). Hearing loss therefore often remains unrecognised, and thus creates an additional barrier to communication (Yeats, 1995; Ware, 1996) and increases the potential for misunderstanding.

3.3 Language and compromise

To enable language, facial expression, body language, sign language, and gesture to be recognized in relation to the interview questions, I invited a teacher or parent as 'passive interpreter' to verify (where necessary) responses both during and after the interviews. This is deemed to be particularly important to accurately identify social and communicative intent obstructed by poor articulation, clarity of speech, 'personalised' signs (i.e. those not in the taught vocabulary), and language or behavioural traits that may otherwise be misinterpreted. Due to the sensitive nature of the topics being discussed, the third person also offered me the opportunity to be briefed immediately prior to the interview so that any 'triggers' to emotional distress were identified and damage to the person's well-being avoided. The interpreter also assisted in a very basic hearing test to ensure the participant could hear adequately.

My challenge was to reduce the barriers to effective communication by engaging in conversation with the participants at a level they could understand. The questions themselves were modified to use appropriate terminology, which was also subjected to ethical scrutiny, particularly considering their element of offering developmentally appropriate interactions, sometimes in the face of chronological age, which has been passionately debated (Nind & Hewett 1996; Smith, 1996; Samuel & Maggs, 1998). Therefore one of my responsibilities was to ensure that the participants were never patronized or made to feel inadequate by inappropriate language.

I decided to interview six participants. This was partly due to 'convenience' sampling of participants, who were difficult to contact (Wardhough, 1996), and partly due to the fact that issues of representativeness are less important in phenomenological studies. However, nine interviews in total were conducted, as three participants unfortunately failed to make any meaningful contribution. My sample size was not so much a criterion for judging the rigour of a sampling strategy, but rather for judging the extent to which issues of saturation had been explicitly thought through. I acknowledge my contradiction in applying the term 'saturation' as being used erroneously in a purist context (Davey, 1999), as phenomenological experiences are unique and therefore cannot be replicated. However, the principles of saturation can be applied, as my intention was to identify themes *via* the collective individual experiences. An appraisal was made after the final interview in relation to the need to extend or conclude the data collection process, the latter course of action being decided upon.

The interviews were semi-structured due to the nature of the participants' disability. This method enabled me the opportunity to provide the participant with some scope to expand upon an answer while restricting the likelihood of the participants 'rambling' (Bryman, 1988: p. 47) as a result of any short-term memory or concentration difficulties. The 14 questions (see Appendix iii) evolved from the literature review and were presented in a modified format. The interviews lasted between 30 and 40 minutes. This was based upon both an estimate of concentration levels and Cowles' (1988) suggestion that the time for in-depth interviews on sensitive topics should be limited because of their stressful nature. When questions evoked prolonged emotional responses, I offered to stop the interview, at least temporarily, to reduce any distress or confusion. Both the consent givers and the participants were asked before the interview if they agreed to the interviews being audio taped, if they had refused, the interviews would not have taken place. Consent givers were required to sign a consent form (see Appendix ii), which outlined the aims of the research; the areas and topics to be covered in the interviews; the way in which the interviews would be used; procedures to maintain confidentiality; individuals who could be contacted for support or counselling if the interview raised issues that participants found disturbing; an explicit offer to answer questions or provide further information; directions on whom to contact and how to contact them with questions about the study; assurances that participation in the research was entirely voluntary and that participants had the right to refuse to answer any question and to withdraw at any time; and details of who to contact in the event that they had any complaints about the conduct of the interviews. The consent form was read to the participants using terminology they understood. The participants were also reminded of some of the key elements of this form at the beginning and end of the interview as was appropriate. Consent givers were also provided with a signed statement (see Appendix iii) assuring them of confidentiality and outlining the procedures that would be taken to ensure that the participants' identities were protected, and also explaining what would happen to tapes and transcripts. While parents or teachers were invited to support the participants during the interviews, their role was only to provide assistance with language problems and clarification of any ambiguous information, and to assist me to gain greater insight into the participants' accounts (Case, 2000), as requested.

Confidentiality was further assured by material containing identifying information, letters, consent forms, audio tapes etc. being kept in a locked filing cabinet in my office at the University of Southampton. All participants were asked permission for their (anonymised) transcribed contributions (electronic files) to be retained for future reference. Otherwise, immediately after the successful completion of the Ph.D., all material will be destroyed.

3.4 Data collection and analysis.

Experience leads me to concur with Marshall and Rossman (1999: p. 150), who state that data analysis can also be a 'messy, ambiguous, time-consuming...process.' This section illustrates my proposed method of analysis and my strategy of 'creating chaos and then finding order within it' (Babbie, 2001: p. 369).

The interviews were transcribed verbatim. My method for creating themes from the transcriptions was informed by Strauss and Corbin's (1990: p. 101) definition as:

> the part of analysis that pertains specifically to the naming and categorizing of phenomena through close examination of data. During open coding the data are broken down into discrete parts, closely examined, compared for similarities and differences, and questions are asked about the phenomena as reflected in the data. Through this process, one's own and others' assumptions about phenomena are questioned or explored, leading to new discoveries.

My analysis was conducted in two stages, which encompassed the processing and quantifying of the data.

i. Influenced by Babbie (2001: p. 358), who suggests qualitative data analysis is 'as much an art as a science', the first stage of processing was undertaken electronically using the colour (highlight) palette function of

Microsoft Word XP. I manually highlighted individual statements, with each new significant statement (unit) being assigned a specific colour. Similarly to using qualitative data analysis programs, e.g. Nonnumeric Unstructured Data, Index Searching and Theorising (NUD*IST), I then imported units from the highlighted text into spreadsheets in Microsoft Excel. Although this manual method was labour intensive when compared to using qualitative analysis software, my objection to using software related to cognitive processes being turned into an activity that was to some degree 'mechanical' (Polit & Hungler, 1999: p. 579).The spreadsheets were prepared within a framework of the interview questions to aid organization of the data. The spreadsheet accommodated 14 questions (see Appendix iii) from six participants. Each column represented one participant and ranged from 1.1 to 6.14. Therefore, column 6.14 identifies participant number six (P6) being asked question number fourteen. Units were identifiable via the abbreviation and colour. All supporting extracts (quotes, or more likely individual words) from the text were cut and pasted into a second spreadsheet and retained their identifiable colour highlights.

ii. The second stage of quantifying the data was a process similar to concept mapping to explore relationships. This more graphical or visual process enabled the units to be clustered into categories to develop an overall thematic structure for the analysis. During this stage I determined the usefulness of the data in illuminating the questions being explored. I also searched for alternative credible explanations for these data and the

> linkages among them. I concur with Marshall and Rossman's (1999: p. 157) statement that "Alternative explanations *always* (authors' italics) exist...the researcher must...demonstrate how the explanation offered is the most plausible of all." Therefore, I presented my findings as 'my interpretation of the event', rather than suggesting 'the data revealed.' The final categories represented a prolonged analytical engagement with the data.

My involvement in the school during the period of the research included numerous observations of classroom activities such as story time, art, music and RE, in my capacity of School Governor.

3.5 Case studies

My research aims guided me to the obvious specific setting of the Special School. The study was defined by, and intimately linked to, this environment. While many participants with ID attend mainstream schools, this study was never intended to explore inclusion, an inevitable influence if mainstream education were the setting. Furthermore, generally, lower functioning pupils with severe ID are more likely to be located within the province of special education. Therefore, this provided me with a clearer distinction between the experience of pupils with severe ID and the experience of those pupils in mainstream education. A small Special School located in a semi-rural area between two cities in southern England was selected as a realistic (sampling frame) site for the research. The school population was 94 pupils with an age range between 2 and 19, where ninety-one pupils have Statements of Special Educational Needs. The school was designated as a school for pupils with severe intellectual disabilities, but also catered for pupils with profound and multiple intellectual difficulties and pupils on the autistic spectrum with very complex communication and behavioural difficulties. The socio-economic circumstances of the pupils were average (13.27% of pupils are eligible for free school meals), although a few experienced considerable disadvantage. There were few minority ethnic pupils and very few pupils with English as an additional language. The most recent Ofsted inspection (June 2004) commented upon the school's pastoral care as being 'high quality' and described RE as being 'good'. Pupils in years 1 to 6 (chronological ages 5–10) are introduced to RE by the 'effective use of sensory stories.' This involves tasting and smelling foods shared during religious festivals within different faiths. By Year 9 (age 13) the higher attaining pupils supposedly grasp that many Christians believe that God created the world. By Year 11 (age 15) pupils experienced the relevance of faith in peoples' lives. This was supported by visits from the Salvation Army and Franciscan monks. The Ofsted report comments on 'Candle Time', a weekly period of time set aside for pupils to reflect upon the happenings in the day, as a useful forum for spiritual development.

A purposive sample is one that is selected by the researcher subjectively and linked to the research aims. The participants were selected from the latter stages of their compulsory education, or recent graduates of compulsory education, attending a Further Education unit within the School's domain, and therefore representative of the 'end product' of formal RE. My criteria for selection included (i) the participants being classified as having severe ID; (ii) the participants being aged between 13 and 19 (based upon the Ofsted evaluation of understanding of Creationism/Intelligent Design); (iii) the participants being willing to share their experiences; and (iv) the participants possessing the ability to articulate their thoughts and feelings. This information was obtained via the 'Invitation to Participate' letter (based upon the conversational style of core and additional elements proposed by Jester (1998)) and subsequent discussion with teaching staff and parents. My protocol was as follows:

i. Approaching a member of the teaching staff for an informal discussion on the feasibility and administration of the study.

ii. Approaching the Head to gain permission for the pupils to be contacted via their parents/guardians, inviting participation on the research.

iii. 'Invitation to Participate' (see Appendix i) letters being distributed to all teachers of classes that contained potential participants – although not necessarily based upon chronological age. This envelope contained a return slip and stamped addressed envelope, which was returned to my home address.

iv. Selection of research participants and contacting parents and school to arrange interviews.

v. As initial response was insufficient (i.e. <3 per cent), I arranged to contact recent school leavers via the Head.

3.6 Issues of rigour

This study is robustly designed to respond to 'canons of enquiry – criteria against which the trustworthiness of the project can be evaluated' (Marshall & Rossman, 1999: p. 191). Marshall and Rossman propose four constructs that reflect the assumptions of the qualitative paradigm. The first is 'credibility' (internal validity), in which the goal is to demonstrate that the research aims were accurately identified and described. It is my belief that the study's credibility may be challenged from three particular perspectives: (i) my personal connections with the topic, (ii) my (perceived) non-disabled bias, and (iii) the negative perception of the ability of severely ID people to both hold a belief and articulate it, therefore undermining the 'truth value' of the study (Lincoln & Guba, 1985: p. 290). Firstly, my own autobiographical reflections are illustrated in 2.12 *Autobiographical meaning*. This should be considered alongside my analysis on the concept of bracketing in 2.10 *Epoche (bracketing).* Secondly, my response to the issue of the non-disabled researcher working in the field of disability studies is presented in 2.3 *Vulnerability, dependence, and the human condition*, 2.4 *Deconstructing disability*, 2.5 *Theory of action*, 2.6 *The representation of others*, and 2.7 *The pleasure principle.* Finally, issues relating to the participants' ability to think and articulate are considered in 6.3.2 *Theory of mind.* My credibility is further enhanced by my immersion in, prolonged engagement with, and articulation of, my chosen methods of data collection and analysis as described in this chapter.

The second construct Lincoln and Guba propose is 'transferability' (external validity). Transferability is used to judge the extent to which the findings can be applied to other contexts. Specific strategies used to achieve transferability include thick descriptions and purposive sampling (Marshall & Rossman, 1999). Thick descriptions are richly described data that provide the research consumer with enough information to enable a mapping of similarities between my context and another. The judgements as to how transferable my findings are will be ultimately determined by the quality and quantity of my data, its collection, and analysis. In respect to purposive sampling, this issue has been addressed in 3.6 *Case studies*. Due to the originality of this study, it is suggested that the onus of demonstrating the applicability of one set of findings to another context rests more with the researcher who would make the transfer (Marshall & Rossman, 1999) than myself. As Lincoln and Guba (1985) point out:

> The burden of proof lies less with the original investigator than with the person seeking to make an application elsewhere. The original inquirer cannot know the sites to which transferability might be sought, but the appliers can and do. . . . The responsibility of the original investigator ends in providing sufficient descriptive data to make such similarity judgements possible.
>
> (Lincoln and Guba, 1985: p. 298)

The third construct is 'dependability' (reliability). An inquiry would provide its audience with evidence that if it were replicated with the same or similar respondents (participants) in the same (or a similar) context, its finding would be repeated. Similarly in relation to *saturation* within phenomenology, replication is problematic. Von Eckartsberg (1998) presents an example of the potential for variable responses:

> How is it that we can say what we experience and yet always live more than we can say, so that we could always say more than we in fact do? How can we evaluate the adequacy or inadequacy of our expression in terms of its doing justice to the full lived quality of the experience described?

(Von Eckartsberg, 1998: p. 15)

In other words, there is no accurate fit between experience and language in the first place (Seamon, 2000). However, Churchill et al.'s (1998) phenomenological experimentation with this problem concluded that, though there may be differences in emphases, there are similar core themes. In this sense, the experiment indicated that phenomenological interpretation offers *some* degree of equivalence, since a 'somewhat coherent set of themes can be gleaned from...different interpretive research results' (Churchill et al., 1998: p. 181). Therefore, although there were differences among interpretations, these differences did not so much indicate the failure of phenomenology as a method but, rather, demonstrate the existential fact that human interpretation is always only ever *partial.*

The final construct, 'confirmability' (objectivity) refers to the degree to which the results could be confirmed or corroborated by others. This last construct can be accomplished using an audit trail (Lincoln & Guba, 1985). It is a procedure whereby an independent third party (albeit sceptical but reasonable) can review the documents and records of the process and activities of the research project. In doing so, the independent third party is able to make a judgement about the dependability of the procedures employed by the researcher and the extent to which the findings are confirmable. Such an audit can gain access to data and analysis procedures: my raw data (taped recordings), the transcriptions of the audio material, spreadsheets used in coding the data, and all supporting notes.

3.7 Ethics

Crotty (1995) cynically argues that much of what passes for codes of ethical practice is just professional etiquette. A concentrated discussion of ethics *per se* within this work is intentionally avoided as I have instead attempted to embed my ethical conduct within all relevant chapters. This is particularly prominent in 2.7 *The pleasure principle*, where I have considered placing emphasis on *persons* rather than *acts* to present a foundation for my own ethical behaviour. Brock (1996) noted that "framing questions of ethical practice exclusively in terms of principles (beneficence, autonomy, etc.) is in serious doubt" (p. 160). Instead, virtue-based ethics are being examined as an alternative ethical system (Meara & Day, 2000; Pettifor, 1995). Such concepts as honesty and integrity become dispositions that support the achievement of excellence in socially established cooperative human activity (Brock, 1996).

People with severe ID are often perceived as being vulnerable to exploitation in research (Lacono & Murray, 2002). In response to this charge, my participants were encouraged to be included in the consent-giving process at the initial stage (see Appendix ii). I then asked the participants' proxies to give their consent to an interview, which was audio taped, and to the use and analysis of the interview in the thesis, and in any publication based upon the thesis.

I was also aware that phenomenological interviews were more intimate than normal social discourse (Usher & Holmes, 1997), but I was clear that the interviews should not serve any 'pseudotherapeutic relationship' (Ramos, 1989: p. 57). However, I needed to acknowledge that some psychological distress might be experienced during the course of discussing such sensitive topics. To reduce this likelihood, the consent form identified the parent or teacher who would be available to provide support following the session if necessary. Participants were also reminded of these facts at the beginning and end of the interview and were reminded of their right to withdraw at any time and to have a break during the session. Participants were also offered the opportunity to be debriefed by having the transcribed material read to them by me to clarify the accuracy of the data, and as a form of recognition and gratitude for their participation. (However, none requested this service.)

Chapter 4 Presentation of findings

4.1 Introduction

It is useful at this stage to consider the practicalities of gathering data within the study's epistemological and philosophical frameworks. While saturation was reached by the same method as interviewing more articulate participants, my competence to transcribe interviews was more often applied to the linguistics of individual words or individual Makaton [1] signs. For example, during one interview, a participant was reading his library book to me. The communicative interaction involved the following:

Interviewer: "What's happening on this page?"
Participant: (Blows on the page)
Interviewer: (Pointing at the page) "What's this?"
Participant: [Signs] "*House*."
Interviewer: (Pointing at the page) "What's that?"
Participant: [Signs] "*pig*."

This 'reduced' narrative (not used in the findings) was a partial account of the following extract of text:

> So he *huffed* and he *puffed* and he *huffed* and he *puffed.* The house of straw fell down and the wolf *ate* up the first little *pig.*
>
> (The Three Little Pigs. Ladybird Easy Reading Series)

To understand my approach to this problem, a metaphor for the type of communication employed by the participants is found in Picasso's series of engravings *El Toro* (1945–1946) where, over a number of images, he gradually strips the animal of its nuances; the final result being a minimal, single-line drawing that retains the essence of the bull: movement, breathing, fighting, and dying. Such plausible reductionism is a central component of this study's hermeneutic integrity. Many of the more articulate participants' quotes are representative of other participants' single-word responses, disorganised sentence construction, or Makaton signs.

4.2 Findings

For clarity, the findings are presented in three sections: Phenomenology of Mortality, Manifestation of Religion, and Metaphysical Experiences. The dualism of art and science plays a further role in this chapter. In the early part of the twentieth century, post-impressionism was the time we ceased only asking 'what does this represent', to also ask 'how does this make us feel?' This is instinctive, a further challenge to the concept of 'bracketing', but more importantly in this context, relevant to how the often emotive findings impact upon the researcher.

4.3 Phenomenology of Mortality

Experiential

The participants illustrated personal experiences of death. Additionally, they exhibited an understanding of some 'post-modern' causation:

> "People die of diseases. Rhonda died of cancer. George died of cancer (grandmother's friends). Nanny was in hospital...Nanny died too."
>
> "Your heart...your heart can kill you."

P6's mother revealed how her son's younger sister had died from a congenital heart defect during post-natal care. Her son had visited the baby in hospital and had his photograph taken with her. Furthermore, this participant's grandfather had died from a heart attack shortly afterwards.

P2 had previously visited a former long-term care worker in a hospice towards the end of her terminal illness. The participant's mother explained how her son was informed of the care worker's cancer prior to the visit, although she did not believe he understood how the disease was linked to the care worker 'going to heaven.' The participant followed the conversation and signed 'bed' and 'doctor' at appropriate times to confirm his mother's account. However, P2 began to exhibit some mild agitation over his recollection of the incident and this line of enquiry was terminated.

P9 confirmed his mother's account of both his grandmother's and grandfather's deaths. He then signed 'picture.' His mother explained how both grandparents had died of cancer when her son was very young and did not believe he had any memories of them. However, P9 knows his relationship to them from photographs that were regularly shown to him.

Three of the participants talked about a fellow pupil (*pseudonym* Liam) who had died earlier that year. The death was disability related, the result of an epileptic seizure. One participant had known Liam for 6 years and used personalised signs for 'Liam' and 'friend.' A second participant asked if I knew Liam, 'Liam at school? Liam who died?'

The participants also illustrated experiencing mortality via the death of a family pet.

> P3: "My hamster died."
>
> Mother: "The vet asked if you would like to say goodbye, didn't he."
>
> P3: "Yes. I cuddled my hamster and I said to him: thank you very much for making me happy."
> Mother: "We buried him in the garden."
> P3: "Yes. I sang him a song."

When attempting to establish an understanding of the finality of death, the responses were mixed. While some participants believed their dead family and pets would come back to life, others suggested a greater comprehension of mortality:

> "You don't come back. You have to stay in heaven for a *very* long time."

Although every participant had a first-hand experience of death, only a minority described frequenting cemeteries and none had visited a chapel of rest or been involved in any aspect of the funeral liturgy. Only a small minority of the participants' parents had considered the effects of grief, bereavement or loss. This enquiry came as a surprise to some parents who admitted funeral rites in particular were not something they had thought appropriate. One parent suggested that an environment such as a cemetery might prove to be too 'unsettling' for their child. However, the participants who were familiar with a cemetery exhibited an understanding of the burial tradition and were occasionally supported to visit the graves of family members.

> "I put flowers on the grave. That's to make it look nice."
>
> "There are flowers and messages (sympathy cards). You get messages when you die."
>
> "That's where the coffins are."

It has only been in more recent times that photographs of the deceased have been fixed to memorials in the UK [2]. One participant described the 'picture' of his 'baby (sister)' on a headstone. This memorial appeared to assist the participant to associate the grave with the infant.

Medicalisation

A common theme emerged from the experiential narratives, encapsulated in the following quote:

"Liam went to hospital in an ambulance."

The parents and participants presented death as a pathological state, rather than a natural and normal life process. Almost all the participants' accounts located the place of death as being a hospital or hospice, thereby making death a medical event. Many parents discussed treatment, and in doing so used a modified language to reinforce information to their offspring, e.g. "The doctor couldn't make Liam better". This discourse included the wider context of community-based care, in which Macmillan (palliative) nurses treated dying relatives at home.

As identified in my literature review, people with severe ID generally have more limited exposure to environmental factors such as death due to accidents. However, the participants offered a number of scenarios in relation to trauma:

> P3: (Whispering to mother) "Don't tell him about *Casualty* Mummy [3]."
>
> Mother: "It's alright to talk about *Casualty*."
>
> P3: "A boy was on fire. He died. Fireworks are very dangerous. I don't like fireworks."
>
> "You can get run over (road traffic accident) if you run in the road. You would be taken to hospital if you were run over."
>
> "If you get run over… you can die of shock. People who are frightened die of shock."

All participants expressed a fear of hospitals, but in particular, a fear of ambulances. One participant's explanation was "I don't like people making me better." This was a reference to treatment and possibly the response to her mother's reassurance that attending hospital would 'make you better.' All parents illustrated examples of how problematic it is to encourage their children to attend appointments in hospitals and dental surgeries.

The medicalisation of death is a particularly significant manifestation of the disappearance of death from the public domain. As Elias (1985 p.850) notes: "Never before have people died so noiselessly and hygienically as today in these societies, and never in social conditions so much fostering solitude"

4.4 Manifestation of religion

Knowledge

The participants illustrated a philosophic system of God being *creator*. However, this old-earth creationism was almost completely applicable to inanimate objects in the physical world.

> "God made the trees strong."
>
> "Jesus made the whole wide world."
>
> "God made the world. He made it beautiful. Do you know about Adam and Eve? Eve ate the apple…very naughty Eve."

The confusion between 'God' and 'Jesus' was neither Biblical nor rationalist unitarianism. In other words, Jesus was neither perceived as the son of God, nor an independent agent, but as the same entity.

> "I think he might be a man with a beard. Yes...I think that's the right answer."

> "He (Jesus) was crucified. Nails in the hands (gesturing stigma). Mummy saw a film (*The Passion of the Christ, 2004*). He was hit with a whip. He had his flesh ripped out. I wasn't allowed to see the film."

There were no metaphysical or metaphorical descriptions of God. None of the participants were aware of alternative beliefs to the Christian theological account.

Expression

Much of the data revealed familiarity with the church environment, predominantly through experiences during school hours.

> [Signing] "Light a candle. Sing." (Laughs and claps hands.)

> "I sing and I say my prayers."

> "I was a bridesmaid. I'm going to get married to my boyfriend in a church."

> "I used to sing (school choir)."

> P6: "I light a candle. I pray. You must be very quiet. Did you know I saw God?"
> Interviewer: "No I didn't. Where did you see him?"
> P6: (Whispering) "In church."

Further investigation revealed 'God' may have been a statue or a painting.

There was no evidence to conclude the participants had generally gained religious beliefs by pondering the argument for and against the existence of a particular supernatural agent. More likely, and similarly to most people, they were groomed into finding a culturally acquired description of such an agent that appeared plausible. Participants' narratives suggested informal and formal religious education via 'school', 'mummy', 'book' (bible and other publications) to explain their understanding and acceptance of God. My questioning of the existence of God was perhaps their first ever implicit challenge to the *consensus gentium*.

Interactions

The participants' God had spatio-temporal properties and was therefore perceived as a physical entity, although located in, and confined to, a celestial domain (heaven). The participants' God was not omnipresent; but although this God was not *everywhere*, he saw and heard *everything*. However, within the context of this question, this was not a deity that was all knowing to the extent it could empathise with *intuition*, i.e. the cognitive and emotional; this God was anthropomorphic so knew only what could be detected by the physical senses. While there is reference to theistic judgement, this did not necessarily represent a relationship between theology and ethicality.

> "God watches me. If I do a good thing, like sharing…it makes him happy. When I pull my sister's hair…it makes him unhappy."
>
> "If I'm a good girl…like helping mummy…it makes Jesus laugh. If I do a bad thing…like fighting with my brother…it makes him very cross."
>
> "God can see me. Dead people can see me. It makes them happy if I tidy my room."

Ecclesiastical

The participants illustrated a pre-*Age of Reason* Christian view of heaven as a physical place 'in the sky'. Such (obviously non-verifiable and non-falsifiable) descriptions included a "garden" (interestingly represented in the Qu'ran as 'jannah' meaning 'garden') or variations such as a "park." However, there were no complexities relating to the continuation of existence and gaining access to heaven. Such universalism assumes that *all* people will ascend to heaven without undergoing the processes of the predominantly Protestant belief that entry into heaven is dependent on faith (in Jesus) nor the predominantly Catholic and Eastern Orthodox theologies of purification via purgatory or limbo.

> P2: Points upwards.
> Interviewer: "The sky? (No response.) Heaven?"
> P2: Claps hands and laughs, an idiosyncratic affirmative gesture, similar to the sign for "happy."
>
> [Signing] "House. (Prompt from mother.) Garden."

> "Heaven? (pause) It's a fairground."
>
> "Heaven is in the big blue sky (laughter)."

The concept of heaven was described as a place populated by God, angels, and the deceased.

> "God is in heaven. The angels are in heaven."
>
> "It's where the dead people go…and they read books."
>
> "You go to heaven. Dogs, cats, goldfish, hamsters *and* people go to heaven."

The participants' basic universalism was contradicted when the concept of hell was introduced. However, only one of the participants could articulate a response, representing esoteric knowledge of this aspect of an afterlife.

> "Hell is a prison…I think. If you are bad, you go to hell and you are put in chains."

This view was consistent with other similar material interpretations, e.g. Dante's *Divine Comedy*, and Christian concepts of hell being a place of punishment (in this case, *unlike* Eastern Orthodoxy).

Similarly to the concept of God in heaven, the devil resided in hell and was therefore not omnipresent.

> "I think the devil is a snake…a cunning snake."

4.5 Metaphysical experiences

Transference

Irreversibility was cited as a key feature of death. However, when asked what survives the body after death occurs, the participants did not illustrate an ethereal existence that could be interpreted as a 'soul'. There was no traditional dichotomy (body and soul) or trichotomy (body, soul and spirit). Their explanations illustrated a resurrection or relocation of the (deceased) physical body.

> P2: [Signing] "Dog. Sky."
> Interviewer: "Did you bury your dog in the ground when it died?"
> P2: "Yes."
> Interviewer: "Did your dog's body go into the sky after it died and was buried?"
> P2: "Yes."

> "Some people are buried. Some people are burnt. Nanny was burnt to ashes in a fire (cremated)."

> "The coffins are in the clouds."

> P5: "You're put in a coffin."
> Interviewer: "Does the body stay in the coffin, buried in the ground?"
> P5: "No, the coffin goes to heaven."
> Interviewer: "So does the body go to heaven in the coffin?"
> P5: "Yes."

> "The people in the coffins watch us to see if we're being good or naughty."

Such a phenomenon suggests that the participants interpreted death as a type of non-existence in our world. That is, the person or animal *did* exist, but does not exist *any longer*. The entity therefore has a present non-existence. However, the deceased manifests as a physical body relocated in a celestial domain. Interestingly, despite none of the participants having ever attended a funeral, all understood the purpose of the coffin in the burial ritual, and made numerous references to it. However, the deceased person was restricted to the open casket itself, unable to 'get out', but able to function using the normal senses.

The inability to comprehend a 'soul' may be explained by the Bundle Theory. The basic idea of the theory is that however we might choose to conceive of, or describe a *thing*, it will be a conception, or a description of a *property* of a thing. In other words, there is nothing that can be described, or even conceived about a *thing,* which is not a property *of* the thing. Therefore, the bundle theorist concludes, to conceive of an object is to conceive of a bundle of its properties. The only conception we can have of an object, such as a corpse, is as a bundle of its former properties.

Transcendental dimensions

Further descriptions of prayer emerged during discussion of *Candle Time*. This event deviated from the day-to-day human-divine interactions presented earlier. The act of prayer was a supernatural interaction where 'talking' and listening' were metaphors for communication with a transcendent realm. Such 'moments of silence' [4] were more commonly employed to express thoughts and emotions, which included elements of secular contemplation, reflection, and meditation.

> "I say prayers...thank-you for food (grace)."
>
> "I pray about sins (referring to a confessional aspect of prayer). In Candle Time, I think about all the things I like doing...I like art....I like singing."
>
> "When I see the candle, I think about Evan (sister's baby who had died)."
>
> "I think about the pictures (God) in church."
>
> [Signing] "Home...food...dancing...love... Mummy...love Adam (mother's partner)."
>
> [Signing] "Blow out candle. Good-bye" [5].

Postscript

During my research, a teacher informed me of a pupil who took a particular interest in religion. She told me of a conversation she had with the child's mother in relation to the child's suitability to participate in the study. It was agreed between the teacher and the parent that non-participation was 'in the girl's best interests'. The teacher explained how the pupil exhibited autistic traits of 'obsessive behaviour' towards cemeteries and in particular, expressed an interest in the supernatural, often prompted by the US television series *Buffy the Vampire Slayer* [6]. The teacher and parent believed that being interviewed by me would have 'encouraged' the girl's behaviour by enabling her to discuss her belief in the existence of ghosts and demons. Although

I did not pursue this potential participant, I believe this was a missed opportunity to further enhance the study.

Endnotes

[1] Makaton is designed to help hearing people with learning and communication difficulties, it is an aid to communication not a language as such. BSL is a language with its own grammar and is used fluently by deaf people. In the UK, Makaton signing is based on BSL, and it takes the signs from BSL. As with spoken languages, where there are regional variations of dialect and accent, there are also variations in the signs that are used throughout the UK. The signs from BSL matched to Makaton have been standardised to those used in the South East / London region. This standardisation is to avoid confusion for Makaton users if they move around the UK.

[2] This practice is still prohibited by some community councils in the UK.

[3] BBC TV A&E hospital-based programme.

[4] This act has proved to be controversial in the US where oral school prayer has generally been replaced by the controversial practice of 'moments of silence' or 'moments of reflection.'

[5} Candle Time was conducted at the end of the school day. Candle Time was also representative of the traditional school bell to indicate the end of the working school day.

[6] The show is notable for attracting the interest of scholars of popular culture. It has been the subject of numerous conferences and articles in academic journals. Many *Buffy* stories are thinly veiled metaphors for the anxieties and ordeals of adolescents.

Chapter 5 Pathology of health and well-being

5.1 Introduction

In the first part of this chapter, I begin to discuss the findings by contrasting normative fear and anxiety in ID and non-ID children. I then consider the social model of disability in relation both to physical access and to its impact on phenomenological research. Psychosocial barriers to accessing healthcare are illustrated before exploring the consequences of regarding ID *per se* as an illness. Finally, I speculate on the consequences of health inequality to illustrate how equity is an ethical value, and how, when applied to health, it literally becomes a matter of life or death (Braverman & Gruskin, 2003).

In the second part of the chapter, I turn my attention to bereavement and the consequences of managing maladaptive behaviour when supporting people with ID. Within the context of the school community, I consider the teachers' often compromised pastoral role and the potentially catastrophic effects of loss on the ID.

5.2. **Medical ingress**

5.2.1 Fear and anxiety

Gullone et al.'s (1996) study of fears of youths with and without intellectual disabilities [1] suggested that the strongest fears for both groups related to the fear arousing stimuli of death and danger-related incidents. The overall samples indicated that for the most part, the most intense fears are not age-related or gender-related. In fact, they appear to suggest that such fears are less cognitive in nature and lend further support to the proposal that humans are predisposed to developing or learning fears which have survival value. The participants' narratives relating to road traffic accidents are interesting in the context of Gullone et al's findings, where those with intellectual disabilities cited being hit by a car as their greatest fear [2].

Normal fear has been identified as one of our most important emotions (Gullone et al., 1996). Such fear constitutes an adaptive reaction to a real or imaginary threat. Cognitive development and learning pathways do not sufficiently explain normal fear experiences. In particular, they cannot account for the distribution of fears. For example, many people in the UK fear spiders but not dogs, when the latter pose a significantly greater risk of causing harm. However, the stimuli most feared represent a threat to survival or have posed a threat in the evolutionary history of the species.

Such stimuli include certain natural disasters, 'dead people' and 'breathing difficulties' (Gullone & King, 1993). In the 21st century, the consequences of the 9/11, Madrid and London bombings may add terrorism to the list of stimuli. Such real or perceived omnipresent violence, such as exists in the Israeli-Palestinian conflict [3], may leave children feeling permanently unsafe (Arafat, 2003). This situation may be extenuated by the fact that caregivers themselves have similar fears, thus making psychosocial support more difficult.

There has been little research in examining normative fear in people with intellectual disabilities, which is surprising as this group is particularly vulnerable to increased levels of emotional disturbance. Vandenberg's (1993) study examined the fears of (mild/moderate) intellectually disabled children (aged 7–12). It was found that more fears of imaginary creatures were reported when compared to a non-disabled group, where such fears are more typically found in younger children. This suggests that normal fears are linked with the level of cognitive functioning. Therefore, fears relating to the unknown by people with ID provide support for the suggestion of this being indicative of lower-level cognitive functioning (King et al., 1994), resulting in less sophisticated evaluations of 'reality-based' threat. Instruments for assessing *fear* include a number of assessment tools but only a few have determined any 'psychometric soundness' (Gullone, 1996: p. 702). A more obvious method would be observational, although difficulties observing a wide range of stimuli are acknowledged.

5.2.2 The social model and accessibility

To consider a fear of hospitals (nosocomephobia), we need to explore how healthcare is accessed and experienced by the ID. The term *access* is predominantly used in disability discourse in two ways: to *have* access where a physically accessible service exists, and to *gain* access where a service is successfully used (Alborz, 2005). In relation to the former, social model approaches generally argue that the disabled are excluded by unnecessary attitudinal and environmental barriers (Dewsbury et al., 2004). In explicating the various ways in which disability is a social construct, the social model both implicitly and explicitly suggests that the removal of such barriers will afford the same opportunities for disabled people. However, the social model has predominantly been applied as an urban socio-spatial audit. While environmental access and transport are important issues, simply constructing a ramp to a building's door would not address the needs of the ID. As Priestly (1998) suggests:

> There is a world of difference between the ways in which barriers are created and the way in which we can best come to know about them. Disabled people's experiences will always be the most immediate way of identifying barriers, but that does not negate the fact that those barriers might exist outside their experience.
>
> (Priestly, 1998: p. 85)

The importance of social constructionism lies not in the fact that X is a construction, but in *how* it is constructed. From a more philosophical stance, I have previously addressed the irony of certain disabled authors' hyperbole in criticising their non-disabled peers on the basis of 'standpoint' epistemology, i.e. the 'absurd position that it is impossible to understand another culture' (Dewsbury et al., 2004) or experience, especially perhaps in relation to disability. However, the social model has been quoted by both disabled and compliant non-disabled researchers to analogise a 'disabled experience'. Corker (1999) suggests why this is problematic:

> Disability, like most dimensions of experience is polysemic – that is ambiguous and unstable in meaning – as well as a mixture of 'truth' and 'fiction' that depend on who says what, to whom, when and where.
>
> (Corker 1999: p.3)

The social model has undoubtedly been the dominant paradigm in research and understanding of disability in recent years. Vic Finkelstein, one of the architects of the social model, describes how his fictional story of an imaginary village where non-disabled people were disabled by an environment designed for, and inhabited by, 'normal' wheelchair-using people, was his earliest attempt to promote a different interpretation of disability (Finkelstein, 1975). However, such concepts have been readily found in classic literature since the early seventeenth century, e.g. *Gulliver's Travels* and *Alice in Wonderland.* As a result, I do not believe the social model was ever as radical as some authors proposed in the first place, but simply the 'ordinary business of sociology' (Dewsbury, 2004: p. 151).

5.2.3 Finkelstein's adjective

Vic Finkelstein reflects back to the early 1970s and describes how phenomenological researchers 'encouraged us (the disabled) to talk about our awful experiences' (Finkelstein, 2001a: p. 2). Finkelstein's use of the adjective 'awful' modified the disabled experience. In their politicking to eliminate the body pathology of the medical model, social model theorists produced a hierarchy which has enabled some disabled people to escape from their 'social prison' (Finkelstein, 2001a: p. 1). Authors such as Finkelstein (2001b) argue that the social model is a tool rather than an explanation. Despite this, the body (impairment) is rendered synonymous with its dysfunction. As a result, the biological becomes detached from the cultural (Hughes & Paterson, 1997).

The utopia of an accessible environment, coinciding with the development of information technology over the last twenty years, has enabled many people with disabilities (in theory at least) greater opportunity to access education and benefit from the subsequent social advantages of employment. However, it is generally recognised that people with ID have been excluded from the wider disability movement (Chappell et al., 2001). The social model's 'emancipatory struggle' (Finkelstein, 2001b: p. 4) left 'impairment' research to the jurisdiction of the predominantly medical profession, considered to be 'the traditional oppressors' of disabled people (Bricher, 2000: p. 781). Despite the fact that medical involvement may only be a small aspect of life for some ID people, health professionals have considerable power to control other aspects of a disabled person's life, as the professionals are gatekeepers of often scarce resources (French 1994a), a factor often pertinent to medical ethics and life-or-death decision making.

5.2.4 Overshadowing

It is disappointing to find statements from contemporary NHS-authored research papers that state, "Children with disabilities have the same rights to access general, i.e. non-disability National Health Service (NHS) services as other children"

(Wharton et al., 2005: p. 275). If, for example, ethnicity or even religious preference preceded 'children' in this statement, attention would naturally be drawn to the unnecessary inclusion of race or religion. The Department of Health (2001) correctly suggests that "Disabled children have exactly the same healthcare needs as other children, additional to any arising from their particular disabilities" (Department of Health, 2001: p. 40). Although this statement's intent is well-meaning, both reports are indicative of the compartmentalisation of disability healthcare, a process not dissimilar to the 'inclusion' ideology of Special Education.

Scheer et al. (2003) reported a lack of knowledge where doctors cannot distinguish between a disability-related health problem and a non-disability-related health problem. 'Overshadowing' (Alborz et al., 2005: p. 178) is a term used to illustrate how some parents feel that their concerns about their child's health are not taken seriously when health professionals attribute symptoms to the disability rather than to an unrelated specific medical condition. A lesson from recent history reveals the dangers of wrongly applying specific healthcare concerns to a particular group. Gay men were one of the first groups to experience AIDS-related stigma from being labelled at high risk for contracting HIV. Because the initial AIDS cases were identified primarily among homosexual men, a population already experiencing stigmatization because of sexual orientation, the media in the early 1980s described the disease as the 'gay plague,' and the US Government Agency Centre for Disease Control for a time used the term 'gay-related immune deficiency'. Shortly after the term 'gay plague' first appeared, the *New York Times* reported that a 'double epidemic' was spreading: AIDS and a growing fear and intolerance of homosexuals (Beauchamp, 1983).

5.2.5 Psychosocial barriers

I now turn my attention to *gaining* access, where a service is used successfully (Alborz, 2005). Here, the dualistic concept of psychosocial barriers is applicable to both service user *and* service provider. In the context of medical egress, they manifest in ways ranging from passive resistance and aggression in the former to a lack of pragmatism and/or discrimination in the latter.

Evidence suggests that where the organisation of health services fails to take account of the needs of parents and their children with ID, willingness to approach services may be affected (Alborz et al., 2005). Hart (1998) and Barr's (1997) studies of access to hospitals for adults with ID reported a general lack of understanding of medical processes and procedures. Examples from the studies were consistent with Wharton et al.'s (2005) findings in suggesting that both adults and children with ID may be less fearful of traumatic procedures if time is taken to explain the process. Wharton et al.'s (2005) study identified a number barriers to healthcare, which included a lack of planning for the additional needs of children with disabilities, the consultation process not being flexible enough to prioritise treatment, and appointments not made at the start or the end of the day to reduce waiting times. Many other barriers to access have been identified in the literature, including socio-economic disadvantage; inadequate knowledge and awareness of health issues; negative, discriminatory or nihilistic attitudes to people with disabilities; communication issues and poor inter-sectoral collaboration (Durvasula & Beange, 2001).

Two per cent of a general practitioner's patient list will be persons with an ID, of which an estimated 0.5 per cent of these may be diagnosed as 'severe' (Department of Health, 1998). Researchers agree that the relationship between health care provision by GPs and the health needs of people with ID is fraught with barriers. Dovey and Webb (2000) found that GPs require extra time for patients with ID when compared to non-intellectually disabled patients, the consequence being that GPs are not paid for additional consultation time. GPs also refer to behavioural problems in their ID patients as being a major problematic factor in making an accurate diagnosis (Phillips et al., 2004).

5.2.6 Sociology of the body

Overcoming the impairment-denial agenda enables us to consider the carnal, the emotional, the cognitive, and the cultural to form a 'sociology of the body' (Hughes & Paterson, 1997: p. 336). This is a paradigm at odds with the social model constructionist's purely extrinsic causation of disability. It is suggested that the social model's fundamental flaw is the failure to accept the reality of intrinsic causation. In relation to vulnerability, dependence and the human condition, the social model overlooks the similarities between disabled and non-disabled people. Intrinsic barriers probably affect all of us at one time or another. For example, is the non-disabled person with a social phobia disabled by society?

This provides the opportunity to consider the theoretical conceptualization of health and disease, where the bio-psycho-social model (BPSM) (Engel, 1977; Engel, 1980) enables exploration of the *individual* rather than wider political considerations. The BPSM's multi-factored perspective suggests that an interaction of the biological, psychological, and social aspects of a person's life are the determinants of his or her health, the onset of illness, and often the prognosis.

Similarly, in relation to death and dying, there has been a similar individualisation of a social phenomenon. Aries (1974) argues that during the medieval period dying and death constituted an integral part of daily life. Death was an event that produced communal responses and was surrounded by a multiplicity of practices:

> The death of a man still solemnly altered the space and time of a social group that could be extended to include the entire community. The shutters were closed in the bedroom of the dying man, candles were lit, holy water was sprinkled; the house filled with grave and whispering neighbours, relatives and friends.
>
> (Aries, 1981: p. 559)

Protestant emphasis on calming those predominantly Catholic deathbed dramas sought to 'limit the pain, mess and anguish' (Shilling & Mellor, 1997: p. 120) that accompanied death. Reformation promoted the development of affect control, which was necessary to achieve a socially approved departure from this world. The individualisation of death sought to separate the living from the dead in a way that would have made little sense to the medieval culture of the *danse macabre* (the dance of the dead).

> Painted on the cloister wall of a number of celebrated churchyards...[the *danse macabre*] portrayed a circle where the dead alternate, holding hands, with the living, and lead them in a dance around the graves.
>
> (Bossy, 1985: p. 31)

Rather than being an open, communal event, death is now a relatively hidden, private experience where hospitals can be seen as the institutional expression of the modern desire to sequester bodily evidence of death away from the public gaze (Shilling, 1993).

Presently, 55 per cent of all deaths occur in hospitals in England (Review of the Registrar General on deaths in England and Wales, 2000). However, the participants' exposure to patients in hospitals and hospices represented an outcome of 100 per cent death rate. Therefore, the participants' behaviour in relation to their perceived association between illness/trauma and mortality is subjective but rational behaviour. Furthermore, any demonstration of anxiety or distress by the parents or carers of those with an ID may well contribute to the creation of negative responses to stimuli such as hospitals.

5.2.7 Health inequity: risk and incidence

The notion of equity has many definitions, but common to them all is a concern with *fairness* as an ethical value (Leeder & Dominello, 2005). There is growing research evidence that people with ID have difficulties accessing NHS services of all types and have negative experiences of using health services (Giraud-Suanders et al., 2003; Hatton et al., 2002).

Health screening of adults with ID registered with GPs reveals high levels of unmet physical and mental health needs (Barr et al., 1999). Regular health screening of people with ID through co-operation between specialist ID teams, GPs and primary health care teams improves health status and access to other mainstream health services (Cassidy et al., 2002; Martin et al., 1997). Information to prompt GPs to take a more active role appears ineffective (Jones & Kerr, 1997).

There are significant variations in NHS total expenditure and expenditure per person on services for people with ID across different areas of England, with lower spending in rural areas (Forsyth & Winterbottom, 2002), and significant variation in the services provided to people with ID by specialist NHS Trusts (Bailey & Cooper, 1997).

The following determinants of poor health and mortality contextualise the potential consequences for the intellectually disabled of not accessing health information, assessment, screening, and specific medical treatment:

Respiratory disease is the leading cause of death for people with ID compared to the general population (46%–52% vs. 15%–17%) (Hollins et al., 1998).

Although the incidence of deaths from cancer in the UK is currently lower than the general population (11.7%–17.5% vs. 26%), the incidence of cancer amongst people with ID is rapidly increasing due to increased longevity amongst this population (Duff et al., 2001). In particular, people with ID have proportionally higher rates of gastrointestinal cancer than the general population (48%–58.5% vs. 25% of cancer deaths) (Duff et al., 2001). Furthermore, children with Down's syndrome are at particularly high risk of leukaemia compared to the general population (Hasle et al., 2000; Hermon et al., 2001).

Women with ID are much less likely to undergo cervical smear tests than the general population (19% vs. 77%) (Djuretic et al., 1999); (24% vs. 82%) (Pearson et al., 1998). The uptake of breast and cervical screening by women with ID is poor partly due to ill-founded assumptions made by primary care teams, screening services, and carers that women with ID are less at risk than other women (Department of Health, 1998). Additionally, most women with ID undergoing cervical smear tests do not understand the purpose of the test (Broughton & Thomson, 2000).

Studies of the incidence of coronary heart disease (CHD) in the UK are lacking, although CHD is the second most common cause of death amongst people with ID (14%–20%, Hollins et al., 1998) and rates of CHD are increasing due to increased longevity and lifestyle changes associated with community living (Wells et al., 1997). Almost half of all people with Down's syndrome are affected by congenital heart problems, a much higher rate than the general population (Hermon et al., 2001). Surgical treatment in Poland and the USA of congenital heart defects in children with Down's syndrome produces a similar degree of positive benefit compared with children from the general population (Reller & Morris, 1998), although there is evidence that cardiac surgery is less likely to be offered to children with Down's syndrome (Kmietowicz, 2001).

The prevalence rate of epilepsy amongst people with ID has been reported as 22 per cent (Welsh Office, 1996), compared to prevalence rates for the general population of 0.4%–1% (Chadwick, 1994). Seizures are commonly multiple and refractory to drug treatment (Branford et al., 1998). Uncontrolled epilepsy can have serious negative consequences on both quality of life and life span, although guidelines on the successful management of epilepsy in people with ID are available (Kerr & Bowley, 2001a, 2001b; Working Group of the International Association of the Scientific Study of Intellectual Disability, 2001). Epilepsy experienced by people with ID is the most persistent and difficult to treat (Shovron, 2000). When epilepsy is difficult to control, emergency interventions are required more often (Brown et al., 1998).

Linakar & Nottestad (1998) reported that supporting individuals in the community, as opposed to institution-based care, has led to deterioration in some individuals' health status, the obstacles to good health being the knowledge, abilities, and skills of social care staff (Band, 1998) and perhaps parents. In a study of the correlation of risk factors and sudden death in epilepsy, Langan (2000) proposed that people with ID may be at an increased risk of sudden death from epilepsy.

Prevalence rates for schizophrenia in people with ID are approximately three times greater than for the general population (3% vs. 1%) (Doody et al., 1998). Reported prevalence rates for anxiety and depression amongst people with ID vary widely, but are generally reported to be at least as prevalent as the general population (Stavrakaki, 1999), and higher amongst people with Down's syndrome (Collacott et al., 1998).

Children with ID are more likely to experience anxiety disorders (8.7% vs. 3.6%) and conduct disorders (25.0% vs. 4.2%) than children without ID (Emerson, 2003). Challenging behaviours (aggression, destruction, self-injury and others) are shown by 10%–15% of people with ID, with age-specific prevalence peaking between ages 20 and 49 (Emerson et al., 2001).

People with mental health problems and borderline intellectual functioning are particularly difficult to treat (Hassiotis et al., 1999) and people with ID are at risk of receiving no mental health service, due to the lack of communication between mainstream psychiatry services and ID psychiatry services (Hassiotis et al., 2000).

A high proportion of people with ID are receiving prescribed psychotropic medication, most commonly anti-psychotic medication (40%–44% long-stay hospitals; 19%–32% community-based residential homes; 9%–10% family homes) (Robertson et al., 2000b). Anti-psychotics are most commonly prescribed for challenging behaviours rather than schizophrenia, despite no evidence for their effectiveness in treating challenging behaviours and considerable evidence of harmful side-effects (Emerson, 2001).

People with ID are between 8.5 and 200 times more likely to have a visual impairment compared to the general population, and around 40 per cent are reported to have a hearing impairment, with people with Down's syndrome at particularly high risk of developing vision *and* hearing loss (Carvill, 2001). People with ID are unlikely to be assessed for vision or hearing impairments due to staff attributing lower levels of functioning to the person's ID (Lavis et al., 1997), and are unlikely to receive aids to vision or hearing (McCulloch et al., 1996).

The prevalence of dementia is much higher amongst older adults with ID compared to the general population (21.6% vs. 5.7% aged >65) (Cooper, 1997a), and is associated with a range of maladaptive behaviours (Cooper, 1997b) and health problems (Holland, 2000). People with Down's syndrome are at particularly high risk of developing dementia, with an age of onset 30–40 years younger than the general population (Holland et al., 1998).

People with ID have substantially lower bone density than the general population (Aspray et al., 1998), with increased fractures occurring throughout the life span, particularly in people with epilepsy (Jancar & Jancar, 1998).

Thirty-six per cent of adults with ID and 80 per cent of adults with Down's syndrome have unhealthy teeth and gums (Barr et al., 1999), with adults living with families having more untreated decay and poorer oral hygiene, and adults living in residential services having more missing teeth (Tiller et al., 2001). People with ID are most likely to receive dental care from community dental services, although coverage is considerably less than optimal (Pratelli & Gelbier, 1998; Tiller et al., 2001).

No data is available concerning the prevalence of HIV amongst people with ID, although some adults with ID are known to engage in behaviours placing them at risk of contracting HIV, and effective HIV education and prevention services for people with ID are scarce (Cambridge, 1997; MacDonald et al., 1999).

People with ID are much more likely to be either underweight or obese than the general population, with women and people with Down's syndrome at increased risk of obesity (Robertson et al., 2000a). Less than 10 per cent of adults with ID eat a balanced diet, with an insufficient intake of fruit and vegetables and a lack of knowledge and choice about healthy eating (Robertson et al., 2000a). Over 80 per cent of adults with ID engage in levels of physical activity below the minimum recommended by the Department of Health, a much lower level of physical activity than the general population (Robertson et al., 2000a), with people of lower ability in more restrictive environments at increased risk of inactivity (Robertson et al., 2000a).

Finally, referring physicians and transplant centres are reluctant to consider an individual with DS for heart or heart-and-lung transplantation. Currently referral rates do not reflect the high prevalence (40%) of surgically treatable cardiac problems in individuals with DS. Physicians cite co-existing medical problems and high rates of infective and malignant complications of DS as factors that could reduce the likelihood of a satisfactory outcome. They judge that because there is a limited supply of organs, it is ethically sound to use them preferentially for individuals without DS. They also argue that it is difficult to obtain informed consent from individuals with ID. However, there is concern that widely held beliefs are not supported by the evidence and that individuals with DS are receiving sub-optimal care without justification (Leonard et al., 2000).

5.3 **Bereavement**

5.3.1 Stressful life events

Despite the participants' first-hand familiarity with death, formal education on this topic remains very much implicit. Herman Feifel placed emphasis on the multidisciplinary nature of death studies and argued how death education benefited all, including children (Feifel, 1977):

> We need to remind ourselves that the field of death, dying, and bereavement in Herman Feifel's vision, is both science and humanity. Death education needs to attend to both its scientific and humanistic goals.
>
> (Wass, 2004: p. 303)

Most particularly, the humanistic perspective, the philosophical foundation of the study of death that he articulated, is reflected in the goals of death education, which stresses both acquisition of knowledge and development of self understanding and clarification of values, meanings, and attitudes toward death. Feifel (1982) observed that although we become more knowledgeable about death, there remains a persistent avoidance. There are numerous indications of avoidance and ambivalence towards death in contemporary society. Advances in medical and biological sciences raise expectations for further extending human lives and unrealistic hopes for physical immortality bolstered by an anti-aging industry (Wass, 2004). Therefore, criticism of death education must be tempered by consideration of the larger cultural context in which these efforts are made.

Feifel (1977) suggested that as death is part of our culture, death studies could be provided in a low-key manner and embedded in larger curricular contexts, thereby being unlikely to cause psychotic episodes as some have feared. However, at present there is a well-established relationship between adverse or stressful life events and psychopathology amongst the general population of children (Tiet, 2001a, 2001 b). Firstly, the type of life events most closely associated with child psychopathology is unpleasant events involving a threat to the child (Hatton & Emerson, 2004). Secondly, intellectual ability can act to increase the severity and impact of such negative life events (Sandberg & Rutter, 2002). Analysis of the 1999 social survey of the UK's Office for National Statistics on the mental health of children and adolescents (aged 5–15) with and without ID, found the most common adverse life events experienced by children with ID were parental separation (39%), serious illness requiring hospitalisation (34%), and the death of a pet (27%) (Office for National Statistics, 1999). Additionally, the experience of such adverse life events would be associated with a greater likelihood of child conduct disorders and emotional disorders (for both disabled and non-disabled groups).

Bereavement is a sensitive subject and researchers can meet with anxiety and resistance (Abdelnoor & Hollins, 2004). Much of the literature suggests that many children will experience the death of a parent, grandparent, and, more rarely, a sibling, classmate, or teacher during their school years (Lowton & Higginson, 2003). However, my research proposes the incidence rates may be much higher in special schools.

Problems exist in measuring both short-term and long-term outcomes of a school-age child's bereavement (Jones & Tannock, 2000). In the UK, Dowdney et al. (1999) reported teachers' assessments of bereaved pupils' behaviour as being significantly more depressed, aggressive and delinquent than age and gender-matched controls. Harper & Wadsworth (1993) reported people with ID as having intense reactions to bereavement, similar to the reactions to post-traumatic stress disorder, which included breathing difficulties and pretending to be dead. In the absence of clear explanations, disenfranchised children will struggle to understand what is happening and may rely on their imagination to explain the situation (Bennet & Dyehouse, 2005: p. 21). This manifests in my data where one participant misinterpreted the physiological effects of shock as being related to *fear* rather than *trauma.*

5.3.2 Impact on the school community.

Children of primary and secondary school age spend a large part of their day with individual teachers, such that the school may be viewed by the pupils as a secure second family (Holland, 1993). This relationship becomes even more established in special schools, as the reception year model is usually maintained, i.e. the curriculum is delivered by an individual teacher. As children in special schools are not always chronologically grouped by age, such an arrangement is often extended, whereby a pupil may remain with the same teacher for a number of years. Furthermore, teachers and support staff are often engaged in the intimate personal care needs of their pupils e.g. providing assistance with eating, dressing, and toileting.

School has been interpreted not just as a place of education, but as the hallmark of vital socialisation by providing a sense of community (Speaker & Peterson, 2000). Unlike in the US and Australia, in the UK children do not generally have ready access to school-based counsellors. More usually in the UK, the school itself must provide support to bereaved children for 'routine' deaths (Lowton & Higginson, 2003) as opposed to those occurring through, for example, disaster. Information accessible to children through the media, especially high-profile incidents such as the murders in Dunblane Primary School (Scotland) in 1996, and Beslan School Number 1 (Russia) in 2004, is probably dealt with on an ad hoc basis, if dealt with at all.

Many children in Holland's (2003) study said that schools could have helped them by listening, acknowledging their loss, and informing their peers about the death (Holland, 2003: p. 76).

5.3.3 Classroom management.

Shipman et al. (2001) found that 88 per cent of 229 nursery, primary, secondary and special schools in Southeast London reported having bereaved children in school. The management of bereaved children therefore appears to be an issue for the majority of school staff in the UK. Teachers are often assumed by others to perform a supportive role in bereavement (Rowling, 1995). Some researchers advise that an explanation regarding death from a schoolteacher is useful for children (Stuber, 2001). Certainly, teachers may be rightly perceived as being an important contact in the student's bereavement experience. However, British teachers' reactions to managing bereaved children within their classes are largely unreported (Lowton & Higginson, 2003). Sources of support for schoolchildren in this area such as education, training, or bereavement support services appear to be 'patchy' (Lowton & Higginson, 2003: p. 719). Rowling & Holland (2000) asserted that few schools have bereavement policies in place despite there being less likelihood of mishandling incidents if procedures and processes are in place.

Many societal influences were found in Lowton and Higginson's (2003) study to impact on teachers' management of bereaved students. At national level, the decline of mourning traditions in British society and lack of identification of bereaved children were generally regarded as influential in teachers' management of bereaved students. Occasionally, teachers would only learn of pupils' bereavement through essays they had set or by the child's spontaneous reportage of a family death (Lowton & Higginson, 2003). However, these scenarios are less likely to occur in special schools where pupils with severe ID are typically less likely to be able to communicate such an event.

5.3.4 Teachers' attitudes.

Teachers and parents alike describe feeling uncomfortable with discussing death with children (McGovern & Barry, 2000), reflecting the wider problems of society in acknowledging issues surrounding bereavement. Together with society's silence and teachers' reluctance to pry (Lowton & Higginson, 2003: p. 738), staff may inadvertently complicate children's grieving process through omissions and refusals to answer questions, leading to a diminished capacity to understand (Cunningham & Hare, 1989). Both children's bereavement reaction and educational outcomes will be adversely affected if grief is unmentionable in society (Yule, 1989).

The effects of stressful events that teachers may be expected to participate in need to be made explicit so that support is given to staff as well as students (Rowling & Holland, 2000). Unfortunately, a lack of support for teachers from the educational system generally (Creese et al., 2000) may prevent this. Teachers' pastoral role appears to be understated and largely unacknowledged (Lowton & Higginson, 2003: p. 739).

5.3.5 Consequences

MacHale & Carey's (2002) study provides evidence that bereavement has a significant impact on people with ID and that this group is emotionally and cognitively capable of grief. Abdelnoor and Hollins' (2004) studied the effect of the death of a parent or sibling on secondary school children as measured by academic performance, anxiety, self-esteem and school-related health questions. While their findings on health and self-esteem were inconclusive, both academic performance and anxiety scores were significantly affected. The study suggested that the effect of bereavement may be prolonged and that intermittent support could be needed for a considerable amount of time.

Furthermore, multiple bereavement is a common problem since people with ID may face additional losses (Kloeppal & Hollins, 1989). They may suddenly lose a parent and confidant, their homes and possessions, and familiar community and routines. It has been suggested that people with intellectual disabilities may exhibit reactions to grief that are labelled as 'challenging behaviour' or 'psychiatrically disturbed' because of their limited comprehension and ability to express grief (Hollins & Esterhuyzen, 1997).

Some people with ID cannot verbalise their thoughts or feelings, which makes discovery about traumatic events more difficult (Focht-New, 1996). As a result, it is not uncommon for healthcare providers, parents, or other primary caretakers to assume that people with ID do not understand the concept of death or its subsequent impact (Read, 2001). Grief may not be recognised, creating yet another loss. 'In essence, the individual may be left to grieve in the shadow of the loss and in the darkness of the lack of education, support and guidance' (Clements et al., 2004: p. 800).

There is most likely frequent misinterpretation of atypical behaviours that are not recognised as normal grief responses in the ID. These seemingly senseless behaviours might be disturbing to healthcare providers and may result in the provider's failing to identify pathological grief, leading to additional developmental and emotional disruption and derailment (Clements, 2004).

'Challenging behaviour' was coined to reflect the fact that such behaviour is not intrinsic to the individual but should be viewed as a response to environmental, social, individual and historical characteristics. Studies suggest that 12–17 per cent of those administratively defined as having an ID will display challenging behaviour (Emerson, 1998). Approximately 40–60 per cent of these will show more severe problems: physical aggression, self-injury and destructiveness towards the environment tend to be the most commonly reported. Certain risk factors increase the likelihood of challenging behaviours. These include the severity of ID; having additional secondary impairments; reduced mobility and communication skills; and certain behavioural phenotypes (Emerson 1998).

The school's place as part of the community was perceived in Lowton and Higginson's (2003) study as being a place of safety, normality, and routine to bereaved children. As a result, bereaved children have exposed teachers to behaviour that was not appropriate for them to display at home. These authors quoted problems with teachers discussing death and dying due to the multi-faith nature of their class, for example, the perceived conflict between the concepts of heaven and reincarnation. In common with other findings (McGovern & Barry, 2000), many school staff reported being apprehensive of talking to students about death and bereavement, despite children initiating discussion of these issues (Lowton & Higginson, 2003: p. 731).

Time and curriculum pressures appear to be the two most significant obstacles to dealing with death and grief in the British classroom; indeed, these factors contribute to teachers declining to participate in research into such issues (Lowton & Higginson, 2003). There is little free time within the British educational system for teachers to deal with issues that fall outside of the curriculum.

Endnotes

[1] Participants with an ID cited fear of their own death as seventh on a list of ten, whereby those without an ID cited the same fear as ninth on their list.

[2] Those without an ID cited this incident as being eighth on a list of 10. In the UK, road traffic accidents contribute to a category of other injuries (including poisonings) ranked as the ninth most likely cause of death (British Heart Foundation, 2005).

[3] Arafat (2003) illustrates how 93 per cent of Palestinian children report feeling permanently in fear of violent attack.

Chapter 6 Hermeneutics of religion

6.1 Introduction

According to the 2001 Census (Office for National Statistics, 2003), the UK population includes widely diverse religious communities, including approximately 42 million Christians, 1.5 million Muslims, over 500,000 Hindus, 340,000 Sikhs, over 250,000 Jews and a wide range of less numerous religious communities. However, little policy, practice, or research attention is paid to the role of religion in the lives of people with ID (Turner et al., 2004). In fact, the White Paper 'Valuing People' (Department of Health, 2001) contains only a single mention of religion (see p. 20). Therefore, when people with ID are asked about their lives, religious issues are rarely included (Swinton, 2002), with such interests often ignored or discouraged. There are a number of reasons for this issue to be given higher priority. First, as for any citizen in the UK, people with ID have a fundamental human right of freedom of thought, conscience and religion, now enshrined in UK law as Article 13 of the Human Rights Act (1998), and services that do not respect these freedoms are open to legal challenge. Second, service practices fundamental to current English policy, such as person-centred planning, emphasise the importance of meeting aspirations (Routledge & Sanderson, 2003). The person-centred planning process should therefore routinely include (if chosen) a spiritual and religious dimension. Finally, there is some evidence that spirituality and religious expression can have positive effects on physical and mental health generally (Swinton, 2001).

In this chapter, I consider three broad themes. Firstly, I explore the issues pertaining to the pedagogy of RE and the creation of an intellectually accessible curriculum. Secondly, I consider assumptions that ideas about God require a high level of abstract thinking, leading to decisions as to what the necessary cognitive threshold is for the membership of religious communities. Thirdly, I consider the conflicts embedded within state-sponsored RE to ask whether values and belief systems are forced upon children and adolescents with ID. Finally, I summarise the chapter by presenting the belief system of the participants.

6.2 **Pedagogy**

6.2.1 Political and social influences

What is generally not well reported is that in 1987 there was discussion between the then Secretary of State for Education and representatives from the Church of England about whether Religious Instruction could be changed, not to Religious Education, but to Religious Studies. The reason was that many teachers were already adopting a more phenomenological approach, which enabled them to stand back from the truth claims of the various religions in order to study them more 'objectively' (Brown, 2002). However, Parliament would only go as far as adopting RE. Today, Religious Education must be taught in all schools, even though there are no requirements set down for it in the National Curriculum. This is to allow each Local Education Authority (LEA) to vary what is taught to reflect demographic considerations determined by their local SACRE.

The 1996 Education Act states that an agreed syllabus must reflect the fact that the religious traditions in Great Britain are mainly Christian, whilst taking account of the teachings and practices of the other principal religions represented in the country. A glance at any locally agreed syllabus for Religious Education will indicate a curriculum focused on the acquisition of the six principal religions represented in Great Britain rather than a curriculum based upon central concepts (Broadbent, 2002): a focus on *religions* rather than *religion.* Currently, decisions about the content of RE at both LEA and school level are dominated by a perceived need to teach pupils the 'facts' about individual religions (Broadbent, 2002: p. 25). In October 2004, the first non-statutory national framework for teaching Religious Education was launched. Developed jointly by the Quality and Curriculum Authority

(QCA), the DfES, major UK faith groups and RE professionals, the framework set out the national expectations for teaching and learning in RE to help ensure all children benefit from consistently high quality RE teaching. However, the resulting model syllabuses were no more than religious content unrelated in any educational way to the developmental stages and interests of pupils (Broadbent, 2002).

6.2.2 Curriculum chaos

Hirst (1974) asserted that a liberal education is a 'deliberate, purposeful activity directed to the development of individuals and particularly with the development of mind' (Hirst, 1974: p. 32). He identified eight 'distinct disciplines' or forms of knowledge, one being religion, the others being mathematics, physical sciences, human sciences, history, literature, fine arts and philosophy, and claimed that these forms of knowledge constitute the ways in which our experience of the world is structured. Each form of knowledge has four distinguishing features, namely central concepts particular to itself, a distinctive logical structure, distinctive expressions or statements, and particular techniques and skills for exploring experience. For religion, Hirst suggested *God* and *sin* as examples of central concepts. The logical structures of religion might be perceived in more than one way: it might be studied through the consequences of its central concepts, for example, the consequences of a belief in a Creator God. Alternatively, religion might be studied phenomenologically, namely through its ritual, mythology, doctrines, ethics, society, and the experiential dimension. In its creedal statements, religion is abundant in distinctive statements and expressions, while particular techniques and skills for exploring experience may be found in the practice of prayer. For Hirst, the purpose of an education based on these forms of knowledge would not be focused on learning a vast body of knowledge, but rather on understanding the way in which it 'works' (Hirst 1974: p. 47).

Stressing the integral links between teaching, learning and assessment is not simply to reinforce the link between these disciplines and the curriculum, but to also illustrate how, in RE, assessment can get caught up in philosophical issues about the nature and purpose of the subject (Keast, 2002). The existing national framework affirms the legal basis of religious education and gives non-statutory guidance for Agreed Syllabus Conferences (ASC) and faith communities to consider in determining which religions are to be studied. It is suggested that Christianity should be studied at all key stages and ASCs, and schools should ensure that by the end of Key Stage 3, other principal religions represented in Great Britain, i.e. Buddhism, Hinduism, Islam, Judaism and Sikhism, should have also been encountered in sufficient depth. It is only 'recommended' (p. 14) that secular philosophies such as humanism are studied. In fact, at key stage 3, it suggests that a 'secular world view' (p.29) may be introduced 'where appropriate.'

The Qualifications and Curriculum Authority's (QCA) (2001) *Curriculum Guidelines for Pupils with Learning Difficulties* presented generic guidelines for teachers working with pupils who may still be working towards Level 1 when they are sixteen years old. Accompanying the generic material are subject booklets with specific guidance and 'P' (progress) levels. These levels precede Level 1, so that the progress of pupils with ID can still be assessed and reported on. However, the participants' attainments may at best be within the upper P scale [1] range (P4–P8) for much of their school careers (that is below level 1 of the National Curriculum i.e. under 5–7 chronological age).

Historically, RE has been dogged (both from within and outside the profession) by feelings of ambivalence regarding the appropriateness of the subject for children with ID, particularly those whose difficulties are of a severe and complex nature. This may have been due to perceptions, perhaps misplaced, regarding communicational barriers, and the controversial nature of religion itself. Furthermore, there may be a general unwillingness to address spiritual issues, which is indicative of a wider failure to address emotional needs in people with ID. This situation became more acute with the implementation of the National Curriculum, introducing academic subjects into the special school curriculum, which was previously more concerned with developmental and functional activities. This presented a particular challenge to teachers of children with severe ID, because of the difficulty of conceptualising subjects for the very early developmental level. Additionally, special needs teachers may have felt tempted to give it a lower priority than some other curricular subjects, particularly when the timetable still had to accommodate the time-consuming range of specialist therapies and medical treatment required by their pupils.

6.2.3 Critical thinking

Theological and philosophical discourse has a strong place in the religious traditions. Gates (2002) considers a question that goes beyond surface meaning: Is there anything beyond death and what form may it take? He suggests that such a question may be one that any person may ask at any time in their life. At around Key Stage 2

(KS2), children begin to question the authenticity of the Bible. Questions of historical verification, scientific scrutiny, and 'empirical check-out' (Gates, 2002: p. 108) are systematically asked and pursued as children get older. Indeed, this interrogation should be encouraged within education. However, certainly in relation to children with ID, Gates suggests:

> Constraints of cognitive development can be used as a disincentive against the promotion of symbolic understanding before a certain age and stage, the same can also be invoked to discourage any priority being given to critical thinking.
>
> Gates (2002: p. 101)

There is much in contemporary western culture which takes as unquestionable norm that the goal of education is human autonomy (Gates, 2002). Therefore, enabling the pupil to think for himself or herself becomes the overarching goal of every subject. The Archbishop of Canterbury, Rowan Williams, concedes that religion could not, or should not, claim a sort of immunity from prosecution:

> Of course education shows people the difference between good and bad arguments, it sensitises students to what rhetoric is, how illegitimate persuasion works as well as proper argument and commendation.
>
> (Williams, 2004 http://www.number-10.gov.uk/output/Page5480.asp)

However, the participants in this study would be unlikely to possess the cognitive capacity to employ the thinking skills to *challenge* the authenticity of a taught belief system. Let us consider Bertrand Russell's (1952) famous challenge to the existence of God:

> If I were to suggest that between the Earth and Mars there is a china teapot revolving about the sun in an elliptical orbit, nobody would be able to disprove my assertion provided I were careful to add that the teapot is too small to be revealed even by our most powerful telescopes. But if I were to go on to say that, since my assertion cannot be disproved, it is intolerable presumption on the part of human reason to doubt it, I should rightly be thought to be talking nonsense. If, however, the existence of such a teapot were affirmed in ancient books, taught as the sacred truth every Sunday, and instilled into the minds of children at school, hesitation to believe in its existence would become a mark of eccentricity and entitle the doubter to the attentions of the psychiatrist in an enlightened age or of the Inquisitor in an earlier time.
>
> (Russell, 1952: pp. 543)

Swinburne (1991) appealed to what he calls the *principle of credulity* in support of the argument for religious experience. The principle of credulity states that if we have a perceptual experience of X, then X must play a causal role in producing that experience, or more simply, it seems to a subject that X is present, then probably X *is* present. Generally, Swinburne suggests it is reasonable to believe that the world is probably as we experience it to be. Therefore, unless we have some specific reason to question a religious experience, we ought to accept that it is at least *prima facie* evidence for the existence of God. Martin (1986) mocks such a principle by suggesting that if this is true we would be overburdened with creatures such as fairies and goblins. However, it is not inconceivable to consider how the world of a child with ID may actually *be* overburdened with such imagery. For example, the underlying philosophy of J. R. R. Tolkien's work is based upon the creation of a secondary world or 'the inner consistency of reality' (Tolkien, 1947: p. 38), which enable his fantasy stories to possess credibility in relation to their legitimacy. Within this context, it is also helpful to briefly revisit Vandenberg's (1993) findings which illustrate how increased fears of imaginary creatures were reported from children with ID when compared with a non-disabled group, suggesting how normal fears may be linked with the level of cognitive functioning. Examples of this in the UK include how children's belief in the Tooth Fairy or Father Christmas disappears at certain stages of their cognitive development. Therefore, it does not require a giant leap of imagination to consider how belief in a god is formulated similarly to a belief in fairies or goblins. However, such beliefs are not carried into adulthood by the non-ID due to the maturing functionality of their rational critical thinking and reasoning.

6.2.4 Creating inclusive Religious Education

QCA identifies (2001) four ways in which pupils can make progress in RE, namely:

i. By moving from a personal to a wider perspective.

ii. By increasing their knowledge of religious beliefs, practices and experiences.

iii. Through developing understanding of the meaning of stories, symbols, events and pictures.

iv. Through developing and communicating their individual responses to a range of views.

(QCA, 2001: p. 4)

However, Broadbent and Brown (2002) suggest how RE syllabuses are weighted down with information partly because the religious are most concerned that pupils *know* everything about their faith and partly due to the obsessive belief that everything has to be assessed. How then do we teach religion in such a way that it can be inclusive?

When we reflect upon our lives, it becomes clear that we are constantly involved in a cycle of activities in which our physicality, our cognition, and our affections are bound together; such is the essence of personhood. However, when education values the cognitive faculty above all other aspects of personhood, how does such bias impact upon the ID?

> This emphasis upon measurable achievement is very evident in current curriculum policy, with 'standards' being interpreted in the currency of the marketplace, while other aspects of human achievement, which are less easy to quantify, are effectively sidelined in schools.
>
> (Gillard, 1998: p. 120)

Hammond (2002) suggests that in spite of some forty years of professional literature concerned to span the gap between students' experience and the religious traditions, the spiritually rich subject matter of an RE syllabus still too often results in spiritually bland exchanges in the RE classroom. Hammond (2002) believes this is more about approach than content. Like much of schooling the majority of approaches surveyed in Michael Grimmitt's *Pedagogies of Religious Education* (Grimmitt, 2000) are largely disembodied and essentially cognitive.

My own observations of the participants in this study demonstrated their enjoyment of a range of teaching methods and resources, including drama, art, narrative, and music. Essentially, their RE was based upon a predominantly experiential methodology, as previously described in the school's Ofsted report. Hammond (2002) asks whether the enactment of ritualistic behaviour as part of RE would perhaps promote a more engaged and fruitful spiritual encounter between pupils and the world of religion. Schechner (1988) stresses that the efficacy of ritual and the entertainment of theatre are not so much in opposition as two poles on a continuum, and adds: "no performance is pure efficacy or pure entertainment" (p. 120). Schechner (1988) suggests that "any ritual can be lifted from its original setting and performed as theatre" (p. 138). The significance for RE is that elements of ritual structure and process can be performed in a context not predetermined by the beliefs and doctrines of faith. The use of music, dress, objects (symbols), words and actions enable the opportunity to engage in the subject of the event and gain access to the experience of others. The understanding gained by means of performance is of a different order to the information resulting from reading a description or watching a film. However, what makes a celebration religious is not the activities but their function in the lives of the participants (Hammond, 2002: p. 194). The (respectfully) performed classroom rituals are not religious. However, they can provide an invaluable means for understanding religion.

Elements of ritual process in the form of experiential learning strategies are fairly widespread in RE classrooms (Hammond, 2002), especially the use of *symbols* and *narratives*. Pupils can respond to symbols from the art and architecture of religious objects and sites. Paul Ricoeur's statement, "symbols give rise to thought" (Ricoeur, 1967: p. 10), depicts this quality and the related need for interpretation (Hammond, 2002). Narratives are the primary mode of communication in religion. The RE teacher recognises that the power of the imagination, as a means of participating in the experience of others, allows an objective study of the human capacity for transcendence. Radford's (1999) account of religious and spiritual education is highly relevant here: he believes that the study of religious texts provides a conceptual framework for the exploration of spiritual experience.

> Religious education is the process of studying literature and works of art in which human beings have attempted to engage in a process of recognition and definition of themselves spiritually.
>
> (Radford, 1999: p. 168)

Webster (2004) asks whether there is a medium particularly suited for use in the classroom, especially with children at an early developmental stage, which can be grasped both cognitively and affectively. She suggests that narrative is well suited to this purpose because "it casts abstract truth which is cognitively perceived, in the form of human experience, with characters to which we can relate and with whose dilemmas we can be induced to identify" (Webster 2004: p. 122). Religious stories are found in all major faiths and encapsulate many aspects of the human condition. Many religious festivals and occasions, both sombre reflection and celebrating or rejoicing, reflect a story.

Webster (2004) suggests that teachers may need to question the traditional emphasis on the need for literacy in order to be able to access and enjoy literature. Grove (1998) asks us to consider literature as an art form that can be experienced at a physical level, just as can a painting, a piece of music, a film or a dance.

> A proper recognition of the sensory appeal of the text , which then generates an affective response and in turn leads to a reflective or cognitive response, immediately makes it much more apparent how story can become an inclusive medium.
>
> (Webster, 2004: p. 122)

Wajnryb (2003) suggests that if *culture* is constructed as the sum total of everything that binds a people together, then the telling of stories is humankind's longest-running means of preserving a collective sense of itself. Stories prompt visualisation, auditory imaging and curiosity, and help us to share experience. Schank (1990) suggests how hearing others' stories can reassure us that we are not alone in our existential dilemmas.

The following quote would not be out of place within the RE of children with ID:

> It brings together intellect and feeling and enables personal expression, reflection and emotional development. As an integral part of culture, past

> and present, it helps pupils understand themselves and relate to others, forging important links between the home, school and the wider world.
>
> (DfEE and QCA, 1999)

However, the subject in question is music, a significant cultural aspect of all religions. During my teaching observations, music appeared to make a dramatic impact, engaging children of all abilities. Music has powers to alter and match moods, to sustain and evoke emotion, to induce trance or ecstasy states, to express worship, and to entertain (Bowker, 1997). At the same time it is an activity in which the class and teachers can be engaged in the same time, for example, singing and chanting.

6.2.5 Irreligion

On 20th January 2004, the Institute for Public Policy Research (IPPR), with the support of the British Humanist Association, held a seminar entitled *What is RE for? Getting the National Framework Right.* As the Government and Qualifications and Curriculum Authority (QCA) considered the formulation of the first ever National Framework for RE, this roundtable discussion aimed to provide a space to explore some of the pertinent issues and feed into the debate. The IPPR 'think tank' argues that since only 7 per cent of the population attend church, mosque or synagogue, the subject should be modernised and brought into line with where we are at present as a nation.

The IPPR suggests that there are two standard justifications for compulsory RE: (i) a social justification, to the effect that the study of religion equips pupils for life in a multicultural society, and (ii) a moral justification, to the effect that the study of religion is morally educative. The social justification suggests how an understanding of religious individuals and communities better equips pupils for life in a multicultural society. Whether or not pupils hold religious beliefs themselves, they will live and work among people who do, and they will be better able to communicate and negotiate with such people if they understand their beliefs and values. This is reflected in RE, as *learning about religions* articulates the objective of equipping pupils with an understanding of religious individuals and communities. It requires that pupils should come to have knowledge and understanding of religious beliefs, teachings, practices and lifestyles.

However, the IPPR suggests there are objections to social justification: firstly, religion in contemporary Britain is a far less significant social phenomenon than it once was: Britain is now a country in which the great majority of people neither belong to religious institutions nor engage in religious activities. Secondly, there are many more kinds of difference between people than differences of religion. The IPPR report suggests placing more emphasis on other thought systems that are not religious, like atheism and agnosticism. The Archbishop of Canterbury, Rowan Williams, suggests the report misdiagnoses the 'problems' with RE.

> What is implied is something like this, I think. A person's religious commitment is in some sense an obstacle to freedom, the freedom to reach a rational conclusion based on adequate evidence, and as such it should be subjected to criticism on behalf of the educational system. It is essentially a prejudice and so a fair target for challenge. This

> criticism is carried out in the name of a neutral procedure that can be identified as rational - the reaching of conclusions safely based on evidence - and administered by educational professionals.
>
> (Williams, 2004 http://www.number-10.gov.uk/output/Page5480.asp)

Although Williams suggests he is not in the business of planning a curriculum, he suggests how it is possible to construct lessons in religious studies (although 'Religious Studies' does not exist in the National Curriculum) focusing upon what fundamentally constitutes a testing of religious hypotheses. Williams suggests pupils may be introduced to certain biographical and autobiographical texts and other literature, for example, the testimonies of Etty Hillesum, Simone Weil, Andrei Sinyavsky. He suggests that pupils should later be introduced to the works of Iris Murdoch or Fyodor Dostoevsky on the death of God prior to reading Philip Pullman's *His Dark Materials* (Williams, 2004). Williams suggests that if the IPPR report's implication is that RE produces young adults incapable of looking critically at religion, the statistics hardly suggest too much ground for concern. However, while Williams' reading list would certainly provide a rich and provocative experience, the introduction of biographical and autobiographical texts is aimed at pupils aged fifteen-plus, while the works of Murdoch and Dostoevsky are targeted at pupils aged seventeen-plus. As a result, the concept of critical thinking employing such a methodology is ineffectual for the needs of the RE teacher as previously outlined.

Williams disagrees with the IPPR's recommendation to introduce thought systems such as atheism and agnosticism. He states that any attempt to teach atheism as a system is a deeply confused aspiration (Williams, 2004). However, this would be a point many groups, such as humanists, would challenge. Additionally, the teaching of irreligion does not necessarily imply an impiousness or lack of belief in the supernatural or in deities; such a person may be a non-religious or non-practising theist. In particular, those who associate negative connotations with 'religion' or see it only as 'organized religion' often hold spiritual beliefs despite describing themselves as irreligious.

6.3 **Cognisance**

6.3.1 Language and belief

Religion would seem to be a truly universal trait among humans. Every human tribe that has ever been encountered has some form of belief in a spirit world and most (although perhaps not all) have some sense of an afterlife (Dunbar, 2004). All engage in rituals and prayers for the benefit of an unseen world. We have no evidence of any kind that would seriously suggest that any other species aside from ourselves has anything remotely resembling religion. However, this is not simply because other species lack language, as language is not what makes religion or religious belief possible.

Peter Nichols' 1960s stage play, *A Day in the Death of Joe Egg*, revolves around a married couple, Sheila and Bri, and their relationship with their daughter who has cerebral palsy and cannot communicate, whom they nickname 'Joe Egg'. A *mise en scène* shows Joe Egg in a wheelchair after returning home from her daycare centre:

> (Bri) "Home again: safe and sound... What was that? Saw Jesus. Where was he, eh? (Joe Egg makes a moan like a baby, or animal, that is unconscious.) I see..."
>
> (Nichols, 1967 p.17)

Nichols suggests that the disabled child's communication is animalistic. This poses the question: is society anthropomorphic or zoomorphic towards the ID? MacIntyre (1999) suggests there is a reinforced cultural tendency to forget what does indeed distinguish human beings from members of all other species. Among these reinforcements are the philosophical enquiries into the nature of language, on which Heidegger, Husserl and Gadamer have been the defining influences. Commonly, a pattern of argument is as follows: some particular human capacity is made the object of enquiry: the capacity for having thoughts, or beliefs, or the ability to act for reasons, or the power to frame and use concepts. It is then shown how, contrary to the views of some philosophical predecessor, the human exercise of this particular capacity involves the possession and use of language. It is finally further concluded that, because nonhuman animals do not possess language, or at least the requisite kind of language, they must also lack the capacity or ability or power in question. Therefore, it has been argued that nonhuman animals cannot have thoughts, must lack beliefs, cannot act for reasons and in their encounters with the objects of their experience must be innocent of concepts (MacIntyre, 1999).

In my Presentation of Findings, I suggested how some participants were at the extremities of language-based methodologies. All the participants who contributed to the study struggled with comprehension and expression to some degree during the interviews and three of the original participants failed to contribute anything coherent at all. However, the danger of suggesting that language is necessary for thought and subsequently for religiosity or spirituality is potentially dehumanising. Advances in speech and language therapy and the development of alternative methods of communication, e.g. signing and gesture systems, pictorial symbol systems, and (augmentative) information, communication and technology methods such as electronic communication aids, have enabled children with ID to communicate effectively without using oral language. Therefore, while I remain consistent with Gadamarian thinking which places language at the core of understanding, I interpret language as a range of methods that enable communication.

It is a fact that some apes may well have the (measurable) capacity to exhibit a higher IQ than that of a person with a severe ID. This example creates two interesting perspectives in relation to status. If we humanise the ape, we elevate the animals' status and are increasingly forced to confront ethical and moral issues of animal rights, for example, their use in medical research, their incarceration in zoos, etc. This leans towards Singer's (1975) view that species is, in itself, as irrelevant to moral status as race or sex. (Singer's 'Great Ape Project' is pressing for the extension of three basic rights to the great apes: the right to life, the right to liberty, and the right not to be tortured.) However, if consequentially we dehumanise the person, we reduce this group's status to confront other dilemmas. For example, if the ID person's status is relegated, we may make them increasingly vulnerable: I have previously illustrated how there may be little difference in 'quality of life' decision making between the medical and veterinary professions. So how do we manage such propositions?

Gould (1999) states that in biological terms, with species defined by historical and genealogical connection, the most mentally deficient among us is as fully human as Einstein. If we suspend as unprofitable the search for a cultural way of differentiating humans from other animals, it is possible to take another approach to identify the human quality that no other animals possess.

6.3.2 Theory of mind

The research questions were designed to confront a fundamental basis for this research: to discover if the participants actually demonstrated the cognitive ability to *comprehend* 'religion'. It may be useful to look to science to understand what it means to be human (Fernandez-Armesto, 2004) to frame this line of enquiry. Dunbar (2004) states how most living organisms that have brains of some kind are probably aware of the contents of their minds, for example, they know they are hungry or that there is a predator close by. Such organisms are said to possess first-order intentionality. Having a belief about someone else's beliefs (or intentions) constitutes second-order intentionality, the criterion for theory of mind.

However, second-order intentionality is not really enough to drive a metaphysical belief. If religion is to have any useful purpose, then the gods must be able to understand what *I* want. So it seems likely that religion must presuppose third-order intentionality: I believe (i) that there are gods who can be persuaded to understand (ii) what I really desire (iii) and who, having done so, will act on my behalf (Dunbar, 2004).

Such intentionality may extend to five or six orders. However, not all people can aspire to these heights. There is considerable interest in the possibility that schizophrenic individuals (and perhaps even those suffering from bi-polar depressive disorder) score poorly on theory of mind tasks – at least during the more extreme phases of their illness. This may explain why paranoia is often a component of schizophrenia, whereby mind-reading modules are working overtime without the benefit of the more rational part of the mind to act as a brake on the more outrageous inferences made on the basis of tenuous evidence (Dunbar, 2004).

Another group who also score poorly are autistic people. However, theory of mind has been rarely studied in people with severe ID (Jervis & Baker, 2004). In the few studies conducted, differing results have been found. These may be attributed to a variety of factors, e.g. the different chronological ages of samples. More recently, researchers in the field of ID have begun to explore the possibility that theory of mind is differentially impaired across different genetic syndromes (Abbeduto et al., 2001). Despite the popularity of theory of mind tasks, they are associated with interpretive problems when used in studies of individuals with ID. In particular, the tasks are linguistically demanding, requiring that the participant is able to process the multi-sentence story, understand the test questions, and formulate appropriate verbal responses. This raises the possibility that, for some participants, poor performance in the false belief task may reflect limited linguistic ability rather than impairments in theory of mind (Abbeduto et al., 2004). Individuals with ID typically have deficits in language and these deficits can sometimes be more severe than expected from measures of their non-linguistic cognitive ability (Rosenberg & Abbeduto, 1993).

6.3.3 The great divide

This appreciation of the complex nature of human mental life leads to the inevitable question: is theory of mind unique to humans or is it a more general feature of animal psychology? Dunbar (2004: p. 54) asks: 'Are we alone in the extraordinary mental universe in which we live?' One of the difficulties in answering this question may relate to the way that we naturally ascribe human mental states to the rest of the animal world. A number of attempts to devise foolproof false belief tasks for use with animals have been undertaken, and even allowing for the most charitable interpretation of these results, neither chimpanzees nor dolphins perform anything like as well as six-year-old children. Dunbar (2004) suggests that the issue really boils down to the question of whether animals really *need* the theory of mind to work effectively in the kind of societies they live in.

The conclusion here is that apes and humans share a number of important advanced cognitive abilities. However, they differ in one respect: the extent to which humans can detach themselves from the world as they experience it. This allows humans to reflect on the world as they find it, to wonder if it could have been otherwise. In contrast, apes (and almost certainly all other animals) have a much more direct experience of the world, always in the here and now:

> Herein lies the great divide between ourselves and our ape cousins: the world of the imagination. We can imagine that something can be other than it is. We can pretend that there are fairies at the bottom of the garden. We can construct rituals and beliefs that have no intrinsic reality other than in

> our heads. Other animals cannot do that because they cannot step back from the world and wonder how it might be if it was different from the way they perceive it to be.
>
> (Dunbar, 2004: p. 164)

6.3.4 Interactions

Ever since Thomas Huxley's (1894) essay on *Evolution and Ethics*, it has been clear to many scholars that the Darwinian perspective on evolution has profound implications for one's perspective on human existence, humankind's place in nature, and religion (Kurland, 1999). Religion, in its most basic form, requires us to suppose that there is a world other than the one we see. In order to be able to engage in religious activities, we have to believe that this parallel world is occupied by beings who have intentions that can be influenced by behaviour such as prayer. If these beings have intentions that we are *unable* to influence, then religion has no role to play (Dunbar, 2004). Therefore religion, if it has any real value, has to be able to influence the future for us.

The participants believed that a physical action, e.g. sharing or helping others, would elicit God's pleasure, whereas, for example, aggression or violence would incur God's displeasure. This can be considered consistent with a God that can be persuaded to understand what the participant desires, i.e. gratification in their behaviour. However, from this standpoint, to suggest that the participants' understanding of the typical emotional states of *happiness* and *unhappiness*, or more accurately, due to their transient nature, *pleasure* or *displeasure*, may elicit benevolence or non-benevolence from their God is speculative. Theistic judgement, as one of the fundamental principles of (predominantly) Christian religion, was not demonstrated. Therefore, although *action* and *reaction* were understood, this did not unambiguously demonstrate third-order intentionality, i.e. that God would subsequently act on their behalf.

If the concept of theistic judgement is removed, we find the potential for the participants' understanding of Buddhism, Hinduism and Sikhism, only a different kind of moralistic appraisal, i.e. karma. The role of God to act on the participants' behalf was therefore not necessary, as their progress to heaven was not dependent on retributive 'justice'. This is not to suggest the participants did not understand the concept of reward and punishment, in fact quite the opposite, as many of their general behavioural incentives were based upon the psychology-based child behaviour management programmes of rewarding positive behaviour, e.g. star charts, and sanctions, e.g. time-out. However, it *is* to suggest that such concepts were not demonstrably understood in relation to religion.

Exploration of the evolution of mind and the capacity for religion identifies a number of signposts that suggest that religious belief is more cultural than spiritual in nature. Perhaps by providing us with a satisfactory and convincing explanation of the appearance of complex traits in evolution, Darwin has eliminated the need for a God to have created us: a creator is logically unnecessary, because the Darwinian mechanism leaves nothing for such a God to do (Kurland, 1999).

My conscience has wrestled with the suggestion that while God can be found within the normal human frontal lobe cortex, it may be found absent within the brain structures of the more severely ID. Similarly, God may also be outside the functioning capacity of other electrochemical processes that exist within those with, for example, brain injury and very young children. However, if God is a creator, he is a patient one. From the macro scale of evolution to the micro scale of foetal growth, we can only be aware of God at a certain stage of neurological development within the central nervous system. If we believe in evolution *and* God, there must have been a moment when God either put a soul into a formerly animal lineage, or the soul must have evolved alongside the biological development of the brain. Of course, it could be argued from a metaphysical standpoint that we do not necessarily need to *know* the existence of something for it to actually exist. However, without the ability to comprehend God, one must ask what would be the point of such an existence?

Grimmitt (2000) suggests how the function of RE is not about discovering a *truth* about God. Cooling (2002) suggests there is no final agreement on what right or wrong answers there may be in RE. Religion may claim there is an afterlife that can be neither proved nor disproved. After all, while the theist can (theoretically) be proved right, it is only the atheist who can be proved wrong.

6.4 **Doctrine**

6.4.1 Truths and untruths

Additional to concerns about the scope for misunderstanding resulting from presenting children with concepts beyond their comprehension and the fondness of governments for using RE to promote morality in order to produce compliant citizens, there are fears about religious indoctrination (Webster, 2004). Within the National

Curriculum, especially when learning *about* religion, we see creationism introduced at an early stage. Furthermore, the concept of intelligent design is explicit in education through literature, songs, etc. However, the idea of evolution is not introduced until KS2 (aged 7 plus), a cognitive level many ID children will never attain.

On 26th March 2002, 43 eminent scientists of the British Humanist Association (BHA), wrote to the Blair government and relevant government departments, raising concerns that some state-funded schools were exploiting science to teach creationism [2], while presenting Darwinism as 'a matter of faith' (Channel 4 News 11/3/02). The BHA's position on the teaching of creationism in schools was, broadly, that it was wrong to present creationism either as the literal truth or as a bona fide scientific theory. In the US, this issue appears to be an even larger problem. In 1996, the Alabama State Board of Education insisted that an insert was pasted into biology textbooks. Known as the 'Alabama Insert', the text began by stating: "This textbook discuses evolution, a controversial theory some scientists present as a scientific explanation for the origin of living things, such as plants, animals, and humans." In 2005, the Kansas School Board requested a change to the definition of science so that Darwinism could be challenged in the classroom (Wilgoren, 2005), prompting the prominent evolutionary theorist Richard Dawkins to suggest how 'ignorance is God's gift to Kansas' (Dawkins, 2005).

To induct children into a particular faith is an approach favoured by many Catholic, Evangelical Christian, Islamic and Jewish schools. This would be an approach favoured by many anti-realists who maintain their religious truth claims are right because these are the claims taught by the teaching authority of their religious group.

The function of RE is therefore seen as being to help children to accept these framework beliefs. However, this could also be favoured by realists who are convinced that they alone have an understanding of truth, and that the function of schools is to educate children into these ultimate truths. Young people will grow up within a firm framework, which will be endorsed by their parents. However, the problems are that each group grows up with a conviction of the rightness and perhaps superiority of their own perspective and with little realisation of the cultural relativity of many claims to truth.

The idea of such confessionalism can generate considerable controversy. Stinson (2005) suggests there is a danger that the creation of an education system to suit religious interests may lead to segregation and sectarianism and warns of how faith schools can be established by religious trusts taking ownership of community schools. Such concerns were not helped by the Labour Government's 2006 proposals for local authorities to hand more control over to self-governing trusts (Bennet & Charter, 2006).

The participants in this study conformed to an indoctrination into Christian religious beliefs, a situation described as an abuse of power within the context of state-funded education (Cooling, 2002). Hand's (2002) objection to such education (typically found in faith schools) is that by definition RE presents religious propositions, and as no religious propositions are known to be true, teaching for belief in not-known-to-be-true propositions is indoctrinatory.

To defeat this premise it would be necessary to show that there are at least some religious claims for which the evidence is decisive. St Thomas Aquinas, famously argued that there are (five) ways of proving the existence of God. If one of these proofs were successful, it would have to be admitted that a person who believed in God on the basis of that proof was in possession of religious knowledge. However, no attempt to demonstrate the truth of a religious proposition has stood up to rational scrutiny.

The theory of truth (realism) suggests that statements such as 'Jesus rose from the dead' or 'The Holy Qur'an was dictated to the Prophet by the Archangel' are true only if such historical events actually occurred. Opponents of this premise argue that religious propositions are in principle unverifiable. However, if one cannot distinguish between the circumstance under which an assertion would be true and the circumstances under which it would be false, it is not clear that anything has been asserted. Something must count as evidence for or against a proposition, and there must be a point at which the evidence accumulating on one side or the other becomes rationally decisive.

The assertion that teaching for belief in not-known-to-be-true propositions is indoctrinatory is an argument that philosophers of education have been making for many years. I. A. Snook wrote in 1972 that:

> Christian teachers of all persuasions are expected to teach for belief in certain propositions, the propositions varying from sect to sect. It is clear

> that such teaching is indoctrination because whatever the particular proposition, the evidence for it is inconclusive: it is rejected by other competent authorities. That all religious propositions are doubtful in this sense is sufficient to indicate that teaching for belief in them is always indoctrination.
>
> Snook (1972: p. 74)

A way in which many of us acquire a great many of our beliefs is by the exercise of perceived authority. When a person perceived by others to be an intellectual authority asserts that a proposition is true, he/she places them under a rational obligation to accept his/her assertion. It should be clear that imparting beliefs in this way does not count as indoctrination. The exercise of perceived intellectual authority is to be sharply distinguished from the exercise of psychological power. If a person believes what he/she is told because the force of the person's personality is overwhelming, or because of fear of the consequences of disagreeing, the belief is non-rational and the person can be described as being indoctrinated. However, if people believe what they are told because they consider someone to be an intellectual authority, they are only doing what reason dictates.

Hand (2002) contends that other than the early years of schooling pupils do not normally regard their teachers as intellectual authorities on religious questions. He suggests that children learn very quickly that there are no legitimate religious authorities and that their teachers are in no position to testify to the existence of decisive evidence for the truth of religious propositions. Pupils may respect their teachers' religious beliefs, and recognise them as authorities on the history, philosophy and sociology of religion, but do not regard them as authorities on questions of religious truth. However, 'early years' in this context refers to an intellectual level to which the ID are permanently consigned.

However, religious authority is not always challenged, especially in relation to the epistemology of *truth*. Consider for example the Abrahamic religions of Christianity and Islam. The Catholic Church, for some time now, especially with Pope Benedict XVI as head of the Congregation of the Doctrine of the Faith, has identified truth relativism as one of the problems of today. Relativism is accused by the Church of being a denial of the capacity of our mind and reason to arrive at truth. Truth, according to Catholic theologians and philosophers, following Aristotle and Plato, is *adequatio rei et intellectus*, the correspondence of the mind and reality. Thus, they say, relativism is linked to secularism, an obstruction of God in human life. Pope Benedict XVI in his address to the cardinals during the pre-conclave Mass which elected him as Pope, talked about the world 'moving towards a dictatorship of relativism' (Dionne, 2005). Similarly, Islam remains an undisputed authority by its believers with its exclusive claim to God (Zacharias, 2005). However, the search amongst the contradictions of numerous belief systems for one 'true' religion has yet to rationally prioritise one set of beliefs over another. It may be argued that it is more probable that all religions are false than that all religions are true. Therefore, until the *Deus absconditus* (hidden God) shows itself, the fight for credence, both literally and metaphorically, will probably continue.

6.4.2 Improvisation

Let us consider the participants' beliefs in relation to a brief overview of the six major religions in the UK. God as creator was understood by all participants. This makes the Gods of Christianity, Islam, Judaism, and Sikhism a possibly more accessible concept, with Hinduism slightly less so as God has no physical form. Additionally, Buddhism's lack of a deity may be more difficult to comprehend.

Although the participants demonstrated an understanding of how their behaviour directly influenced God's emotional state, they possessed little or no understanding of *sin* or *hell*. In fact, the participants exhibited a (universal reconciliation) belief that the deceased would progress to heaven regardless of their mortal behaviour. However, the concept of karma was not made known to the participants so we are left to speculate whether Buddhism [3], Hinduism and Sikhism would be as accessible as Christianity, Islam, and Judaism.

The participants believed that after death, the physical body transcended mortality to adopt an immortal, but still physical, existence in a celestial domain (heaven). In this form of afterlife, people are confined to coffins but have the ability to observe earthly activity. This belief is closer to reincarnation doctrines such as Buddhist, Hindu, and Sikh afterlife ontology than it is to the phenomenon of an ethereal existence (soul) as found in Christianity, Islam and Judaism.

However, there are a number of significant factors we need to take into consideration in relation to the participants' religiosity: impaired cognitive and imaginative capacity, lack of instruction in or emphasis on other belief systems (e.g. atheism), and their lack of critical thinking and natural scepticism. For example, when beliefs are called into question, it is usually the result of a 'surprising phenomenon' (Herrmann, 2003: p. 2) which is inconsistent with previously accepted 'truths'. A successful enquiry will either reaffirm previous beliefs or adapt or replace them with new understandings leading to the stabilisation of opinion, although such stability is only ever temporary. However, my findings demonstrate how the participants are taking their childhood beliefs into adulthood without the inherent capacity for re-examination. Such *consequences* of belief could be described as a lack of pragmatism: a middle way between metaphysical realism and relativism, between dogmatism and scepticism (Herrmann, 2003).

Endnotes

[1] P4 Pupils use single elements of communication, *for example, words, gestures, signs or symbols*, to express their feelings. They show they understand 'yes' and 'no'. They begin to respond to the feelings of others, *for example, matching their emotions and laughing when another pupil is laughing*. They join in with activities by initiating ritual actions or sounds. They may demonstrate an appreciation of stillness and quietness.

P5 Pupils respond appropriately to simple questions about familiar religious events or experiences and communicate simple meanings. They respond to a variety of new religious experiences, *for example, involving music, drama, colour, lights, food, or tactile objects*. They take part in activities involving two or three other learners. They may also engage in moments of individual reflection.

P6 Pupils express and communicate their feelings in different ways. They respond to others in group situations and cooperate when working in small groups. Pupils listen to, and begin to respond to, familiar religious stories, poems and music, and make their own contribution to celebrations and festivals. They carry out ritualised actions in familiar circumstances. They show concern and sympathy for others in distress, *for example, through gestures, facial expressions or by offering comfort*. They start to be aware of their own influence on events and other people.

P7 Pupils listen to and follow religious stories. They communicate their ideas about religion, life events and experiences in simple phrases. They evaluate their own work and behaviour in simple ways, beginning to identify some actions as right or wrong on the basis of the consequences. They find out about aspects of religion through stories, music or drama, answer questions and communicate their responses. They may communicate their feelings about what is special to them, *for example, using role play*. They begin to understand that other people have needs and to respect these. They make purposeful relationships with others in group activity.

P8 Pupils listen attentively to religious stories or to people talking about religion. They begin to understand that religious and other stories carry moral and religious meaning. They are increasingly able to communicate ideas, feelings or responses to experiences or to retell religious stories. They communicate simple facts about religion and important people in religions. They begin to realise the significance of religious artefacts, symbols and places. They reflect on what makes them happy, sad, excited or lonely. They demonstrate a basic understanding of what is right and wrong in familiar situations. They are often sensitive to the needs and feelings of others and show respect for themselves and others. They treat living things and their environment with care and concern.

[2] The British Humanist Association (BHA) reports how creationists are now teaching in at least one state-funded school in the UK, Emmanuel College in Gateshead. The BHA call for: a tightening up of the legal requirements in National Curriculum Science to prevent creation stories being taught as anything other than religious myths; clear guidance from GCSE examination boards to teachers and pupils that creationism is not a scientific hypothesis; reform of the Science curriculum to enable teaching about Darwinian evolution well before KS4, which may become optional in the future, suggesting it is taught at KS2.

[3] Buddhist karma works within a complex cosmological system. There are six major destinies for rebirth. They are: hell, the level of hungry ghosts (those who wander around on earth and are never satisfied), common animals, human beings, spirits, and

Brahmas (gods). To be reborn in hell, as a hungry ghost or an animal, is the result of evil karma. To reborn as a human being, a spirit, or a god, is the result of good karma.

Chapter 7 Ghost in the machine

7.1 Introduction

The death of a loved one is generally assumed to be one of the most stressful experiences that people encounter during the course of their lives (Matthews & Marwitt, 2004). Suffering such a loss strongly affects the psychological and physical well-being of the bereaved. Although most bereaved individuals report returning to an adaptive level of functioning following a loss, there has been considerable interest in those cases that fail to follow anticipated patterns.

In this chapter I initially consider the contradictions of secular and religious duality and the physiology of death itself. Next, I challenge contemporary ideas on grief and mourning to present how the participants maintain a connection with the deceased. Finally, I consider the participants' belief in an embodied soul to explain how such an intuitive notion is not unique.

7.2 The physiology of death.

7.2.1 Dualism

The participants had variable degrees of understanding of four aspects of the biology of death: universality (the fact that all living things die); irreversibility (the fact that once dead, one cannot come back to life); cessation of corporeal life (realisation that death involves the termination of corporeal functions and organs), and causality (an appreciation that it is precisely the termination of all corporeal functions that causes death). For example, it was understood that cancer and heart problems were causes of death, although they did not understand the specific aetiology.

Some of the participants' understanding of the irreversibility of death is particularly interesting. In Speece and Brent's (1992) study, they asked (non-disabled) children (aged 5–10 years) and adults if a dead person can come alive again. In reply, 93 per cent of children answered no, while only 53 per cent of the adults gave the same answer. Analysis of the adults' justification showed the incorporation of religious elements such as the suggestion of supernatural transformations (e.g. resurrection and reincarnation), which conflicted with the children's more secular belief regarding death being the end of life.

Similarly, Harris and Gimenez (2005) found that older children (aged 11) are less likely than younger children (aged 7) to judge that bodily and mental processes cease to function after death. They were more likely to offer metaphysical justifications than biological ones. The older children therefore demonstrated both a metaphysical and biological concept of death. One possible explanation is that older children have greater exposure to religious education. Additionally, perhaps, they have the cognitive ability to comprehend more abstract ideas. Harris and Gimenez (2005) suggest that adults protect younger children from the finality of biological death by offering them a less threatening perspective, namely a religious conception. Thus, as children come to understand that death implies an inevitable and irrecoverable loss of function for everyone, including themselves, the continuity of function implied by a religious conception of death becomes more meaningful and more persuasive.

It is clear from the literature that the secular and religious conceptions of death co-exist in the minds of children. However, the articulation of both conceptions is contradictory. If children do endorse both versions, they may be overlooking the conflicting implications.

> Children are likely to be especially poor at identifying inconsistent claims that are embedded not in a single text, but in distinct modes of discourse, such as religious verses biological discourse.
>
> (Harris & Gimenez, 2005: p. 160)

This conclusion leads to two different predictions. First, it implies that children should be capable of identifying the inconsistent claims of religion and biology once they are juxtaposed in an explicit fashion. Second, it suggests that dual endorsements may decline amongst adolescents and adults as they become more sensitive to the inconsistency between biological and religious conceptions of death and increasingly opt for one conception over another.

We may therefore consider whether children consider that death affects bodily and mental processes in the same way. Bering and Bjorklund (2004) found that children (aged 7–11) were more likely to understand that biological functioning ceased at death than the cessation of mental functioning. Several analyses showed that children believe that death affects the body differently from the mind (Harris and Gimenez, 2005). Children may be more likely to judge that bodily processes cease at death than that mental processes do. On the one hand, they come to understand that the body and its various parts, such as the brain and the heart, compose an integrated biological system. Therefore, they realise that once that system fails, all of its components fail. On the other hand, given the apparently non-material nature of mental processes, children may not consider that this also forms part of the integrated biological system that ceases to function at death.

It is possible that children have a natural disposition to think in dualistic terms (Bloom, 2004). Alternatively, dualist thinking may be nurtured, at least among many Western children, by their exposure to religious teaching (Bering and Bjorklund, 2004). However, the participants went beyond a distinction between mind and body; they invoked religious concepts such as God and heaven. Granted these points, it is possible that children's dualistic stance toward the fate of the mind as compared to the fate of the body is attributable to a natural mode of thinking, which emerges from the context of religious teaching.

7.2.2 The integrated organism

In the late 1960s, the general acceptance of 'whole brain death' led to the postulation that perhaps not every part of the brain needs to irreversibly cease to function in order for death to occur (Eberl, 2005). Some scholars recognised that the so-called 'higher-brain' functions of the cerebral cortex are responsible for the peculiarly human 'personal' activities of conscious rational thought. Hence, an argument is made that the death of a human person occurs when the cerebral cortex has been rendered irreversibly non-functional. This 'higher-brain' concept of death is seen as the basis for arguing that patients in an irreversible persistent/permanent vegetative state (PVS) should 'no longer be considered persons and thus should be considered dead' (Eberl, 2005: p. 30). The higher-brain concept of death defines the end of a human person's biological existence in terms of the loss of the capacity to think, feel, be conscious and aware (Veatch, 1988). The criterion for establishing this loss of this capacity is the irreversible cessation of the neocortical, i.e. higher-brain, functioning.

To understand Aquinas' account of human death, we need to first establish the Thomistic explanation for human life. Aquinas holds that that a human being's proper capacities do not begin to exist in a developing human embryo at the same time; the vegetative capacities are activated first, then the sensitive capacities, and finally the rational capacities, which signal the existence of a human being. Nevertheless, it is not the case that there are *three* souls informing a fully developed human body. The vegetative soul that first informs a living human embryo is annihilated once the embryo develops to the stage where it has sense organs and sufficient neural development for sensitive operations; it thus becomes informed by a sensitive soul that has both sensitive and vegetative capacities. The sensitive soul is annihilated once the stage is reached where neural development is sufficient to support rational operation and a rational soul that has vegetative, sensitive, and rational capacities is instantiated.

The participants cited the heart as the primary life sustaining organ in the body. Aquinas' account of a human being's death begins with his understanding of a rational soul [1] as a human body's substantial form and its *unitive* function, and as such, when the soul departs, the body is dead. Aquinas understood a rational soul to be the principle of a human body's organic functioning and to operate by means of a primary organ, identified as the heart, although contemporary science may identify it as the brain. Aquinas links a human being's death, defined as a rational soul's separation from the body it informs, with the body no longer able to actualise the soul's vegetative capacities. The clinical criterion for determining the occurrence of this event is the loss of vital metabolic functioning as evidenced by, according to Aquinas, the cessation of respiratory activity.

The whole-brain criterion has become a widely accepted standard for the determination of death, including moral approval from the Roman Catholic Church. However, it has not become a universal standard. Orthodox Judaism generally rejects the whole-brain criterion based on the scriptural reference to God breathing life into Adam and respiration thus being the primary indication of a human being's existence. Certain legislatures have adopted a policy of whole-brain death as the standard – or default – criterion for determining death, but include a 'conscience clause' whereby individuals of certain faiths may have their desire respected that the traditional circulatory/respiratory criterion be used to clinically establish death. Both whole brain and circulatory/respiratory criteria follow the same concept of human death, namely, that a human being dies when his or her body ceases to function as an organism.

Aquinas claims that conscious rational thought does not occur by means of a bodily organ, as, say, sight occurs by means of the eyes and visual cortex. While Aquinas understands the mind not to function through a bodily organ, he nevertheless asserts that the operation of a rational soul's sensitive and imaginative capacities, which do function through bodily organs, is required to provide the mind [2] with its proper object of thought while a human being is embodied. From a Thomistic standpoint, at the loss of higher-brain functioning, a substantial change occurs in which the rational soul separates from the from the body and a sensitive or vegetative soul is initiated as the body's substantial form – depending on whether any sensitive capacities remain in the still living body. The body is thus no longer identical to the body that constituted the human being insofar as it has a different substantial form. The body can continue to be informed by at least a vegetative soul until it reaches the point of deterioration where it can no longer structurally support vital metabolic functions. At this point, the vegetative soul is annihilated, the body ceases to exist as an organic whole, and is reduced to a corpse, a mere collection of basic elements (Eberl, 2005).

7.3 Attachment and mourning

The participants exhibited no obvious signs of complicated grief, i.e. symptoms of separation distress, such as longing and searching for the deceased or preoccupation with thoughts of the deceased, or symptoms of traumatic distress, such as feelings of disbelief or anger (Prigerson & Jacobs, 2001). However, the participants maintained a relationship with the deceased via a function of memory, emotion or imagination. Such imagery was often invoked through photographs, visits to graves, and religious symbolism.

The majority of the participants' parents distanced their children from funeral liturgy, visits to cemeteries, and the general effects of grief and loss. The traditional psychoanalytical presupposition (Freud, 1953) that successful mourning requires an emotional detachment (decathexis) from the deceased has arguably been 'the cornerstone of contemporary western understanding of bereavement' (Hagman, 1995:

p. 909). However, influential as this notion has been, it has largely been replaced in contemporary grief research by the recognition that mourners often remain connected to the deceased, and that this attachment is not inherently pathological or maladaptive (Neimeyer et al., 2002). To the extent there is any sort of consensus, it is that the mourner often finds a constructive way of maintaining a meaningful relationship with the deceased through private memoirs, public memorials, secular and religious rituals, and spiritual beliefs (Becker & Knudson, 2003).

On a psychological level, the relationship with the deceased is variously defined in the contemporary literature as an 'internal dialogue' (Vickio, 1999: p. 164), or a 'continued sense of attachment with the deceased' (Bonanno, 2001: p. 721). However, such a focus fails to account for the mourner's encounter with the 'presence' of the deceased, not as a memory or visitation, but rather as an 'image' encountered in dreams or waking reveries. Although we could explain such experiences as mental events, or could speculate as to their sources as being paranormal events, the actual phenomena may lie somewhere between these two extremes (Becker & Knudson, 2003).

Phenomenologically, encounters with the dead may closely resemble the reality of dreams, literature and fantasy. In other words, while not literal, they remain metaphorically 'real' to those who experience them, often described as 'vivid' or 'disturbing' (Becker & Knudson, 2003). The participant who saw 'God' in church certainly had some sort of phenomenological experience *of* God.

How do we account for such phenomena? Certainly Neimeyer et al. (2002) suggest that the social sciences have rightly avoided being drawn into such a spiritual fray.

However, one possible answer may be an alternative non-dualistic paradigm, as represented in philosophy by the work of Heidegger (1962) and Hillman (1992, 1993). Their central proposition is that the mind is not ontologically separate from the world. Rather, the mind is primordially joined with the world in and through imagination, where imagination is defined not as a mental capacity but as the basic activity of Being itself where *all* events are images. As described earlier in this thesis, Heidegger's concept of *being-in-the-world* is not a spatial relationship, but rather indicates the way that human beings relate to other entities, both human and non-human.

From a non-dualistic perspective, the dead exist primarily as images, that is, as immaterial figures which behave as if they were real persons. Therefore, from a non-dualistic perspective, when we encounter the deceased we are not responding to a ghostly image but to a metaphorical 'person' where the source is of less importance than the immediacy of the imaginary presence. Another implication of a non-dualistic approach is that mourning is an act of 're-membering' (Becker & Knudson, 2003: p. 694) the dead. The term *re-member* is intended to have several layers of meaning, including to recall or recount, and to grant the dead their autonomous membership in the living community. This idea is consistent with the role of angels, where the dead remain tied to the living world to guide and instruct. Therefore, both the living and the dead co-exist primarily as images.

> Angels (they say) don't know whether it is the living they are moving among, or the dead.
>
> (Rilke, 1992 http://www.homestar.org/bryannan/duino.html)

Hillman (1993) suggested that one's image continues to unfold its essence long after its physical manifestation in the world has ended. This unfolding gives a new purpose to biography and to mourning itself: we are not only addressing our private emotions or even our subjective memories, but also responding to our perceived expectations of the dead that we pay attention to them, honour them, or even simply acknowledge what has happened to them.

> Even further, we may see ourselves through their eyes: life evaluated by death, and the living accountable to the dead, interested in their approval and their blessing.
>
> (Hillman, 1993: p. 712)

Mourners need to embrace not only the emotional pain of grief but also its pathological imagery (Becker & Knudson, 2003). Mourning allows us to see that the meaning we make of our loss is not so much constructed as it is co-constructed and co-authored by the deceased. That is, the dead help us to write their stories, and ours as well. As Becker and Knudson (2003) suggest, in a sense, every story has a ghost writer.

7.4 **Soul searching**

The participants did not suggest a metamorphosis from a physical organism into an ethereal existence after death. So what of the soul? We know that area after area of the brain has yielded up its secrets to the probing of neuroscience, and not a trace of it has ever been found. The more our knowledge advances, the less reason we have to suppose that it exists, and the less sustainable the dualist position becomes. All the evidence we currently possess suggests that there is nothing inside our skulls that does not obey the ordinary laws of physics.

Therefore, is there any good reason to suppose there is any sort of existence outside of the functioning brain? From the field of parapsychology, we can consider three arguments. First, there is the alleged evidence of reincarnation. Stories, especially from the East, describe children whose memory claims coincide with the events of some real past life. Second, there is the alleged evidence of spiritualism, where, since from around the middle of the nineteenth century, numerous claims have been made relating to making contact with the dead. Third, there is the alleged evidence of 'near-death experiences,' often from resuscitated hospitalised patients who describe 'out of body experiences.' There are other propositions that the soul is naturally immortal or embodied. However, these theories provide us with even less evidence than that found within parapsychology.

The participants' belief that the physical body is transferred from one realm to another with its physical senses still functioning after death may be easily dismissed. However, the notion of an embodied soul is not unacknowledged. When one reads Socrates' defence during his trial for impiety in Plato's *Phaedo* (Bostock, 1986), while the soul is embodied, it is sensible of what happens in that body, and we can assume such sensibility will inevitably give rise to perceptions and emotions.

Phaedo contains two distinct and intellectually hierarchical views of life after death. One is applied to a philosopher's death, which supposes that at the end of life all aspects of conscious activity that depend upon the soul's awareness of its own body will fall away. As a result, the philosopher's disembodied soul will be capable of pure reasoning but nothing else. Such a soul will enjoy the society of other gods and other men (63b-c, 69e, 81a). The other view (which is the more usual religious view) is that the deaths of non-philosophers suppose that all conscious activities of living human beings will persist into the disembodied state. Therefore the soul retains its desires for things bodily (81e1) and retains its human character as virtuous or vicious, social or anti-social, and so forth (81e-82b). Souls may also retain a memory of their past lives (108b). Dead souls can be punished and rewarded (133d-e), they can *appeal* to one another, *persuade* one another, *forgive* one another, and so on (114a-b). They can also perceive, feel pain, and be frightened. However, this is done without eyes, nerves, adrenalin, etc. The participants make sense of a similar belief, but *re-embody* the soul to enable such metaphysics to be possible.

> The belief in a reasonably 'full' mental life after death is common, and from Homer onwards (Odyssey 11) all those who have pictured it have pictured the souls of the dead as having the shape of human bodies, and as doing just the kind of things that ordinary living human beings do.
>
> (Bostock, 1999: pp. 410-411)

One has to admit that the soul in the form of a human image may not be meant to be taken literally. However, similarly to religious interpretations for Jesus, God or angels, or the experiences from parapsychology, the participants continue to use this image. Similarly, there are few examples from Western literature or art that present an afterlife existence as being anything other than possessing the physical appearance of a human being, although some describe practical metamorphism, as found in Charles

Kingsley's character *Tom* in *The Water Babies* who, after drowning, evolves into an amphibian. From a religious perspective, the human image may be a continuum of the Bible's statement that man was created in the image of God. However, more simply, it may be that we have not agreed a better image to substitute for it.

> Full fathom five thy father lies;
> Of his bones are coral made;
> Those are pearls that were his eyes:
> Nothing of him that doth fade,
> But doth suffer a sea-change
> Into something rich and strange.
>
> (Shakespeare, The Tempest, 1964, I, ii: p. 338)

Endnotes

[1] Following Aristotle, Aquinas defines a 'rational soul' as a soul that has the relevant capacity for life, sensation, and rational thought and is the type of soul proper to the human species. A 'sensitive' soul, on the other hand, has the relevant capacities for only life and sensation, and is the type of soul proper to all non-human species of the animal genus. A 'vegetative' soul has the relevant capacities for only life and is proper to all non-animal living organisms.

[2] The term 'mind' does not precisely correspond to Aquinas' term 'intellect.'

Chapter 8 Recommendations and conclusion

Recommendations.

During 2005, my daughter informed me that a child from her school had been taken to hospital in an ambulance and had died. Although my daughter's accounts are often confused, this fact was verified by school staff the following day; a boy had died of disability-related causation. Despite understanding how the severity of disability for some children rendered their life expectancy to be short, I was disappointed with the way the school had communicated the death. On one level, as a parent, I was not informed of the death due to the school's procedure of only contacting the maternal parent of children whose parents had separated. On another level, as a School Governor, I was not offered the opportunity to contribute a letter or card of condolence or attend the school assembly arranged in the child's memory. Consequentially, and on a more personal level, I was not able to offer timely support and reassurance to my own daughter.

Recommendation 1: Local Education Authorities should consider the potential for higher morbidity rates in pupils with profound and multiple learning disabilities attending special schools. As a result, each school should have an unambiguous and inclusive communication strategy for managing the death of a child.

The single unifying factor in the research was the participants' exposure to death being predominantly (although not exclusively) through the death of classmates. Children who are seriously ill, or have increased health risks such as epilepsy, attending schools for profound and multiple learning disabilities are more likely to encounter the death of peers than mainstream children. However, in my research, the correlation between illness, trauma and death had rendered the medical service's role as not to prolong life, but to manage death. In fact, in the participants' experience, the conveyance function of the ambulance was synonymous with that of the hearse; it was becoming a euphemism. Not surprisingly perhaps, the participants had developed a fear of health services and particularly those in connection with trauma.

Like all fears and phobias, the participants' fear of hospitals and ambulances may have been created by the unconscious mind as a protective mechanism. At some point in each of their pasts, there was an event linking hospitals with fatality. Whilst the original catalyst may have been a real-life experience, the condition may also have been triggered or reinforced by a myriad of benign events such as TV (e.g. hospital-based drama). However, this behaviour is arguably not a 'phobia' at all as the term suggests an *irrational* fear. Apart from the fear of hospitalisation being an extension of a fairly common fear in the first place, the participants were unfamiliar with any positive outcomes of medical interventions.

For some participants, an understanding of their own mortality was gained by the death of others. The phenomenological experience of their memory of deceased school friends and family manifested as a *figure* or *image*, often in context, e.g. 'Nanny was in hospital', a child being taken 'in an ambulance', and imagery of the dead lying in coffins. While these encounters with the deceased are not literal, they remain metaphorically real to those who have them.

Recommendation 2: Schools should work in partnerships with healthcare professionals to promote the work of the medical services while demythologising the role of the emergency medical services.

It is unlikely that children with ID can fully engage with the intangible concepts found within RE, even in a modified curriculum. However, even when classroom-based experience becomes sensory stimulation, our concerns should be more with the learner's psychological and emotional relationship with the process rather than with the obsessive measurement of learning.

It can be concluded that, similarly to the participants' interpretation of death, their God was part of the spatio-temporal world: a physical entity. The ID belief system is also partly deistic: the belief in a God who created the universe and then abandoned it, assuming no control over life, exerting little or no influence on natural phenomena, and giving no supernatural revelation. To understand how the participants made decisions on the truth or falsity of religious propositions cannot be known. However, the principle of Occam's razor suggests that when deciding between models which make similar predictions, we invariably choose the simpler, more logical explanation. Additionally, such processes are influenced by the quality and quantity of information and how it is presented to us, e.g. alternative viewpoints, free of bias, etc. Perhaps as a result, the participants' belief system demonstrated 'the genius of improvisation' (Holloway, 2004: p. 34). However, such improvisation is restricted by RE, as the bias towards teaching Christianity as the primary religion overshadows other religious interpretations of mortality and immortality.

While Christianity may take preference in the classroom, as non-disabled children develop they become more critical of former beliefs and have access to explore alternative religious explanations: such information, reflection, and reappraisal is unlikely to be presented to, or discovered by, the ID. This includes new age beliefs, counselling, psychotherapy, self-help material, popularised philosophy and countless other phenomena. Therefore the bias towards Christianity remains influential into adulthood. This is why many adults with ID still believe folklore accounts to be true, and may well continue to believe there really is a flying teapot revolving around the sun if so taught in childhood.

The participants' particular convictions, while having nothing to do with evidence, do seem to owe a great deal to epidemiology. It may be statistically true that the participants held the same faith as their parents and grandparents: a macro postcode lottery. However, the participants all clearly struggled to understand an ethereal existence. Therefore, exposure to other belief systems, delivered with parity, may well help the ID child to find his or her own answers. For example, the way the participants understand the possibility of the physical transcending death is not too distant from the concepts of Buddhism. A tolerant religion such as Hinduism suggests that different belief systems are just aspects of the ultimate truth, or alternatively different paths to the same goal. Equally, for those children who demonstrate no preference for religious belief, it is important they understand that they share a secular view with others, e.g. humanists.

The act of faith can give rise to a sense of certainty within the individual. While this may be sufficient for the individual or a group, the question remains as to its reliability as an indication of truth (Dawes, 2003). Perhaps the only way of avoiding this conclusion is to deny that faith requires evidence. Plantinga (2000) makes this argument by suggesting that faith simply emerges within the individual when he or she is placed in the appropriate circumstances. Under pedagogical circumstances, the participants demonstrated the capacity to understand most of the pillars of religious belief. However, their afterlife ontology was purely one of a continued physical existence after death, albeit it on a different plane of existence. When contrasted with the more accepted but complex ethereal existence, the participants' belief in the resurrected *body* is not without simplistic logic. For example, without physical and mental functions, it is difficult to understand how the dead could read a book or feel emotions. Similarly, based upon the punishment model, if a person's soul is consigned to hell, they require a mind and body that can be distressed. Therefore, from the participants' perspective, if the dead exist, they must exist *somewhere*. In other words, in order to locate themselves in heaven and observe the living, they require a corporeal existence. However, this is a reasonable conclusion: the Christian faith is fundamentally built upon the belief in Jesus' resurrection and ascent to heaven: the Bible states how Jesus' tomb was found empty. It is therefore considerably less absurd that the participants believe in the literal ascension of the physical body, as this account is taught to them in RE. However, are more intellectual explanations of the soul any more informed or credible than the theological? The two dominant scientific approaches to the study of the soul can be distinguished by the emphasis they place on two alternative hypotheses: first, that materialistic accounts of human brain function and scientific study of cultural belief systems will ultimately tell us everything we need to know about the common human belief in a non-material soul. Second, non-material conscious entities exist, but conventional materialistic science does not have the tools needed to study the non-material soul. A serious constraint on the scientific study of non-material entities is that past attempts to scientifically study many phenomena that seem to involve non-material processes or entities (for example, paranormal phenomena) have not shown a record of scientific progress and have been dominated by pseudoscientific approaches.

It cannot be suggested from the findings that it is through God that the participants derive a meaning and purpose for life: there is no 'leap of faith.' The participants may be more accurately defined as being 'cultural Christians' (Appleyard, 2006: p. 20) rather than believers, in that they conform to nurture and the generally accepted form of external authority. Additionally, although there is recognition that good or bad actions influence God's pleasure or displeasure, their morality is not influenced by the anxiety of theistic judgment. Examination of the participants' belief system may challenge its credence by questioning the credibility of the person presenting the belief rather than the belief itself. Such *argumentum ad hominem* needs to first consider whether such concepts are that far removed from other religious axioms in the first place. Furthermore, to the ID mind, their beliefs are perhaps no less 'magical' than how ape becomes man.

The education of the ID does not fit the progressive, chronological framework of the NC: subject curricula are more often an end not a means. This is not to devalue post-compulsory education opportunities for the ID, but to illustrate that the mainstream route from compulsory education to higher education.

Contemporary RE is problematic in relation to how it is delivered to the severely ID. However, this is not to argue that RE is unethical, only that the present pedagogy is indoctrinatory. Unlike RE, other subjects in the NC contain proven knowledge and are unchallengeable: the majority of what is taught to a 5 year old remains true for a lifetime unless advances in understanding disprove previous assumptions. However, the early years delivery of RE should only ever serve as a gateway to a number of alternative belief systems, which may challenge Christian-based origins. Perhaps similarly to political allegiance, contemporary allegiance to a single religious belief system is no longer lifelong. In the UK for example, among the over-65s, only 11 per cent say they are non-religious. However, 36 per cent of Britons aged between 18 and

34 define themselves as atheist or agnostic (Haywood, 2006). Therefore Christianity is being challenged, perhaps through the emergence of alternative belief systems, religious apathy, and advances in science and technology.

Recommendation 3: SACREs should consider the religious needs of the ID as a cultural issue. Such provision should be developed nationally to reduce religious subjectivity and demographically hierarchical influences. The present delivery of RE to the ID should be deconstructed to incorporate critical thinking via choice. This should be based upon a phenomenological, sensory-enhanced pedagogy (as described in this thesis) and present orthodox non-hierarchical belief systems *à la carte* to enable individualised interpretations.

Recommendation 4: The NC should contextualise the often implicit subject of mortality found in RE with more explicit explanations contained in other subjects e.g. science and history. The topic of death requires a coordinated and chronological approach rather than being delivered in subject silos.

The participants demonstrated a spiritual aspect to their lives. The use of silence (e.g. Candle Time), symbol (artwork, photographs) and narrative (e.g. story time) exists both within and outside of religion and can act as a bridge between the world of religion and the experience of the pupil. Hammond (2002: p. 197) describes these strategies as the 'gateways to the spiritual dimension of the curriculum.' Spirituality, according to most adherents, is an essential part of an individual's holistic health and well-being. The well-being or quality of life of a population is an important concern in economics and political science. There are many components to well-being: a large part is standard of living and the amount of money and access to goods and services that a person has. These numbers are fairly easily measured; others such as happiness and health are far more difficult to quantify. A psychological definition of happiness consists of both emotions and activities (Seligman, 2002). However, due to its broad scope and personal nature, spirituality can perhaps be better understood by highlighting key concepts that arise when people are asked to describe what gives their life meaning.

Questions about mortality are often closely intertwined with religious questions. Many atheists, for example, may be irritated that religious ideas should be allowed to intrude into the human struggle to identify spirituality. Spirituality is universal among humans and not optional: *all* people are spiritual. A moral person is just as spiritual as an immoral person. Thus spirituality should not be used as an honorific but as a descriptive term (Thomas, 2001). This is to imply that spirituality is a broader and more inclusive term than religion, rather than the other way around.

During National Book Week in 2005, I read to a class of ID children the classic Robert Browning (1888) poem of the *Pied Piper of Hamelin.* While I intended the story to demonstrate how morality can be taught using literature other than religious texts (i.e. the importance of keeping one's promise), the poem offered some greater personal meaning:

> And the Piper advanced and the children followed,
> And when all were in to the very last,
> The door in the mountain-side shut fast.

Did I say, all? No! One was lame,
And could not dance the whole of the way;

(http://www.indiana.edu/~librcsd/etext/piper/bib.html)

One of the children in the class attended from a hospital-type bed in the classroom, her health maintained by a variety of medical equipment. She was paralysed and had no speech, only vocalising the occasional moan and slight facial expression, hardly recognised by those not familiar with her. However, what was important to the child's parents was that she attended school with her friends. During one of the readings, from the slight movement in her eyes and mouth she communicated emotion, and as such, presented a method of assessment. Her spirituality may be found within her most basic senses; but it gave her pleasure and made her life meaningful. My work is at the very edge of understanding the ID mind, but many others remain impenetrable. If these people are not given the same status as their peers we increase their vulnerability.

The consideration that a person with severe ID has the same quality of life as a non-disabled person is rarely made within the literature. Considerations of 'quality of life' should only be relevant in the context of the gravity of illness and should not concern the degree or nature of a person's disability. However, the criteria of healthcare professionals in making decisions to impose or withdraw medical care, and even more specifically the Abortion Act 1967 as amended by the Human Fertilisation and Embryology Act (HFEA) 1990, place little or no emphasis on the person's existing or potential spirituality in relation to their cognitive (i.e. function of the brain rather than existence of the mind) and physical abilities.

I would describe the participants' quality of life as moments of meaning from highly individual experiences, e.g. music, art, physical contact, the taste of food, etc. It would be a mistake to solely judge quality of life in terms of good health or length of life; we need to try to understand how individuals express value and meaning in their *own* lives and how they experience their *own* world.

Recommendation 5: Medical and judicial decision-making on 'quality of life' criteria should be informed by the disabled person's potential or existing spirituality.

From the findings in this study it can be suggested that the ID should be responsive to therapeutic interventions such as bereavement counselling and be receptive to holistic palliative care. However, it is important to illustrate that an understanding of death is not a prerequisite for experiencing the emotions associated with grieving. The absence of the person that has died is the tangible manifestation of the person's or the animal's death, and people with intellectual disabilities will recognise the absence of someone or something they love (Dodd et al., 2005). They will therefore grieve – with or without the comprehension of the abstract nature of death.

Recommendation 6: Genuinely holistic palliative care must address the totality of the ID person's relational existence: physical, psychological, social, and spiritual, as an *ars moriendi* for our time. When life-threatening illness or

trauma strikes, it strikes each person in his or her totality, therefore no single aspect can be disaggregated from the whole.

Conclusion.

While the participants in this study and their peers are generally excluded from political discourse, their RE needs to be contextualised within a worldview so they can be located within local, national, and global communities. Such an approach places additional value on RE. Religion is of rising ideological importance because of its relationship with politics. How RE is taught in the UK needs to be considered within the context of the 21st century. In the West, Prime Minister Tony Blair stated in 2006 that he made policy decisions according to his conscience, which was guided by his Christian faith. He suggested that his ultimate responsibility for sending the UK to war in the Gulf was to God (Reeves, 1996), not to the electorate or the families of those injured or killed. Academics who have studied the role of religion in US political life acknowledge that Bush's repeated references to God have done him little harm with voters: the notion that God is on your side is a very powerful position, and Bush implies it regularly (Domke, 2004). In the Middle East, President Mahmoud Ahmadinejad of Iran claims a 'private, personal channel' (Manji, 2006: p. 19) to the Hidden Imam (descendant of the Prophet Mohammad). The growth of Christian and Islamic fundamentalism may force the monotheistic faiths further into conflict, perhaps leaving the opportunity for alternative belief systems, especially secularism, to flourish.

The study was undertaken by attempting to remain as close as possible to the phenomena itself, thereby attempting to preserve the original and contextual intimacy. However, such philosophical enquiry led to more literary transgressions than I care to remember, which, although not included in this work, nevertheless contributed to my learning experience. My motivation has never been driven purely by gaining an academic qualification. If it was, there were far less problematic issues I could have tackled, far more accessible participants, and far less demanding topics. Additionally, maintaining such a close relationship with the study over the last few years has often been dark and disturbing. Despite this, it has provoked significant reflection and contemplation on mortality and immortality, which has led me to this final assumption: consider the symbol for nothingness: 0; this could represent God, the soul, heaven, ghosts, fairies, or anything we have yet to prove exists. It may be the more rational view that 0 is unlikely to exist, as 0 cannot be detected, and the universe would apparently be no different if 0 did not exist. However, perhaps it is more desirable to believe that 0 exists if it serves some purpose for you – personally and/or culturally – as long as 0 is a relatively plausible idea in the first place.

I acknowledge how, within the human condition, religious propositions are entirely admissible and make a difference to many people's lives by bringing understanding, purpose, acceptance, and strength. Religion, like a doctor's placebo, may be none the less effective for being imaginary. Certainly, religious cultures are far richer in relation to their arts, literature, poetry, and philosophy. Even as an agnostic, I am regularly overwhelmed by the beauty of places of worship and religious festivals. I cannot of course conclude this study with any *de facto* objection that Christian belief is unjustifiable, but only to question how it is taught. I retain my viable *de jure* objection formulated from rationality: 'Ah, ye brethren, this God which I created was human work and human madness' (Nietzsche, 1969: p. 59). However, I continue to observe religious people's certitude with ironic, sinful, envy.

Kevin Partington, 2006

APPENDICES

Appendix i

Invitation to participate

Very few studies in disability, beyond the observational, have attempted to discover the thoughts and beliefs of children and young people with learning disabilities. Therefore, this group remains largely untouched by current research effort.

Could your son/daughter make a positive contribution to educational research, where the study is with them rather than on them? Can you help me explore the religious and/or spiritual beliefs of young people with learning disabilities at St. xxxxxxx School?

My name is Kevin Partington, Community Governor at St. xxxxxxx (Frances' dad). Up to 6 pupils/students will be invited to contribute via a one-off 45 minute interview in school time where they may be supported by their parent or a responsible person, e.g. teacher or support assistant, following parental permission.

The interviews will be recorded for ease of transcription and the final report will take the form of my PhD (doctoral) thesis for the School of Education, University of Southampton, and shared with St. xxxxxxx School. It is hoped this research will be significant in reviewing how we meet the spiritual needs of children/young people with learning disabilities, and how we deliver religious education, nursing, social care, and bereavement counselling.

Without your support this valuable research will not be possible – please do not assume that someone else will volunteer; it is your son or daughter's contribution that will make the difference. Please discuss this opportunity with your son or daughter. If they wish to participate, return the tear-off slip in the stamped addressed envelope. Alternatively contact Kevin Partington h: xxxxxxxxxxx w: xxxxxxxxxxx, or Email: xxxxxxxxxxxxxxxx to volunteer, or for further information. I will get back to you and make the necessary arrangements.

……………………………………………………………………………………………………

MY SON/DAUGHTER HAS EXPRESSED AN INTEREST IN THIS STUDY.

Your Name: ……………………………………………………………………………

Your son/daughter's name: ………………………………………………………

Your contact details (whichever preferred):

Tel: ………………………… Email: …………………………..

Address: ……………………………………………………

……………………………………………………

……………………………………………………

Thank you for your support.

Appendix ii

Consent Form and Statement of Confidentiality

Research Project: CONSTRUCTING MORTALITY: THE ETHICS AND CONFLICTS OF RELIGIOUS EDUCATION FOR CHILDREN AND ADOLESCENTS WITH LEARNING DISABILITIES?

Researcher: Kevin Partington, Research Student, University of Southampton

Aims of the research: I am interviewing children and young people as part of a study leading to a Ph.D. which has the following aims:

- Explore understanding of the concept of mortality from the perspective of young people with learning disabilities
- Investigate the pedagogy of religious education for pupils with learning disabilities
- Identify the transcendental beliefs of young people with learning disabilities

The interview: The one off interview will last up to 45 minutes in a place where you feel most comfortable. At the beginning of the interview you will be asked for permission for me to audio tape the session.

I will ask you to tell me about your experiences of mortality and your religious and spiritual beliefs

Participation in the interview is entirely voluntary. This means no-one can force you to answer any questions if you do not wish to do so and you have the right to refuse to answer any question, or to withdraw from the interview, at any stage and without explanation.

If you find that you are upset or disturbed by discussing some of the topics raised in the interview, you may want to talk to someone about the issues that have emerged. It has been agreed that you should speak to the person that supported you during the interview. You can also take a break in the interview at any stage.

The following procedures will be taken in order to maintain confidentiality

When the tapes or notes are transcribed you will be given a pseudonym. Your real name and any identifying details will not appear on the transcript or in the thesis or in any publication that results from the thesis.

Letters, consent forms, tapes and notes will be kept in a locked filing cabinet (which can only be accessed by me) until successful completion of the thesis when they will be destroyed. Additionally, information pertaining to transcriptions and data analysis contained on my computer's hard drive will be erased. The only exceptions to this procedure will be that an electronic file containing the (anonymous) transcript will be retained if permission is granted by the participant.

After the interview: I will transcribe the interviews from the tapes. The interviews will be described and analysed initially in my thesis and in any research publications that result from my thesis.

Further Details: If you have any questions or want any more information about the interviews or project please contact me: Kevin Partington, at the University of Southampton on h: xxxxxxxxxxx w: xxxxxxxxxxx, alternatively, Email: xxxxxxxxxxx

Following the research, if you have any complaints or issues of concern on how the research was conducted, please contact the research supervisor, Michael Erben, University of Southampton (xxxxxxxxxxx email: xxxxxxxxxxx.

Consent: I agree to participate in this interview and give my permission for the interview to be used for the research purposes outlined above. I have been given a copy of this form and had a chance to read it, or had it read to me.

Signature: ....

Date:...
...

Witness: I confirm that the information contained in this consent form has been read to the above person using language deemed appropriate to his/her level of understanding.

Signature: ....

Date:...

Signature of
researcher:...

Date:...

Appendix iii

Research Questions:

i: Can you tell me any ways in which animals or people can die? How do you know animals and people can die these ways?

ii: Have you ever owned an animal that died? Do you know any person that has died?

iii: What do you think happens to animals/people when they die? (Heaven?)

iv: What happens to the animal's/person's body after they die?

v. What do you think heaven looks like? Can people in heaven see you?

vi: Does everyone who dies go to heaven? Where else do they go?

vii: Can dead animals or people come back to life?

viii: Have you ever been to a church? Can you tell me about the church? What do people do here?

ix: Have you ever been to a cemetery (graveyard)/crematorium? Can you tell me about the cemetery (graveyard)/crematorium?

x: How was the world made? Does God care for the world?

xi: Who is God/Jesus? What do you think God /Jesus looks like? Where is God (Jesus)? How do you know what he or she looks like?

xii: Who is the Devil? What do you think the Devil looks like? Where is the Devil? How do you know what the Devil looks like?

xiii: Can God/Jesus see what you do? What do you think God/Jesus thinks if you do a good/bad thing?

xiv: Do you pray? Why do you pray? What do you pray for? What do you think about during Candle Time?

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