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NAUREEN WHITTINGER BSc (Hons)

RELIGION AND PARENTING A CHILD WITH A
LEARNING DISABILITY

Section A: Religion and parenting a child with a learning
disability: A review of current research literature
(5366 words)

Section B: An interpretative phenomenological investigation
of religion in the lives of parents who have children with a
learning disability (8339 words)

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AUTHOR'S DECLARATION

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

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STATEMENT 1

This thesis is the result of my own investigations, except where otherwise stated. Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

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STATEMENT 2

I hereby give consent for my thesis, if accepted, to be available for photocopying and for inter-library loan, and for the title and summary to be made available to outside organisations.

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SUMMARY OF MAJOR RESEARCH PROJECT

Section A provides a review of the current research literature on religion and parenting a child with a learning disability. Religion is generally associated with positive outcomes, although there are some mixed views regarding religious communities. Most literature is carried out abroad and differences between study designs make it difficult to compare between studies, indicating a strong need for UK research. Implications for services are discussed and suggestions provided for future research.

Section B is a research study exploring the role of religion for parents of children with a learning disability in the UK. Eight participants were interviewed and key themes were drawn out using interpretative phenomenological analysis. Religion helped parents make sense of their child's disability and was an important part of personal identity. Religious communities were perceived to be supportive but parents experienced difficulty participating in them. The clinical implications of these findings are considered. Further research is necessary to gain an increased understanding of this area.

Section C outlines further issues pertaining to the research study including research skills acquired and lessons learned during the completion of the project, implications for future clinical practice, and ideas for future research.

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<u>SECTION A: LITERATURE REVIEW</u>

Religion and parenting a child with a learning disability:

A review of current research literature

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ABSTRACT

Research shows religion is associated with beneficial outcomes in wellbeing and may be significant for individuals facing ongoing challenges, such as parents of children with a learning disability. To investigate the impact of religion in parenting a child with a learning disability, three databases were searched for studies published over the last twenty years, with a hand-search of reference lists from retrieved papers. The literature suggests religion is important to parents of children with a learning disability. Religious beliefs are generally associated with positive psychological and health outcomes, and many parents report that they derive a sense of meaning and feel supported by their religious beliefs. Whilst some parents received help from religious communities, most reported their communities were unsupportive of the needs of families of children with learning disabilities. Differences between participant characteristics and measures of religiosity however make it difficult to compare studies and draw firm conclusions. Furthermore, most research has been carried out in the USA, which has a different cultural, ethnic and religious context to the UK. As such, results may not concur with the experiences of parents in the UK. The clinical implications of the literature are discussed and suggestions are made for future research.

INTRODUCTION

The impact of learning disability in families

Families of children with a learning disability face many stressors which may impact on their day to day wellbeing. These include financial hardships, strained emotional relationships, reduced flexibility in activity, burdens of care, medical treatment, educational hardships and stressors associated with parental grieving (McCubbin, Cauble & Patterson, 1982). In the UK, raising a child with disabilities in the UK costs three times more than raising a child without disabilities (Bennett, 2010). Added to increased financial pressures, mothers report being overwhelmed by their care responsibilities, feeling socially isolated, losing their identity and having to adjust to lower career expectations (Helitzer, Cunningham-Sabo, VanLeit & Crowe, 2002). Some parents also worry about their child's ability to function independently in the future (Floyd & Gallagher, 1997). It is thus not surprising that parents of children with a learning disability are more likely to report increased psychological stress and score higher on measures of depression and anxiety (White & Hastings, 2004).

Lazarus (1993) describes coping as a process, changing from one time to another in any stressful situation. He distinguishes between 'problem-focussed coping' by which a person attempts to change their situation, and 'emotion-focussed' coping which involves changes to the way a person relates to stress. In parents of children with disabilities, active coping strategies, which include information seeking, problem-solving and seeking social support, have been associated with a decrease in parental stress (Blacher, Feinfeld & Kraemer, 2007). Some stressors however are unchangeable and therefore emotion-focussed efforts may at times enable better coping with parenting a disabled child.

Crnic, Friedrich and Greenberg (1983) posit the presence of a disabled child is an ongoing stressor for families, who respond using those individual and family coping resources available within their ecological environment. Guided by Lazarus' research on coping, McConachie (1994) proposes a stress/coping model in which adaptation to the stresses involved in parenting a disabled child are mediated by coping style (beliefs, skills and attitudes) as well as resources. She emphasises that families differ not only in how they organise their resources but also in how they perceive the challenges they face. How parents conceptualise their child's disability is likely to impact on their adjustment; for example, mothers with a high internal locus of control but who also believed in chance report being less burdened by their caregiving responsibilities (Green, 2004). Tunali and Power (1993) hypothesise that parents facing stressful experiences over which they have little control redefine their beliefs about how their needs are best fulfilled. Emerging research shows this; for example, mothers of children with autism place higher value on their parental role than mothers of children without any disability (Tunali & Power, 2002). Similarly, research shows parents of children with developmental disabilities who focus on the positive aspects of parenting their child tend to cope better (Hastings & Taunt, 2002).

Providing emotional and practical support to families of children with a learning disability can significantly enhance parental and family outcomes (Blacher et al., 2007). National policy documents such as *'Valuing People'* (Department of Health, 2001), *'Aiming High for Disabled Children'* (HM Treasury & Department for Education and Skills [DfES], 2007a) and '*Every Parent Matters*' (HM Treasury & DfES, 2007b) recommend that parents of disabled children should be provided with responsive services designed around their needs. However, little guidance is offered to professionals as to how to meet the needs of

individuals. Moreover, it is unclear if the suggested support goes beyond provisions such as respite care and access to special education.

Interventions aimed at providing emotional support to parents would benefit not only parents but the wider family system. Bentovim (1972) suggests that the emotional development of a child with a learning disability may depend on parental responses; for example, how parents cope with negative emotions such as guilt, anger or shame that are associated with adapting to a disabled child. Hastings (2002) goes further in proposing a model in which parental stress, parental behaviour, and childhood behaviour problems are interrelated, but mediated by parental resources and emotional reactions.

The role of religion in family life

Research suggests religion can be an effective coping mechanism for people with a range of physical and mental health problems, with beneficial outcomes in terms of individual physical and psychological wellbeing (Park, 2007; Swinton, 2001). Such positive outcomes might be achieved through increased hope, gratitude, optimism and compassion, increased perceived control, increased social support and a sense of meaning in life (Park, 2007). Relationships with a divine other might also provide individuals with a heightened sense of coherence and help them manage difficult emotions such as guilt, anger or shame (Pollner, 1989).

At the time of the last UK census, over 71% of households identified themselves as belonging to a particular religion (Office for National Statistics, 2001). Pargament (1997, p.154) suggests religion becomes significant when individuals face challenges that push them to the limits of their personal and social resources, a situation many parents of disabled children

may identify with. A study published online by the Joseph Rowntree Foundation (Horwath, Lees, Sidebotham, Higgins and Imtiaz,, 2008) found parents of disabled children, from different faith backgrounds in the UK, felt their religious faith helped them hold positive views about disability. However, not all styles of religious coping are beneficial. Pargament, Smith, Koenig and Perez (1998) found 'positive religious coping' methods (including benevolent religious appraisals, and seeking spiritual support from God and the religious community) are associated with better mental health whilst 'negative religious coping' methods (such as questioning God's power, being angry with God and expressing discontent with the religious community) are associated with increased anxiety, depression and low self esteem.

AIMS OF REVIEW

Aims

This paper will critically review research literature on religion and parenting with the aim of understanding what impact religion has in the lives of families of children with a learning disability. It is hoped that such knowledge might assist professionals in the UK in offering help and support to parents for whom religion plays a significant role. In addition, this review will consider the possible implications of the research literature for UK services and identify directions for future research.

Defining Religion

The central aspects of spirituality include the search for meaning, purpose, transcendence of the self, and meaningful relationships (Swinton, 2001). However, the focus of an individual's spirituality is often recognised and expressed in religious form. Religion can be defined as a

formal system of "behaviours, beliefs, practices and values shared by a group of individuals" (Mental Health Foundation, 2007). Spirituality is difficult to measure within research and therefore most research literature on religion/spirituality has focused on religion only. This review will include all research which meets the above definition of religion.

Defining Learning Disability

This review will use the British definition of 'learning disability'; that is, a condition characterised by intellectual impairment, impaired social functioning and childhood onset (referred to as 'Mental Retardation' in the definition by International Statistical Classification of Diseases and Related Problems, 10th revision) (World Health Organisation, 2007). Studies of parents with autism, an associated condition with a high prevalence rate of learning disability (O'Brien & Pearson, 2004), will also be considered.

Search strategy

In order to locate research literature addressing the role of religion for parents caring for a learning disabled child, electronic searches of the databases PsychINFO, MEDLINE and ISI Web of Knowledge were conducted. Research articles in which variants of the keywords 'Religion' and 'Developmental Disabilities' were both identified as focal topics were selected. The abstracts of these articles were screened manually to identify further research articles relevant to the literature review, the references of these relevant articles were also screened, and this process was repeated until no further literature was identified.

Since attitudes towards children with a disability and the role of religion change across cultures (O'Hara & Bouras, 2007; Pargament, Magyar-Russell and Murray-Swank, 2005), studies that have taken place outside of Western cultures were deemed less relevant to the

aims of this review and were excluded. A detailed outline of the search strategy is available in Appendix 1.

Whilst an attempt to provide a systematic review of the literature has been attempted, it is of note that perspectives on religion may also exist in research that assesses areas such as culture and coping. This review cannot therefore be assumed to be exhaustive, although it is felt to provide a good overview for studies in this area.

EXTANT LITERATURE

Existing research studies on religion and parenting have assessed several aspects of religion and spirituality, including religious beliefs and practices, relationships with members of religious communities and the meanings religious parents ascribe to their experiences. Despite the varied nature of samples and research questions, common themes have emerged from the research. These will be explored further below.

Importance of religion to families with disabled children

Parents of children with a learning disability often indicate religion as an important part of their family life. Poston and Turnball (2004) invited parents of children with disabilities to attend focus groups to discuss factors impacting on their family quality of life. An analysis of participants' comments found numerous parents shared perspectives on spirituality, indicating that religious beliefs and the religious community played an important role in their family life. Similarly, when interviewing parents about how they had adapted to parenting a child with developmental delay, Haworth, Hill and Glidden (1996) found almost one third of mothers spontaneously mentioned religion. These mothers also scored higher on a scale of

religiosity and were more likely to speak about religion in positive terms. Michie and Skinner (2010) reported 62% of mothers of children with the genetic disorder Fragile-X syndrome also indicated religion as significant in their daily lives.

Weisner, Beizer and Stolze (1991) interviewed 102 parents of young children with developmental delays and rated these families on religiosity based on their reported church/temple attendance, inner sense of spirituality, support from religious organisations and clear religious influence in everyday life decisions. Those families rated as highly religious were more likely to engage in joint family activities, score highly on measures of family connectedness and focus effort on family supports, than families who were rated as non-religious. Similarly, Marshall et al. (2003) found parents of children with special needs reported religious practices increased family unity and provided a shared framework for understanding their child's disability. However, religion was not always viewed positively, and for some families, the presence of a disabled child highlighted parental differences in religious practice which could cause additional stress.

Participating in religious activity is likely to be difficult for families of children with a disability due to increased care demands and reduced flexibility. Parker, Mandleco, Olsen Roper, Freeborn & Dyches (2011) found parents of disabled children reported less engagement in both private (e.g. prayer, reading scriptures) and public (e.g. church attendance) religious activity than parents of children without disabilities. In addition, they explored the links between religiosity, spirituality and marital relationships. They defined religiosity as the practices associated with religion, and spirituality as the feelings associated with religion (for example, how much individuals felt God influenced their life and believed prayers were answered). Greater spirituality, but not religiosity, was associated with greater

marital satisfaction. Although the researchers failed to distinguish between parents of typically developing children and parents of disabled children in their analysis, they did find both groups of parents did not differ significantly on spirituality. This suggests that the relationship between spirituality and marital satisfaction could be independent of whether or not parents have a disabled child.

Religion, health and psychological outcomes

Although research suggests religion is associated with good health (Swinton, 2001), only three studies of parents of children with a learning disability have assessed health and psychological outcomes. The first, an Irish study of 60 parents of children with autistic spectrum disorders (Coulthard & Fitzgerald, 1999), found personal religious beliefs and prayer were associated with better outcomes on a measure of general health. However, there was no evidence of a similar association between support from organised religion and general health status. In the USA, Ekas, Whitman and Shivers (2009) assessed the relationship between religiosity and a range of psychological outcomes in mothers of children with autism. One hundred and nineteen mothers, recruited through support groups, were asked to complete self-report questionnaires of religiousness, parental stress and psychological wellbeing. Most mothers in the sample rated themselves as being both religious and spiritual. Higher levels of religious beliefs were associated with higher levels of life satisfaction, life enjoyment, positive affect, self-esteem, overall well-being, optimism, and locus of control, as well as decreased depression, negative affect and parenting affect.

Based on the distinction between religious coping styles drawn by Pargament et al. (1998), Tarakeshwar and Pargament (2001) asked 43 parents of children with autism to complete a survey which included questions about religious coping styles and psychological adjustment.

They found 'positive religious coping' methods were not associated with depression or anxiety. However, greater 'negative religious coping' was associated with increased depression.

Religion and coping

Many studies have investigated the role of religion in coping with the daily stresses of parenting a child with a learning disability. In Poston and Turnball's study (2004), parents said religion gave them strength; they looked to God for help in removing barriers and credited God for the good things in their life. Bennett, DeLuca and Allen (1995) interviewed twelve parents of children with various disabilities. They identified prayer, church/temple attendance and specific religious beliefs as sources of support which gave some parents strength and hope in caring for their child. However, when asked what contributed to a sense of empowerment, only one parent mentioned religion, suggesting others factors are likely to be involved in coping with the stresses of parenting. In addition, five parents found religion to be unsupportive, indicating that the role of religion in coping was not always positive.

Tarakeshwar and Pargament (2001) found greater use of 'positive religious coping' was associated with increased stress-related and religious growth. Greater use of 'negative religious coping' however was associated with increased depression and decreased religious growth. Qualitative analyses of the interview data found most parents saw religion as a source of strength. However, some parents also experienced spiritual discontent, and for such individuals, religious coping may also have presented a source of distress.

Dollahite and colleagues suggest religious rituals may also help in coping with the stresses of parenting a child with a disability (Dollahite, 2003; Dollahite, Marks & Olson, 1998; Marks

& Dollahite, 2001). Fathers of the Latter Day Saint (LDS) Christian faith reported giving their child 'priesthood blessings' (laying on of hands and prayer on behalf of the person who needs healing) enabled a deep connection with their child and an opportunity to do something meaningful to help.

Religion provides meaning

Attempts to establish the cause and meaning of their child's disability may help parents gain a sense of control over their child's illness and handle their anxiety (Chodoff, Friedman and Hamburg, 1964). Weisner et al. (1991) found that most parents who scored highly on measures of religiosity reported having religious beliefs which helped explain their child's disability, whereas most non-religious parents did not incorporate religious beliefs into their understanding. Tarakeshwar and Pargament (2001) suggest religion can provide an understanding of a disorder without an identifiable cause. In their sample of mothers of children with autism, 81% redefined the stresses of parenting a child with autism as a form of benevolence from God who was trying to strengthen them in some way. Even where other explanations exist, as in the case of genetic conditions, parents may still lean on religious understandings. In their interviews of 60 mothers of children with Fragile-X Syndrome, Michie and Skinner (2010) found most mothers used a religious framework to describe a transition from viewing their child's disability as a burden, to viewing it as an opportunity or blessing, or as part of God's purpose or plan. Several other researchers report parents make similar religious appraisals (Bennett et al., 1995; Haworth et al., 1996; Poston & Turnball, 2001; Skinner, Correa & Bailey-Jr., 2001; Weisner et al., 1991;). In addition, some parents believe they had been specially chosen by God because they were able to handle the responsibility of a disabled child (Bennett et al., 1995) or because God wished to test them (Skinner et al., 2001).

For religious mothers, their narratives often included a sense of a larger purpose in their role as a caregiver. Some studies have found parents used religious perspectives to reframe their experiences, including the child being an opportunity for increased spirituality (Skinner et al., 2001). Olson, Dollahite and White (2002) found fathers of disabled children reported important spiritual changes as a result of their parenting experiences, including increased empathy, patience, tenderness and humility. Marshall et al. (2003) reported that parents saw their personal investment in their child with a disability as a unique opportunity for spiritual transcendence, and they derived strength and comfort from this.

Religion, social networks and organised religion

Many parents of children with disability cite their religious community as a source of support (Bennett et al., 1995; Haworth et al., 1996; Olson et al., 2002; Rogers-Dulan, 1998). Poston and Turnball (2004) found parents joined religious communities as a way to share their and develop their spirituality with others. Michie and Skinner (2010) reported that mothers felt others within the community played a role in helping them find alternative perspectives and reframe their experiences in a positive way. Others (Marks & Dollahite, 2001) have suggested family involvement in a religious community can indirectly strengthen parent-child relationships.

Religious communities are often perceived as unsupportive of the needs of families of children with disabilities. Parents have reported difficulty in accessing church services for their child (Poston & Turnball, 2004; Speraw, 2006), have felt their church discouraged them from being active members or taking on important roles (Haworth et al., 1996; Marks & Dollahite, 2001) or had abandoned them (Tarakeshwar & Pargament, 2001). In two studies

(Marshall et al., 2003; Speraw, 2006), parents reported that the reactions of their religious community have tested their faith. In their study of mothers of children with autism, Ekas et al. (2009) found greater involvement in the religious community was associated with more negative and less positive psychological outcomes. They hypothesised that mothers with higher levels of stress might be more likely to get involved in religious activity as a way of dealing with their stress. However, participation within the religious community might itself cause stress due to the hassles involved in taking children with special needs to services or the lack of support received by such parents. This suggestion fits with parental reports outlined within much of the research literature.

Coulthard and Fitzgerald (1999) and Skinner et al. (2001) both found families drew more support from their personal faith than their religious institution. Coulthard and Fitzgerald reported that most parents did not find their clergyman had been helpful when their child was diagnosed or that their church had supported them better than other agencies. Speraw (2006) interviewed 26 parents of children with a range of disabilities and from a range of faith traditions. Parents expressed they had sought help from their religious leaders to accommodate their child within the community; however many felt their child's spirituality or the role their child could play within the community had not been valued. A few parents had found welcoming congregations, although this had been after a long search.

Religious doctrines may determine beliefs about disability and how parents may engage in parenting. Zuk (1959) reported that Catholic mothers show greater acceptance of a child with a learning disability than Protestant and Jewish mothers, which he suggested was due to the greater emotional support offered by Catholicism, including absolution from personal guilt. However, ratings of acceptance were subjective and carried out by psychiatric workers at

initial meeting only. In a later study, Zuk, Miller and Bertram (1961) asked 125 mothers to complete questionnaires which assessed their religious practices as well as their attitudes towards disabled children. Using these measures, they also found Catholic mothers were more accepting of their child as well as more faithful in religious practice than Protestant mothers. These studies suggest religious background does play a role in individual experiences of parenting.

Fathers in the LDS church are taught to place priority on family roles, lead their families in home-based devotional practices and be willing to accept help from the religious community (Dollahite, et al., 1998). Several studies of fathers from this community have reported that fathers drew upon the tenets of the LDS church to find meaning and strength in their fathering role; for example, fathers believed they held a sacred responsibility, God had a divine plan for their family, that their child would later be resurrected in a 'perfect' body and that family relationships would last beyond death (Dollahite, 2003; Dollahite et al., 1998; Marks & Dollahite, 2001; Olson et al., 2002). Marshall et al. (2003) however, reported most parents of LDS faith in their study did not distinguish between LDS and personal spiritual beliefs. Nonetheless, these families reached out to the LDS community for support, which they found valuable in building and expanding their personal faith. This suggests some experiences and beliefs might be unique to this community.

Religion within families from minority ethnic cultures

A UK study of 19 Pakistani and Bangladeshi families of severely disabled children found that, contrary to stereotypical assumptions, only some parents mentioned religion as a cause of their child's disability (Bywaters, Fazil, Wallace & Singh, 2003). Most parents relied on medical explanations, although religious understandings were observed to be significant in

the lives of some parents and were sometimes held alongside medical understandings. An ethnographic study of three South-Asian Muslim families in the US (Jegatheesan, Miller & Fowler, 2010) found these families drew on religious frameworks to help them understand the task of raising a child with Autism, which included respecting their children as gifts from God, feeling blessed to have been chosen as parents of special children and relying on their faith to help them cope. Fathers in this study also believed raising their children to be a test of their morality and spirituality.

Other US studies of families from minority ethnic groups have found religion holds a similar position for such parents as for the majority population. In a study of 250 individuals of Mexican and Puerto Rican origin, Skinner et al. found 92% of parents stated they were 'very religious'. Those individuals who were less well integrated into the majority culture, were more likely to draw support from personal faith and religious organisations and most reported increased faith since their child's diagnosis. Whilst the notion of the disabled child as a punishment from God was also prevalent within their ethnic communities, few parents themselves endorsed this belief, instead choosing to see their child as a sign of their worthiness as parents or as a test from God. Another study of Hispanic parents, (Heller, Markwardt, Rowitz & Farber, 1994) found parents often saw caring for a child as a religious duty and many reported increased religiosity after having a disabled child.

In African-American mothers, Rogers-Dulan (1998) found personal beliefs and support from the church were related to positive outcomes in adapting to a child with a learning disability. Most spoke positively of their faith, but a few experienced feelings of guilt associated with a belief they were being punished by God.

CRITIQUE

There are a number of factors to consider when assessing the relevance of this research to parents of children with learning disability in the UK. The most significant of these is that so far little research into religion and parenting a child with a disability has been carried out in the UK. All but two of the reviewed studies took place in the USA, with predominantly Christian populations. The results may not translate to the UK, where the population is ethnically and culturally different and most people have comparatively little religious involvement (Swinton, 2007). Indeed, King, Weich, Nazroo & Blizard (2006) in their UK study, failed to replicate a straightforward association between religious belief/practice and better mental health as has been widely reported in the American research literature (Koenig, 1998). The only non-American study of religion and parenting (Coulthard et al., 1999) took place in Ireland, where religion may be more deeply embedded in the culture and where religious organisations are more involved in the delivery of services than in the UK.

Swinton (2007) observes that the definitions of religion/spirituality used within research tend to reflect the context in which studies are carried out. Of the papers reviewed here, most have used definitions focussing on individual religious observance, which reflect the American religious context and preferred methods of science (Swinton, 2007). Such definitions neglect the wider role religion plays in family life and the impact of spiritual beliefs that have not been derived from a religious framework. Bibby (1987) observes that the concept of religion is changing from one focussed on established religious traditions, to one where individuals construct their own religious systems. The prominence of Christian terminology within surveys and interviews therefore means researchers may not recognise religious beliefs of non-Christian origin (Hodges, 2002). The difficulty in defining an all-inclusive concept of

religion is likely reflected in the lack of a standard assessment measure for religiosity, which further makes it difficult to situate and compare participant samples in different studies.

The variations between participant characteristics in the reviewed studies also make it difficult to draw clear conclusions from the results. For example, some research included only mothers, or fathers, whilst others included either parent or both. Research has shown that there are gender differences between parental (Dollahite et al., 1998) and religious (Lowenthal, MacLoed & Cinnirella, 2001) experiences which would suggest religion plays a different role for men and women that may not be directly comparable. Samples for these studies were mostly recruited from parent groups, word of mouth or postal surveys. As such, they are likely to consist of parents with increased organisational skills or who use active coping strategies. Those studies which did recruit from special education service providers however (e.g. Skinner et al., 2001) found similar results.

All studies reviewed included children who were likely to meet criteria for a learning disability. In some studies however, children with other forms of disability were also included; for example Bennett et al. (1995) included two children with hearing impairments. There are likely to be different stressors involved in caring for a child with a learning disability and children with other special needs, therefore the inclusion of children with other disabilities makes it difficult to know how religion impacts specifically on parenting a child with a learning disability. Furthermore, the vast majority of studies failed to assess the severity of the child's disability, a factor which is likely to impact on the parental experience.

Many studies found religious beliefs helped parents make sense of their child's disability. Those which used quantitative measures however, may not have completely accessed the

meaning religion holds for individuals. Studies using qualitative or mixed quantitative/qualitative designs are better able to reach such understandings. However, none have offered a rich insight into the daily experience of parenting a child with a disability and the role of religion in this. Whilst some parents have expressed discontent with religion (e.g. Tarakeshwar & Pargament, 2001), others may have felt unable to convey their negative views about their faith because of feelings of guilt, shame or a sense of being a representative for their religion. Five research studies (Dollahite, 2003; Marks & Dollahite, 2001; Marshall et al., 2003; Olson et al., 2002; Parker et al., 2011) recruited an exclusively LDS sample. Where the researchers identified their religion, they stated being of LDS faith themselves. It was unclear if participants were aware of the religious background of the interviewer; however, if so, they might have wished to present themselves in a good light. Furthermore, due to their familiarity with LDS doctrines, the researchers may have displayed bias toward the positive aspects of religious practice or made assumptions about the meanings of comments in their research analysis. As such, the results from these studies may be particularly difficult to generalise to the wider population.

FUTURE DIRECTIONS

Implications for services

The research literature highlights that religion is important for some parents of children with a learning disability. In many cases, religion provides a sense of meaning and an important source of support. However, not all aspects of religion are positive. Some religious beliefs can elicit feelings of guilt, and religious communities are sometimes perceived as unsupportive of families of children with a learning disability.

The 'National Health Service' has always aimed to provide spiritual and religious care for its patients (Ross, 2010). However, in a service context where many users feel their spiritual or religious beliefs are ignored (Gilbert & Watts, 2006), parents of children with a learning disability might be reluctant to discuss religion with health care professionals. Such attitudes may impact negatively on service utilisation, and be particularly damaging for parents of children from ethnic minority backgrounds who already represent a marginalised population (O'Hara & Bouras, 2007). A UK study of parents of adult children with a learning disability (Fatimilehin & Nadirshaw, 1994) found those parents of South Asian origin all described themselves as religious and were more likely to seek help from a holy person than access formal support.

A more holistic approach to supporting parents of children with a learning disability, which promotes open dialogue about religion, would better enable healthcare professionals to support the families they work with. Since religious beliefs may relate to parental wellbeing and may in addition contribute to ambivalence around service uptake, it is important healthcare professionals attend to religious beliefs in their work with parents. NHS reforms have called for the provision of "flexible and innovative responses in chaplaincy-spiritual care" for patients and carers (Department of Health, 2003), which should be designed and delivered at local level according to the needs of the population. The impact of such NHS modernisation on the services offered to parents of children with learning disabilities is however currently unknown.

An increased awareness of the impact of spiritual and religious beliefs and practices for parents of children with disabilities might give clinicians greater confidence in exploring spirituality within a therapeutic context. Whilst there is undoubtedly some common ground

amongst people from the same religious background, healthcare professionals cannot assume that all parents with a shared religious faith will share the same experiences of their religion. It should also be borne in mind that the findings of existing literature, whilst helpful, are not necessarily relevant when working within different health, social and educational systems.

Studies have shown that personal religious beliefs currently offer greater support to parents caring for a child with a disability than organised religion. Working with parents and faith communities to increase knowledge about the causes and implications of learning disabilities might help families gain increased participation and support from their religious communities.

Implications for research

Whilst the research literature gives a good overview of how religion helps parents in finding meaning for their child's learning disability and cope with the stresses of parenting, many areas remain to be discovered. Theoretical understandings of religion/spirituality are largely underpinned by research carried out in the USA. Few studies have assessed the role of religion for parents of children with a learning disability in the UK, which has its own cultural, religious and service context. In addition, much of the current research has focussed on narrow definitions of religion that may not identify the full range of experiences within a culturally diverse population or fit with the religious concepts constructed by parents themselves.

Questions to be explored in UK research might therefore include:

- How do religious parents adapt to having a child with a learning disability?

- How do religious parents find personal meaning for their child's learning disability?

- What are the lived experiences of parents of children with disabilities for whom religion is important?

- What are the experiences of parents of a child with a learning disability who seek spiritual support?

- What is the role of faith communities for parents of children with learning disabilities?

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Candidate: Naureen Whittinger

SECTION B: EMPIRICAL PAPER

An interpretative phenomenological investigation of religion in the

lives of parents who have children with a learning disability

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Abstract

Existing research shows religion plays an important role for some parents of children with a learning disability. To date, most studies have been carried out in America and have focussed on religious observance. This study aimed to assess the personal role of religion for parents in the UK. Eight parents of Christian, Muslim and Jewish faith were interviewed. Data was analysed using Interpretative Phenomenological Analysis, a method designed to capture lived experiences. Religion was found to help some parents make sense of their child's disability and their role as a parent. Having faith gave parents hope and was an important part of their personal identity. The religious community was generally perceived as supportive, although there were barriers to participation for many families, including limited time and lack of family support. Further research assessing parents with other faiths and from specific ethnic groups and religious denominations may broaden understanding in this area.

Introduction

Parents caring for children with a learning disability face a number of daily struggles which may exceed the limits of their personal strengths and social resources. Challenges include financial hardship, increased parental time commitments, strained emotional relationships, alterations to family activities and personal goals, and factors associated with parental grieving (McCubbin, Cauble & Patterson, 1982). The presence of such daily stressors might explain why parents of children with a learning disability have been found to score highly on measures of parental stress, depression and anxiety (White & Hastings, 2004). Mothers of children with a learning disability have reported feeling socially isolated and overwhelmed by their parenting responsibilities, having to adjust to lower career expectations and losing their former identities (Helitzer, Cunningham-Sabo, VanLeit & Crowe, 2002).

In addition to daily challenges, parents of children with a learning disability are also likely to struggle in obtaining a diagnosis for their child and finding appropriate schooling and medical treatment. Parental reactions to stressful events vary between families (Roll-Pettersson, 2001) but Blacher (1984) suggests parents revisit 'stages of adjustment' (shock and denial; emotional disorganisation; and acceptance/adaptation; Kubler-Ross, 1969) throughout their family life-span, consequently forming new understandings. The Double ABCX model (McCubbin & Patterson, 1983) posits families achieve positive adaptation through existing and new resources, shifting perceptions of stressors and family coping strategies.

Increased spirituality is a key theme in the positive experiences reported by parents of children with disabilities (Hastings & Taunt, 2002). For some parents, religion may be a strong source of support. Swinton (2007) reports that there is a growing body of research

literature that links religion to positive psychological and health outcomes. Mechanisms by which positive outcomes may be achieved include social support, providing meaning and purpose, positive emotions and a system of coping resources (Potts, 2004). Religion is not however always associated with positive outcomes. Specific religious beliefs may determine how parents understand and cope with stressful events (Newton & McIntosh, 2010). Pargament, Smith, Koenig and Perez (1998) found better outcomes to be associated with a secure relationship with God and a belief in there being meaning to life, whereas behaviours such as questioning God's power and expressing discontent with the religious community were associated with higher levels of anxiety, depression and low self esteem. This finding suggests the relationship between religion and its outcomes is more complicated than merely whether one does or does not have a religion.

Existing research highlights many ways in which religion might help families hold a positive experience of living with a child with disability. The key themes which have emerged from research in this area are presented below:

Religious beliefs

Religion provides a system of beliefs that can help parents interpret and give meaning to their experiences (Fewell, 1986). Michie and Skinner (2010) observed that mothers parenting a child with Fragile-X Syndrome drew upon spiritual perspectives to find meaning regarding their children's disabilities and their roles as caregivers. Several parents of children with a learning disability believed their child was a blessing (e.g. Bennett, Deluca & Allen, 1995). This was sometimes tied in with the belief that God had specifically chosen them for the task of parenting their child and that this offered opportunities for spiritual growth (Dollahite, 2003). Parents derived hope and strength from a belief that God would assist them in the task

of parenting (Bennett et al., 1995; Rogers-Dulan, 1998). Other parents however wondered if their child was a punishment (Horwath, Lees, Sidebotham, Higgins & Imtiaz, 2008; Rogers-Dulan, 1998) or a test from God (Skinner, Correa, Skinner and Bailey, 2001).

Religious participation

Participation in religious services, rituals and prayer can also be a source of support for parents of children with a disability (Bennett et al., 1995). Some parents have spoken about the importance of engaging in religious practices as part of their family life (Marshall et al., 2003). Parents have reported benefits for themselves and their children; for example, that church rituals had a calming effect on their child (Tarakeshwar & Pargament, 2001). However, not all families felt they could attend religious institutions with their children (Horwath et al., 2008) and religious communities did not always provide families with the appropriate support necessary for them to participate (Poston & Turnball, 2004). Ekas, Whitman and Shivers (2009) reported that parents who were more involved in religious activity scored higher on measures of stress and depression and lower on measures of self-esteem and well-being than parents who were less involved. They hypothesised this was because of the stresses faced by parents when participating in religious services and the lack of support offered by religious institutions.

Interpersonal support

Many parents of children with a disability looked to religious institutions to provide a community with whom they could share and develop their spirituality (Poston & Turnball, 2004). Some parents cited the religious community as an important source of support (Bennett et al., 1995). Other parents however experienced difficulties accessing religious services for their family or were discouraged from being active members because of their

child (Haworth, Hill & Glidden, 1996; Poston & Turnball, 2004; Speraw, 2006). Although some parents reported close supportive relationships with religious clergy, others reported dissatisfaction with the level of support offered (Coulthard & Fitzgerald, 1999; Ferguson & Heifetz, 1983; Speraw, 2006; Tarakeshwar and Pargament, 2001). Coulthard and Fitzgerald (1999) found parents drew more support from personal beliefs than organised religion. Sharing a faith understanding with a spouse was also very important for some parents (Tarakeshwar & Pargament, 2001).

Divine relations

Religion offers parents a relationship with a divine other, who provides a heightened sense of order and coherence and which helps individuals manage difficult emotions such as shame and anger (Pollner, 1989). Having a close personal relationship with God offers people a sense of vicarious control (Ellison & Levin, 1998) which is likely to be especially important for parents coping under conditions of uncertainty. Some parents have reported parenting a child with a disability has brought them closer to God (Skinner et al., 2001), whilst others reported feeling angry with God (Tarakeshwar & Pargament, 2001). Prayer provided parents with the strength to cope with daily stresses (Bennett et al., 1995; Haworth et al., 1996) and a connection with God, which was found to be especially important for those parents who did not attend religious institutions (Rogers-Dulan, 1998).

Establishing a definition of religion

The lack of a universally accepted definition has made it difficult for researchers to adopt a consistent approach to measuring religion. This can make it difficult to compare the outcomes of different research studies. Baetz and Towes (2009) observe that studies often use

definitions that focus on religious observance. These neglect the wider role that religion plays in family life and might be particularly unsuitable for families whose caregiving responsibilities make it more difficult for them to observe religious practices. Measures of religious observance also do not provide information about the role religion plays in the inner world and lived experiences of individuals. Pargament, Magyar-Russell and Murray-Swank (2005) observe that in recent years the concept of religion has changed from one where religious denominations are the focus, to one where individuals construct their own religious systems (Bibby, 1987). To capture the significance of religion for individuals, definitions of religion that encapsulate multiple dimensions would be most useful. These would have the advantages of being consistent with current research literature, but would also take into account the multiple aspects of spirituality and religion that have been found to be related to mental health (Swinton, 2001) and would include those aspects that are more personal to the individual.

Religion and culture

In reflecting on research on spirituality and mental health, Swinton (2007) notes most studies have taken place in the USA, where the population is more religious than the UK. Research has focussed primarily on white, Christian populations and has mainly assessed the functions of religious behaviours such as church attendance, prayer or scripture reading. The studies of religion in families of children with a learning disability have generally followed this same pattern. As such, the results may not translate to the UK, where the population is ethnically and culturally different, where social support, health and education systems differ and most people have little involvement in organised religion (Swinton, 2007). In order to understand

the perspectives on religion held by British parents of children with a learning disability, it is imperative to carry out research in the UK.

Research Aims

The aim of the present study was to explore the lived experiences of parents of children with disabilities for whom religion is important. The primary overarching question was: What is the role of religion in the lives of parents who have children with a learning disability? Considering the paucity of UK research on religion and parenting, it felt important to gain an in-depth understanding of parents' experiences of a broad range of aspects of religion. Of particular interest, was determining the role religion may hold for parents on a daily basis, and how they may draw upon religious frameworks to make sense of their child's learning disability and their parenting role. It is hoped such knowledge can enable organisations working with families to provide a more comprehensive service that takes into account the impact of religion on parents' experiences.

For the purposes of this study, religion was defined as those beliefs, practices and relationships that are commonly shared between followers of a group who have a shared belief in a higher being. What was of central concern was the personal experience of parents for whom religion is an important part of their daily life. As such, the ways in which religion and God were personally relevant to individuals was favoured over explanations proposed by religious institutions.

Method

Research methodology

Interpretative Phenomenological Analysis (IPA) (Smith, Flowers & Larkin, 2009) aims to capture the lived experiences of people and the meanings that they ascribe to these experiences. As such, this qualitative research methodology was felt to be most appropriate in meeting the aims of this research. Participants in IPA are selected on the basis that they are able to cast light on the experience being researched, and as such, they form a homogeneous group. In this study, the homogeneity of the sample primarily resided within the parenting identity of the participants, and to further establish homogeneity, only parents for whom religion was important were interviewed. The design of this study was based on guidelines outlined by Smith et al. (2009).

Participants

The primary inclusion criteria for the study were that participants held parental responsibility for a child with a learning disability and identified themselves as following one of the worlds' nine major religions (Department of Health, 2003). Learning disability was defined according to the criteria for 'Mental Retardation' that is outlined within the International Statistical Classification of Diseases and Related Problems, 10th revision: intellectual impairment, impaired social functioning and childhood onset (World Health Organisation, 2007). Since it was not possible to obtain medical records for this study, children were considered to meet these criteria if their parents reported that they had a learning disability and they were attending a school for children with special educational needs. Standard procedures in the statutory assessment process for eligibility for a special school are rigorous, and include involvement of an Educational Psychologist and other professionals who comment on a child's learning needs. The *Special Educational Needs Code of Conduct* (Department for

Education and Skills [DfES], 2001) defines a child as having special educational needs if "they have a significantly greater difficulty in learning than the majority of children of the same age". As such, it is rare children attending a special school would not meet the diagnostic criteria for 'Mental Retardation'.

Children with a diagnosis of Autism were included in this study if they also met the same criteria. Research has found that over seventy percent of children with Autism also meet criteria for a diagnosis of learning disability (Fombonne, 1999 as cited in O'Brien & Pearson, 2004).

Only those parents whose child had been diagnosed over two years previously were interviewed; it was felt that interviewing parents sooner than this could be distressing for parents and would provide less reliable data as parents would be likely to still be making sense of their child's diagnosis.

Participants were recruited through advertisements in newsletters distributed by organisations who work to support families of children with learning disabilities and Autism. Seventeen parents responded to the advertisements. Ten were eligible to take part and were sent further information. Eight parents confirmed their interest and consented to being interviewed. Further information about these participants is available in Appendix 6.

The sample consisted of six biological mothers, one adoptive mother and one biological father, ranging in age from 24 to 55 years with a mean age of 46 years. These parents had children who had been diagnosed with Downs' Syndrome, Autism and Global Developmental Delay. Six of the parents were married and two were raising children alone.

Two were in full-time employment, four in part-time employment. Of those who were not working full-time, most stated that this was because of their caregiving responsibilities. Four of the parents had two children with a disability.

Six participants identified themselves as being Christian, one as Jewish and one as Muslim. In terms of religious practice, six participants attended religious services, met with others of their faith community, engaged in prayer and read religious texts at least weekly. The other two participants attended church occasionally but met with friends from their church and engaged in prayers at least once a month.

Ethics

Ethical approval for this project was obtained from the Salomons Ethics Panel. Prior to being offered a research appointment, all participants were sent an information letter and consent form (see Appendix 4). This outlined what participants could expect from the interview and what would happen to the information collected. Participants were assured any information about them would remain anonymous in the project report. Due to the potentially sensitive nature of questions within the interview, participants were reminded that they did not have to answer every question and had the right to withdraw at any time. They were offered an opportunity to ask further questions and informed consent was achieved before beginning the interview. After the interview, the researcher asked them if they wished to be signposted to organisations that could provide additional support; none however took up this offer.

Instruments

A semi-structured interview schedule was developed by the primary researcher (see Appendix 5). The questions were designed to elicit information about the religious beliefs,

practices, relationships and experiences of parents of children with a learning disability. The scope and content validity of the schedule was tested through discussions with clinicians with expertise in child psychology and IPA methodology. The interview was piloted with two parents who held religious beliefs and was amended on the basis of their feedback. This process ensured that the interview was likely to elicit information relevant to the research question and put participants at ease.

Basic demographic information was also collected using a short questionnaire designed for the study (see Appendix 5). This included questions about religious affiliation and religious activity.

Procedure

Parents who responded to the advert were contacted by telephone or email within one week. Those who met the inclusion criteria for the study were sent further information about the research, including an explanation of the aims of the project and what taking part would involve. Those who confirmed interest in participating were offered research appointments at a location of their choice; most preferred to meet at their home. Further to gaining written consent and asking parents to complete a short demographic questionnaire, the researcher interviewed participants about their experiences following the guidelines set out by Smith et al. (2009). Interviews, which lasted between 37 and 65 minutes, were recorded and transcribed.

Data Analysis

Following transcription by the researcher, each interview transcript was read whilst notes were taken on points of significance and interest, including content, context, use of language

and initial interpretations. These notes were used to develop emergent themes within each transcript. Connections between themes were drawn out and formed the basis of super-ordinate themes. This process was repeated for each individual transcript. Following this, patterns that emerged across all transcripts were studied and used to develop higher-order themes. This final process attempted not only to highlight commonalities between participants but also to bring out some of the individual experiences of the participants.

Quality Assurance

Transcripts of the interviews were sent to participants to check that the content was accurate. For the purposes of bracketing, the researcher kept a diary of her thoughts around the project. This specifically included notes about each interview. After analysis, these notes were revisited to ensure analysis had gone beyond the researcher's first impressions of the interview and also that no relevant information had been lost in the process of analysis. Regular supervision meetings were held to assist the researcher in making interpretations that were grounded in the data and which attended to how participants made sense of their experiences.

Results

Participants gave accounts that included how they made sense of their child's disability and valued their child. They spoke about the personal impact of their faith and their relationship with God. Participants also discussed the role of the religious community and their family in parenting experience.

The full list of themes that emerged from the transcripts is presented on the following page.

Table 1: Themes illustrating the experiences of parents

Master themes	Sub-ordinate themes
Making sense of disability	God gave me my child for a reason
	Journey of faith and personal development
	Difficulties are part of life
Value of my child	I am fortunate to have my own child
	A child with a disability is just like any other
	Making sense of my child's spirituality
What it means to have faith	Faith is who I am
	Impacts of faith on parenting
	Faith provides hope
	Times of doubt
Relating to God	God is in my life
	God helps me/answers prayer
Family and religious community	Community provides support and friendship
	Community attitudes to disability
	Participation in community activities
	Religion and family relationships

Making sense of the disability

Having a child with a learning disability is often an unexpected event. Parents in this study attempted to make sense of why their child had a disability and how parenting a child with a disability had transformed their life.

God gave me my child for a reason

Most parents recalled searching for explanations for the disability at around the time their child was diagnosed. In answer to their questions, most concluded their child was 'given' to them for a reason, implying a belief in God as a benefactor. Whilst explanations differed,

many parents focussed on the positive experiences that arose from having a child with a learning disability. Such explanations might have assisted parents in coping with ongoing stresses. Two parents explained how having a disabled child had put balance or structure into their lives that they otherwise lacked:

"...it's a will of God, maybe without it I wouldn't have been able to curtail my life so maybe it's just a balance God has granted" (Participant 6).

"it saved me because there were the sort of things I was into and doing that weren't positive things, I wasn't looking after myself" (Participant 2).

Two parents wondered if their child was a punishment from God. Whilst they concluded this was not a likely explanation for their child's disability, they seemed to describe going back and forth in trying to make sense of their situation. Given that there may be no clear answers as to why a child is born disabled, it is possible to understand why these parents struggled in holding onto positive explanations.

"There are times I think 'oh it's a sin that I've committed' but when I look back... I don't think I've committed enough sin for some punishment... I can only think of God's wish" (Participant 6).

Not all parents made sense of their child's learning disability in religious terms, with some preferring scientific explanations such as genetic causality. These more tangible explanations could be viewed as less blaming of parents and could therefore help preserve a positive sense of self.

"You think back and say 'oh what have I done, what have I done wrong, what did I do when I was pregnant?'... After doing more research you know this wasn't your fault" (Participant 1).

Some parents reflected on the process of searching for explanations of their child's disability. One described searching for meaning as his way of coping with his son's disability, whilst another described what seemed to be a frenzied attempt to find answers to her unresolved questions, a process which had brought her closer to God.

> *"When you are seeking for answers you want to go everywhere, look at every book and every thing, so you get closer to things… I got closer to God more"* (Participant 1).

Journey of faith and personal development

Parents made reference to changes in their lives and their perspectives on life which had occurred as a result of having a child with a learning disability. They often framed their experiences as a 'journey' of personal and spiritual development, through which they became better at taking on the responsibilities they faced. As one parent explains,

> *"Having my children, it just strengthened me, focussed me, made me calmer, I started praying more, thinking more, and just being less angry"* (Participant 2).

Other parents may have redefined what was important in their life as a result of their experiences. For some, religious teachings gave new meaning to their child's disability.

> *"there was a verse in the Bible… something about um can you see your children round the table all healthy… so I thought you know it doesn't matter that he's disabled… because he's healthy and he's happy"* (Participant 7).

Difficulties are part of life

Approximately half of the participants saw difficulties as being a part of life. For some, the experience of caring for a child with a learning disability was a test or a preparation for the

next world.

"I expect this life to be difficult, it's sort of a preparation for the next" (Participant 5).

As such, difficulties offered an opportunity for learning and development.

"Life is not plain sailing, life is meant to be ups and downs and through each one

you learn things… if you're going to be developing patience, you're not going to

be given situations where you don't need to use it" (Participant 4).

Value of the child with a disability

Parents made comparisons between their child and others without a disability. They often

redefined their experiences to emphasise the value of their child.

<u>Fortunate to have my child</u>

Mothers stated that they were 'fortunate' to have a child to parent. This was the case not only

for all the biological mothers, but also for Participant 5, an adoptive mother, who was grateful

for being "entrusted" with her children. Mothers described their situation as being favourable

to not having the opportunity to experience being a parent.

"There are people who don't have children you know and if you are lucky

enough to have one, who are you to complain?" (Participant 1).

Such comments suggest motherhood was central to the identity of these participants. For all

families in this study, mothers took on the bulk of the care-giving responsibilities, which

might explain why this identity was so important, and why Participant 8, a father who held a

busy occupation outside of the family home, did not comment on this subtheme.

<u>A child with a disability is just like any other</u>

Two mothers spoke about their child as being the same as other children, but disadvantaged because of their disability.

> *"Just like having any child, it's been a joy. He's very smiley, very happy… it's obviously sort of his disabilities and his health issues that do sort of hold him back"* (Participant 2).

Such comments suggested parents might have struggled with difficult emotions related to adjusting to a child with a disability or with others' negative reactions towards their child. For several parents, a belief that their child with a disability had equal value and status in God's eyes seemed significant, as was recognising the different abilities such a child might possess.

> *"He's a child of God… and is loved and valued by God I think and that simple thing in a sense is itself sustaining"* (Participant 8).

> *"It's looking at him as one of God's children as well and seeing how God has worked in him. It might be in completely different ways from other members of the family… so we all sort of say we've got different gifts"* (Participant 4).

One mother felt caring for a child who God valued was part of her faith; this may have contributed to an increased sense of pride about her parenting experience.

> *"The heart of the Christian faith is… valuing people who the world doesn't value… people who society doesn't value are actually very valuable to God"* (Participant 5).

<u>Making sense of the child's spirituality</u>

Most parents had attempted to understand their child's ability to engage with God; for

example, by observing how their child participated in religious services, prayer or song. Some were pleased to report that their child had an independent relationship with God.

"He had that kind of spiritual sort of relationship going on that had nothing to do with me and it was kind of something of his own… that was nothing to do with how much we'd explained to him" (Participant 7).

Other parents however struggled to get their child to pray or to attend a place of worship. Given that their own personal relationship with God might have assisted them in managing distress, parents might have wished the same for their child. Furthermore, the child's refusal to participate in family religious activity was a source of conflict in some family homes. Two parents with children on the Autistic Spectrum made sense of their child's lack of spirituality in terms of their learning disability:

"(He) sees things in black and white. I've got this, you know complete bizarre thing… he can't see (God), he can't talk to (God)… so as a parent I've got to acknowledge the difficulties he's going to have with that" (Participant 3).

One parent spoke of the struggle he had faced in trying to understand how his son might be able to access God in spite of his disability, eventually recognising his son might express faith through patterns of worship.

"Perhaps he's coming at a completely different understanding of God but I know enough about the Christian tradition, the religious tradition, to say 'well that is a way in which some people access'… and actually learning to cope with different understandings" (Participant 8).

Similarly, other parents also saw their own spirituality as being different to that of their child,

with three suggesting that, in some respects, their child had superior faith to that of their own.

"He comes out with… some profound statements that just you know a little boy

with all those difficulties has such clarity of thinking… just knows God is there

and I think that's what I'm in awe about when I watch him" (Participant 4).

What it means to have faith

Parents spoke about the importance of faith in terms of their identity as individuals and parents. Faith was a source of support for some parents in that it provided them with hope; however some parents also recalled times when they doubted themselves and their faith.

Faith is who I am

For all parents, their religious faith was central to their sense of self and was in their lives before they had become parents to a child with a learning disability. For some, a religious identity had been passed down to them by their own family of origin. Parents who had received a religious upbringing were able to draw on spiritual support from family members in caring for their child, including having family members pray for their child. However, the comparisons that these parents made between their own religious practice and that of their family of origin often left them feeling unhappy. One mother described how she was unable to live according to what was expected of her because she was often too tired to devote herself to religious practice. She reported feeling guilty about not carrying her family traditions forward.

"The guilt is always there, oh God I should have got up in the middle of the night

and prayed… I believe He understands but I do feel bad. I wish, because that's

how I was brought up, my grandparents did, everybody in my family did, we do"

(Participant 6).

Similarly, another mother explained how she felt 'bad' for being less observant in her faith, compared to her parents and siblings, which for her was also accompanied by a sense of guilt.

> *"In the last few years I feel like I'm the black sheep of the family (laughs), they're*
>
> *all so sort of committed and going on with their Christian lives and I'm kind of*
>
> *like, I'm the naughty one"* (Participant 7).

Impact of faith on parenting

Parents' religious identity helped them make sense of their role as a parent to a child with a learning disability and highlighted their responsibilities to God. Some parents felt their religious responsibility was critical in keeping their family together. As one parent said, when comparing herself to other families,

> *"They can pack and leave… I can't do that as a Christian, neither can my*
>
> *husband do that as a Christian, because we believe in the Word of God… some*
>
> *people, without the fear of God, they can (run away)"* (Participant 1).

One parent spoke of being responsible for caring for her child, but recognising that her child ultimately belonged to God. Sharing responsibility for her child with God might have assisted this mother with coping with the emotional demands and uncertainty of raising a child with a disability.

> *"We are looking after him as one of God's children and it is always remembering*
>
> *that he belongs to God first and then we're the ones to care for him"* (Participant 4).

Faith provides hope

Many parents acknowledged the difficulties in parenting a child with a learning disability. However, for many, their faith provided them with hope things would get better.   As one

mother explains,

> *"I think the greatest bit of the religious input is the hope it's given us, the strength to hope for the best and to keep going really"* (Participant 6).

Since the interpersonal support received by many parents was limited, the hope provided by their faith is likely to be crucial in helping parents persevere during times of difficulty.

Times of doubt

Some parents admitted there were times when it was difficult to hold onto hope. However, they emphasised that these moments were short-lived and were often overcome by reconnecting with their faith.

> *"I'm not denying that there are not days where I sort of throw my hands up in the air and go 'oh gosh I feel like I can't cope' but then those, those are but moments… (I) take a deep breath, pray and feel better"* (Participant 2).

Parents spoke about doubt as a sign of personal weakness. In order to overcome this, they often relied on what they had learned from the past. As such, times of doubt provided opportunities for parents to reflect on the development of their parental resources since their child was born.

> *"Now I know better, so I don't have to cry, all I have to do is do more."*
>
> (Participant 1).

Relating to God

All parents talked about having a personal relationship with God which helped them manage the stresses of parenting a child with a learning disability.

<u>God is in my life</u>

Parental relationships with God provided relief from the isolation faced by many parents. Some reported the significance of having someone who understood the difficulties involved in parenting a child with disabilities.

> *"Sometimes you might think 'oh it's just you' but it's not because you can always ask for help and you can always ask for guidance and there's someone you can talk to"* (Participant 4).

Another mother spoke about her struggles to meet her responsibilities as a parent. To her, the knowledge that God was aware of the obstacles she faced was important in helping her reconcile her inability to meet her religious duties as a parent.

> *"I'll be forgiven that; He knows I do the best I can"* (Participant 3).

Many parents held a fatalistic understanding of their situation. Believing God was ultimately in control may enable parents to defer responsibility and escape difficult feelings of shame or blame. Having a direct relationship with a knowledgeable Other might help parents cope, particularly at times of uncertainty.

> *"You can't really do anything to change the way, what's happened… you throw yourself at the mercy of God almost… Whatever happens, just trust in God and that God is in control and He knows what He's doing in the situation"*
> (Participant 7).

For many parents, their relationship with God had changed since their child was born. Many believed their relationship had become stronger, but others noticed less positive changes. These parents attributed these changes, at least in part, to their experiences of parenting a

child with a disability. As one father explains,

"I don't think that sort of emotional awareness of God's presence that I had in the first part, first half of my life, is there as it was... (parenting) is actually emotionally and spiritually draining, and so it makes a spiritual life more difficult to sustain" (Participant 8).

God helps me

Most parents felt God provided them with strength to cope during difficult times. Recalling previous times God had assisted seemed to be a source of comfort.

"You know I will be given the strength to cope with whatever happens, um which has proved to be the case" (Participant 5).

All parents believed God answers prayer. Most described examples of prayers that they believed God had already answered. The contrast between these events and the difficulties parents faced beforehand was discernible, and parents spoke passionately about their positive experiences.

"They didn't think he would necessarily develop at the rate and the only like thing I can hold that down to is sort of God's guidance in him and sort of healing" (Participant 2).

"It was amazing... from being denied that opportunity to have, even approach or consider residential, to just having schools to choose from, I really don't think that would have been achieved without God's support" (Participant 6).

Parents appreciated that not all their prayers would be answered. Two parents spoke about the

dedication and hard work they felt was required of them in their faith practice.

"Faith without work is dead… I believe that what you put into a child you get out of that child, although you must also believe in God" (Participant 1).

Another parent emphasised the importance of knowing what can and what can't be changed.

"I think prayer changes people's hearts and minds and um relationships... I don't believe in a magic wand being waved and things, so and that's why I don't believe that praying for healing for (my son) is a realistic" (Participant 8).

Some parents spoke about the emotional benefits they received through prayer. These also appeared to help parents relate better to their child, with two mothers reporting increased family unity and describing prayer as a buffer against conflict or stress.

"We're calm and sitting together and um I think it calms them down quite a bit, they relax and seem happy" (Participant 2).

"We just sort of have a hug and a pray and that calms him and helps both of us… it unites us because it's something we're doing together" (Participant 5).

Family and religious community

The interpersonal context within which parents and their children were situated provided important opportunities for parents to receive support and help others. However, differences in religious belief within the family left some parents feeling isolated.

Community provides support and friendship

All parents received support from members of their religious community. Whilst this

included practical support such as cooked food or babysitting favours, it was the emotional support that parents reported as being most significant in helping them cope with their situation.

> *"We had a lot of support from our church and people you know they've been kind*
>
> *to us and helped us get through it"* (Participant 7).

Friendships within the religious community were particularly valuable to parents. Some described the importance of having friends who shared their religious understanding of situations, which implies a sense of being isolated in contexts where people may not share or respect their religious understandings.

> *"It's given me a caring community because I found it hard to make friends and*
>
> *was very isolated"* (Participant 5).

> *"(They) are on the same wavelength, they don't think you're completely bonkers*
>
> *for wanting to make your child go to synagogue… they understand how*
>
> *important it is "* (Participant 3).

A few parents spoke of their religious community as being like a family, which might be suggestive of close bonds and altruistic behaviours within this group.

> *"It's almost like an extended family really. I think especially you know you've got*
>
> *that sort of trust between each other"* (Participant 7).

Community attitudes to disability

Parents felt that their children were generally loved, accepted and understood by their religious community, which was also seen to make concessions for their children.

"He likes to shout actually, in the middle of a sermon sometimes. Well, because they know how he is, they actually think it's quite nice, they wave to him" (Participant 2)

However, not all community members were accepting of children with a learning disability. Some parents had moved to another place of worship that better catered for their family.

"My last church was a bit intolerant of the boys' behaviour and you know they were finding it quite hard to cope… that's why I went to my present church which actually has a group for special needs " (Participant 5).

Alternatively, another parent spent time educating her church community about learning disability. She felt her community were now able to understand and accept her children's behaviour, although such progress had taken many years.

"At first some of them were really like condemning… but I had to educate them, I had to do seminars of Autism in the church, so everybody in my church is like Autism trained (laughs)… we are talking about special needs so they know, they love and accept my children now" (Participant 1).

Parents found explanations for the reactions of community members who did not accept their children's behaviour. On the whole however, they felt the religious community reacted well to their child and being with their religious community was a positive experience.

"Some of them have never seen a disabled child so they don't know what it is to have children with challenging behaviour, but largely they're good" (Participant 6).

<u>Participation in community activities</u>

Many parents who took part in this study identified their employment status had altered as a result of their parenting responsibilities. The religious community provides some opportunity to take on different roles, through which parents might employ alternative skills, thereby contributing to increased self-esteem. One mother regarded supporting others through her faith community as another way of expressing her faith in God.

> *"As God has given to me, I have to give back as well, into the community you know. So there's a lot of work that I do, that helps me grow spiritually"*
> (Participant 1).

However, many parents struggled to participate in community activities as often as they wanted. Barriers to involvement included limited time, lack of family support and being unable to attend all activities with their child. The impact of reduced community participation often impacted the entire family.

> *"...because of her condition (we) probably just go for an hour and leave, so the other children don't get that opportunity to see what it is or what it's like"*
> (Participant 6).

<u>Religion and family relationships</u>

Some parents reported that religion was central to their family and how they parented their child. However, parental couples did not necessarily hold the same religious world view, a factor which contributed to some parents to feel isolated in their faith.

> *"It has meant that faith as a means of dealing with it has not been something we've been able to share as a family, which for me is a disappointment"*
> (Participant 8).

Two mothers reported that their husbands had lost their religious faith since the birth of their child with a disability. This had impacted on the religious practice of the entire family.

"It's been really hard sort of going on and carrying on without my husband being supportive, it's gradually tailed off" (Participant 7).

The mothers were left feeling guilty or angry, indicating that they felt some responsibility for what had happened and for not practicing their faith as they would wish.

"I'm very cross with myself for letting it go that far and I want to pull it back but I don't feel that I can do that without the support from my family and they don't seem to care" (Participant 3).

"We dedicated our children when they were babies and we kind of unmade that promise to God that this is how we're going to bring them up… I feel guilty because you know I made that promise and it's kind of it's not happening at the moment" (Participant 7).

One mother explained how the contrast between her current religious practice and the religious practice of other families made it difficult for her to continue attending church. The loss of her 'religious family' highlighted her feelings of envy and may also have reinforced her experience of being powerless.

"I remember how we used to be as a family all going to church together, and then sitting there and seeing other families, it's almost the thing of jealousy because I think I want that, I want that for my family" (Participant 7).

However, despite their difficulties, both these mothers had retained their own religious faith in the face of such adversity. One retained hope that she might be able to turn things around for her family in the future, although did not relate any plans for how she might go about this.

"It's stacked away in the corner somewhere for when I'm not exhausted"

(Participant 3).

Dissemination of results

Brief summaries of the findings of the study were sent to all participants in this study and the organisations from which parents were recruited (see Appendix 7). Copies were also provided to the Salomons Ethics Panel.

Discussion

The findings from this study are consistent with existing research on religion and parenting a child with a learning disability, which has also found that parents draw on religious frameworks to find meaning in their experiences (Michie & Skinner, 2010) and gain strength and hope (Bennett et al., 1995). Whilst some parents outlined understandings they had reached in the past, for many, the process of making sense of their situation was incomplete. This was unsurprising considering the ongoing struggles families faced. The emergence of new understandings concurs with the metaphor of 'a journey' which some parents used in constructing their experiences, and also with Blacher's (1984) suggestions that parents continue to revisit the stages of adjustment throughout the family lifespan.

Individuals facing stressful situations that they are unable to change, such as parenting a child with a disability, may redefine their situation in an attempt to cope better with the losses they face (Tunali and Power, 2002). Parents in this study reassessed what was most important to them as a family, emphasised how their child was equally valuable to others, and saw themselves as fortunate to have the opportunity to parent. In line with previous research (Hastings & Taunt, 2002), some also reported increased spirituality as a result of their experience of having a child with a learning disability.

Religious faith and practice was central to the identity of parents, and in many cases, impacted on how they constructed their caregiving role. Some reported difficulty balancing incompatible goals such as meeting their child's needs and observing regular religious practice or maintaining a committed relationship with God or the religious community. Such parents drew on their sense of being known and understood by God to help them reconcile such conflicts. Whilst parents discussed some negative aspects of religion, such as times of doubt and considering whether their child was a punishment from God, many reported a positive, personal relationship with God and believed God answered their prayers. Ellison & Levin (1998) suggest that a close relationship with God offers individuals a sense of vicarious control, something which may be of high relevance to this group of individuals.

As in previous research (Coulthard & Fitzgerald, 1999; Poston & Turnball, 2004), parents in this study reported mixed feelings about the level of support they received from their religious communities. Having a child with a disability resulted in increased isolation from the religious community for many parents, mainly due to barriers in participation such as limited time, their child's behaviour and lack of family support. Friendships with members of the religious community were however an important source of support. Pargament (1997)

suggests religious communities provide opportunities for people to receive emotional and spiritual sustenance by both reaching out and supporting others. Such opportunities for bi-directional support were not always replicated within the family unit. Similar to Tarakeshwar and Pargament (2001), many parents in this study also stated the importance of shared faith understanding with their spouse. Conflictual interactions are higher in marriages where partners differ in religious affiliation, beliefs and practices (Mahoney, 2005); this might explain why the interpersonal support received from friendships with others from the same religious community might be especially valuable for some parents.

Whilst this study has highlighted several ways in which parents in the UK might draw upon religion in their experience of parenting a child with a learning disability, its scope was broad and the sample small. As such, it only provides a limited understanding of parents' experiences of religion. Furthermore, although the analysis aimed to include individual perspectives, it primarily drew on commonalities between the accounts of parents which may have meant some themes specific to certain individuals were overlooked.

Implications for Research and Clinical Practice

The heterogeneity within the study sample in terms of religion, ethnicity and gender could be explored in further research to ascertain themes that might be of central relevance to parents from a particular background. Such studies would assist in reaching a better understanding of how theological orientations might impact on parental experience. In this study, only parents of Abrahamic faith were interviewed. Additional research that includes parents from other backgrounds is important if we are to understand the role religion might play for parents from other faiths that are widely represented in the UK, such as Hinduism, Sikhism and Buddhism.

Participants in this study came from a wide range of ethnic and religious backgrounds. Rogers-Dulan and Blacher (1995) propose culture and ethnicity to be major factors in how families adjust to having a child with a disability. Similarly, Zuk, Miller and Bartram (1961) have suggested religious affiliation impacts parental attitudes and adaptation towards a child with a learning disability. The religion denomination and ethnicity to which parents belong might influence their experience of parenting a child with a learning disability and is another area which could be explored in future research.

Ainge, Colvin & Baker (1998) caution against making generalised predictions for individual families based solely on the fact that they are parents of a child with a disability. The range of themes discovered within this small-scale study highlights that individuals reach different understandings and have dissimilar ways of coping when faced with similar experiences. However, an increased awareness of some of the themes that prevail amongst religious parents might enable health services and individual clinicians to provide a more holistic care package. Considering the barriers to participation within the religious community, offering opportunities for parents to come together to discuss and celebrate religion could be an important step in reducing the sense of isolation from their religious community that many parents experience.

It is encouraging that health professional training programmes now include some teaching on spirituality (Royal College of Psychiatrists, 2010) but it is yet to be seen whether these provide clinicians with the language and confidence necessary to begin such conversations. Moreover, research has shown religious leaders are cautious in providing care to people with mental health problems because they feel inadequately trained (Foskett, Marriott & Wilson-Rudd, 2004). If such leaders feel they also have inadequate knowledge of learning disability,

it might explain why some parents found religious leaders to be unhelpful. Working to educate and support religious leaders could be important in helping parents feel accepted by their religious communities and increase parents' opportunities for participation.

Conclusion

For some parents of children with a learning disability, religion is an important part of their experience of parenting. Some parents reported religious beliefs helped them make sense of having a child with a disability and cope with the tasks of parenting. Many felt blessed to have been given the opportunity to parent and reported that their faith gave them hope. A personal relationship with God and the religious community was important to parents. Whilst many experienced difficulties in participating, they retained links to their religious community through personal friendships. Many of the findings of this study concur with previous research findings relating to religion and parenting a child with a disability. However, few studies to date have been carried out in the UK. Further research with more narrow research questions is therefore necessary to gain increased understanding of how religion is important for different parents.

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Candidate: Naureen Whittinger

SECTION C: CRITICAL APPRAISAL

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Overview

This critical appraisal aims to answer the following questions:

1. What research skills have you learned and what research abilities have you developed from undertaking this project and what do you think you need to learn further?

2. If you were able to do this project again, what would you do differently and why?

3. Clinically, as a consequence of doing this study, would you do anything differently and why?

4. If you were to undertake further research in this area, what would that research project seek to answer and how would you go about doing it?

Development of research skills and abilities

As my first experience of carrying out a major research study using a qualitative design, this project has enabled me to grow in my confidence in distinguishing between qualitative methods and in independently designing a qualitative research project. I chose to use Interpretative Phenomenological Analysis (IPA) for my study because I was interested in understanding the lived experiences of my participants. Having a method of analysis in mind helped me formulate clear research questions and guided my research design. I learned how the priorities in phenomenological research differ from quantitative research; for example, the emphasis on lived experience in IPA required me to remain open to uncovering new understandings rather than focus on confirming or disconfirming a pre-set hypothesis. Whilst I feel carrying out this project has taught me more about qualitative research, I would still like to develop a working knowledge of other research methodologies, such as narrative analysis and grounded theory.

Based on my chosen methodology, it was necessary for me to design an open-ended interview schedule that combined descriptive and narrative questions, as well as prompts for further information. I learned to put aside my expectations and ask questions which sought to understand the participant's experience. Consulting others on this schedule ensured my questions elicited both descriptive and analytic information. Piloting the interview with parents was crucial in determining the validity of my questions and how they might feel to participants. This felt important, especially since I am not a parent myself. In addition it helped me to practice the skills required within IPA interviewing: curiosity, attentive listening and probing for further details. My interview skills continued to develop as the project progressed, and I found myself more able to deviate from the structure of my interview schedule in order to make further enquiries, whilst still holding in mind the

questions I needed to ask. I would like to build upon my interviewing skills in future research using a less structured schedule.

Having had some prior experience of thematic analysis, my initial attempts at coding were mostly descriptive. I learned however that further interpretations could be arrived at when attending to factors such as language, metaphor and the actual recording. Noting down questions that stemmed in my mind from reading the transcripts was useful in assessing possible meanings and drawing links between different parts of the same transcript. I would like to further develop my analytic skills, and in future dedicate more time to analysing data. Furthermore, since an individual's experience can be investigated in a number of ways (Smith, Flowers & Larkin, 2009), I would like to develop my abilities in IPA by attempting varied research designs. For example, a single case study would require me to spend a considerable amount of time on one transcript, or a comparison method (for example, comparing the role of religion for different faith denominations) would give me first hand experience of how IPA can be adapted to answer different research questions.

Retrospective appraisal of the research design

This study yielded similar results to those of previous studies, suggesting that religious parents of children with disabilities in the UK might have similar experiences to those in USA. Whilst attempts were made to bracket my assumptions about the data, it is possible my prior knowledge of the literature may have influenced which additional questions I asked during the semi-structured interview. Moreover, some of my assumptions may have been inherent in the research design. For example, my definition of religion was prioritised over that of my participants, which was communicated to participants in the information letter and

at the beginning of the interview. Although I hoped that my multidimensional definition would encourage parents to share a range of relevant experiences, it is possible that my definition may not have fit with how parents defined religion for themselves. Fischer (2009) recommends asking participants to give a written account of experiences prior to interview which gives the participant time to reflect on their experience, and gives the researcher a base from which to start an interview. Asking parents to write a few words about what religion meant for them as a parent prior to my interview may have been a better starting point than the introductory questions in my schedule.

Themes that emerged from this research included how parents made sense of having a disabled child, what role the community played for them, their relationship with God and the impact of disability on faith within the family. The breadth of the research question did not however permit an in-depth exploration of any one of these areas. As the first interpretative phenomenological study of the role of religion for parents of children with disabilities, I intended that this project should take a more exploratory approach. However, a narrower research question may have yielded a greater understanding of these parents' experiences; for example, I could have asked how parents with religious faith adapt to having a child with disability or how parents with religious faith experience the religious community.

The eight parents who participated in this research differed in features which might have been highly relevant to their experiences of parenting. For example, their children varied in terms of age, gender, time since diagnosis, severity of problems and current care needs. The experiences of raising children with different needs may be very dissimilar. For example, a parent who is raising a child who is unable to communicate is more likely to experience isolation than a parent of a child who is highly dependent in terms of physical needs. The

children's diagnoses were Autism, Downs Syndrome and unidentified learning disabilities. It may have been better to have sampled parents of children with one of these diagnoses only.

Responses of parents at the time of interview cannot be assumed to be fixed. Parents in this study were also at various stages in terms of their family life-cycle and therefore might have been renegotiating different roles and relationships according to the stage which they had reached (Carter & McGoldrick, 1989). Those parents of younger children might pass through a number of changes to their individual belief systems before they reach similar conclusions to those parents of older children. It might have been better to sample parents of children of a particular age bracket; for example in primary education, or children reaching adulthood.

Only those parents who were highly motivated to respond to an advertisement participated in this study. Such parents may differ from other parents for whom religion is important in terms of time, ability to organise or confidence. Furthermore, it is possible parents with less positive experiences of religion saw this study as being irrelevant to them due to being currently less active in their religious practice. Recruiting families from parent groups or from mental health services might have been a way to access a wider group of parents with religious belief, although this would have provided a completely different sample.

Research outcomes pertaining to my future clinical work

My decision to study the role of religion for parents was based on my personal observations of the inclusion of religious/spiritual practices and education within some families with whom I have worked. Like many other clinical psychologists, I have often struggled in finding the language with which to explore religion/spirituality with my clients (Crossley &

Salter, 2005). The opportunity to examine the role of religion in individuals' lives using an in-depth interview has given me greater confidence in exploring such issues with clients.

The findings of this research have highlighted for me the central position that religion can occupy in some individuals' lives. I am aware that within a mental health setting, overlooking the subject of religion may give a message that health professionals do not understand or even respect religious beliefs (Dein, 2004). Since this could undermine the therapeutic relationship, or fail to address information that might be important in psychological formulation, I feel it is important I attend to an individual's religious or spiritual beliefs. Hathaway, Scott and Garver (2004) suggest an assessment of religion/spirituality should be part of routine practice for psychologists. My research has prompted me to consider how I might seek such information. Based on the work of the National Forum for Spirituality and Mental Health, the Royal College of Psychiatrists [RCP] (2010) have suggested asking clients if they are in any way religious or spiritual, what keeps them going during times of difficulty and if there is anything that gives their life meaning and purpose. Such questions seem to be a good important starting point.

Some parents in my study experienced feelings of guilt and anger, which were related to their attempts to make sense of their experiences within a religious framework. Offering an opportunity to explore religious/spiritual matters is one way in which I could assist individuals in my clinical work. Some clinicians and researchers have already made attempts to acknowledge spiritual or religious beliefs within psychological therapy, leading to the creation of new psychological approaches such as spiritually augmented cognitive behaviour therapy (D'Sousa & Rodrigo, 2004). This incorporates the exploration of beliefs associated with meaning, purpose and connectedness within a traditional cognitive behavioural approach

and is one approach that could guide me in future clinical work with clients for whom religion is important.

In the context of carrying out this research, I was acutely aware of my limited knowledge of certain religious customs, practices and scriptures. Within my clinical work, there may also be times when I do not have the sufficient knowledge or resources to assist with or understand matters pertaining to an individual's religion. It will be necessary for me to be open about my limited knowledge and helpful for me to consult other sources. It may also be relevant for me to liaise with religious professionals such as hospital chaplains, and for those clients who feel they might benefit from in-depth religious counselling, I could signpost them to trained religious professionals. As such, it will be important for me to familiarise myself with the religious demographics, institutions and support groups in the locality in which I work.

Further research ideas

Currently in the UK, there is an increasing interest in spirituality within the healthcare system, which is driven by national policy and an increasing awareness of the metaphysical (Ross, 2010). Research mainly focuses on the religious/spiritual practices or experiences of individuals, and therefore largely ignores the wider context in which individuals are situated. Rogers-Dulan and Blacher (1995) propose family adjustment to parenting a child with disabilities is influenced by interactions between religion, culture/ethnicity, family structure and family functioning. This model suggests it is important to consider the family environment and cultural context to gain a true understanding of the role of religion.

Several parents in my study reported how the religious propensities of other family members impacted on their own religious practice. Some parents felt unsupported in their attempts to provide a religious upbringing to their children, something which was very important for them. Since religion provides guidance on goals related to family life, Mahoney (2005) suggests the degree to which family members share religious views could either escalate or dampen conflicts within the family. Many parents in my study reported feeling isolated in their religious belief. However, it was not within the scope of this study to pursue a detailed exploration of family factors.

A grounded theory approach (Glaser & Strauss, 1967) could be used to investigate how religious factors influence interactions within parental dyads or families of children. This would involve semi-structured interviews of both parents and possibly other adult family members depending on the emerging themes. Questions would focus around broad areas such as attitudes towards religion, the role of religion in the family, and how religion influences relationships between family members and vice versa. These would be used to generate a theoretical account of the phenomena.

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Candidate: Naureen Whittinger

SECTION D: APPENDIX OF SUPPORTING MATERIAL

Submitted October 2011

APPENDIX 1: Literature Review Search Strategy

Electronic searches were conducted on the databases PsychINFO, MEDLINE and ISI Web of Knowledge for the period up to 7 October 2011. The terms and results of the search are outlined below. Terms were varied according to subject headings available within the databases and were taken from keywords found within relevant papers on this topic. Where possible, relevant keywords were exploded to include their more specific terms. Searches were limited to peer-reviewed journals.

Database searched		Search terms used	Articles to screen (n)	Relevant articles (n)
PsychINFO	1	exp Religion *OR* exp Religious Belief *OR* exp Spirituality *OR* exp Faith		
	2	exp Disabilities *OR* exp Developmental Disabilities *OR* exp Pervasive Developmental Disorders *OR* exp Mental Retardation *OR* exp Learning Disabilities *OR* exp Disabled (Attitudes towards) *OR* Mental Handicap.mp *OR* Intellectual Disabilities.mp *OR* exp Autism		
	3	Articles containing 1 *AND* 2	179	13
MEDLINE	1	exp Religion *OR* exp Spirituality *OR* exp Religion and Psychology *OR* Faith.mp		
	2	exp Disabled Children *OR* exp Disabled Persons *OR* exp Developmental Disabilities *OR* exp Child Developmental Disorders, Pervasive *OR* exp Mental Retardation *OR* Learning Disabilities.mp *OR* Mental Handicap.mp *OR* Intellectual Disabilities.mp *OR* exp Autistic Disorder		
	3	Child *OR* Adolescent		
	4	Articles containing 1 *AND* 2 *AND* 3	170	11
ISI Web of Knowledge	1	Religion *OR* Spirituality *OR* Faith		
	2	Disability *OR* Retardation *OR* Learning *OR* Handicap *OR* Autism		
	3	Children *OR* Child		
	4	Articles containing 1 *AND* 2 *AND* 3		
	5	Search limit: Social Sciences or Psychology	193	12
Handsearch of references (to identify additional articles)				6
Total				**22**

Table 1: Search results from PsychINFO, MEDLINE and ISI Web of Knowledge.

Articles from all three searches were screened manually to identify their relevance to the literature review, initially on title and abstract and then on full text. This produced a total of eleven relevant papers, the references of which were screened to identify any further relevant literature. This process was repeated for any additional articles until no further articles were found. Using this strategy, a further seven articles were identified as being relevant to the topic area.

Studies were deemed relevant if they primarily assessed the role of religion for parents caring for children with a learning disability.

The following studies were excluded:
- Studies which assessed children with physical disability or learning difficulties (eg. dyslexia).
- Studies which assessed the role of religion for children with a disability.
- Studies which were carried out in non-Western cultures.
- Studies which assessed attitudes of people other than parents towards children with a disability, or which did not focus on religious attitudes.

APPENDIX 2.1: Ethics Approval in Principle

This has been removed from the electronic copy.

APPENDIX 2.2: Full Ethics Approval

This has been removed from the electronic copy.

APPENDIX 3: Research Advertisement

The role of religion for parents of children with learning disabilities

Dear Parent,

I am a trainee clinical psychologist interested in looking at the role of religion in the lives of parents of children with a learning disability. Previous research has shown that some parents of children with disabilities identify religion as a strong source of support, and for some, an increased sense of spirituality is one of the key positive aspects of caring for a child with a disability. However, there is little research looking at how religion affects how parents make sense of their experiences of caring for a child with a developmental learning disability. To find out more, I would like to talk with people in south London who hold parental responsibility for a child who has been formally diagnosed with a developmental learning disorder at least two years ago and who feel that religion has had an impact on their parenting experience.

We know that religion means different things to different people. I am interested in all types of religious experience, including religious beliefs, religious practices like prayer, religious participation in your faith community, your relationship with God or a higher being and your relationship with others of your faith community. It doesn't matter if you don't regularly attend a place of worship or view yourself as all that religious, so long as you have a view on how religion has contributed to how you make sense of your experiences of parenting a child with a disability. I am particularly interested in how you feel your religion has influenced your experiences.

The interview should last no more than an hour. I hope the information you can provide will help psychologists working with parents and families to better understand parents' experiences so they can work more sensitively and effectively with families.

*If you think you might like to take part in this research or wish to find out more, please contact me either by e-mail to **nw99@canterbury.ac.uk** or telephone on **01892 507673** (research line – please mention my name when leaving a message) leaving your name, address and daytime contact telephone number and good times for me to contact you.*

Please note that this research is entirely independent of any services you may be receiving and your decision whether or not to participate will not affect any services you may receive.

Yours sincerely,

Naureen Whittinger
Trainee Clinical Psychologist

APPENDIX 4.1 Participant Information Letter

The role of religion for parents of children with learning disabilities

INFORMATION LETTER

Dear Parent,

Thank you for your interest in my study, which hopes to explore the role of religion in the lives of parents of children formally diagnosed with a developmental learning disability (for example, Autism or Down's Syndrome). I am interested in talking with parents in south London about how religion affects how they make sense of their experiences of caring for a child with a learning disability.

What do you mean by religion?
In this study, I will be defining religion as:
- Religious beliefs
- Religious practices such as prayer, meditation and pilgrimage
- Religious participation in your faith community
- Your relationship with God or a higher being
- Your relationship with others of your faith community

How religious do I need to be?
It doesn't matter if you don't regularly attend a place of worship or view yourself as overly religious. I am interested in talking with people from a range of different backgrounds. As long as you have a view on how religion has contributed to how you make sense of your experiences then you would be welcome to take part.

What are the benefits of taking part?
There are no immediate benefits. However, I hope the information that you can provide will help any support person working with families to better understand parents' experiences so they can work more sensitively and effectively with them.

Am I eligible to take part?
Yes, if you hold parental responsibility for a child (or children) aged between 2 and 18 years who has been formally diagnosed with a developmental learning disorder (such as Autism or Downs' syndrome) and you feel that religion has had an impact on your parenting experience. As it can sometimes be difficult for parents to talk about their experiences soon after their child has been diagnosed, it is important that your child received the diagnosis at least two years ago. If this isn't you, but you know someone who might be eligible, I would be very grateful if you could pass on this letter to them.

What will I need to do?

I will be asking you some questions about how you feel your religion has impacted on your experience as a parent of a child with a learning disability and how you make sense of these experiences. The interview should last no more than an hour. There are no right or wrong answers and you will not be judged on what you tell me. I'm simply interested in hearing about your experiences in as much detail as you care to give.

What if I get upset during the interview?

Sometimes researchers can't predict the questions that will cause participants distress. You are not obliged to answer any questions that make you feel uncomfortable. Please let me know if you find yourself getting distressed during the interview. Although I do not work for child services within your area, I can advise you on where you might be able to access support and help.

Will you be recording the interview?

Yes, in order to get a good idea of some of the themes that parents discuss in the interviews, it will be necessary for me to record and transcribe the interviews. These recordings and the transcripts of your interviews will be kept on a password-protected CD separate from anything which would enable anyone to identify you. The information will be stored in a locked cupboard for ten years, after which it will be destroyed.

What happens to the information I tell you?

Anything that you tell me during the interview will be anonymised which means that someone who works for another organisation will not be able to identify you. The only time that I will need to break this anonymity is if you tell me anything that makes me concerned about your safety or the safety of your child.

Once the information I receive from families is analysed, I am hoping to write up a report for publication. It is important that you are aware that I will be using parts of the interviews (quotes to illustrate the main themes) within my write-up but that all references to your family such as your names and your child's school details will be anonymised so that it should not be possible to identify you. I am happy to send you a copy of your interview transcript so that you have the option of removing any other information that you feel could be used to identify you or your family. You can let me know at any time during or after the interview if you wish for me to do this.

How do I take part?

If you've read this information letter and would still like to take part in this study, then please contact me either by:

e-mail to **nw99@canterbury.ac.uk** or

phone on **01892 507673** (Please note, this is a dedicated research line - please mention my name when leaving a message)

Please leave your name, address and daytime contact telephone number and good times for me to call you.

Please note that this research is entirely independent of any support group or services you receive and your decision whether or not to participate will not affect any services you may be receiving from any organisation.

When and where will the interview take place?
I will attempt to call you within one week to discuss the project further. If you are asked to take part in the study, then we will arrange an appointment for the research interview. This will most likely take place at a local community setting, although if this is not practical then we will discuss the option of meeting elsewhere.

<u>Please note that you have the right to withdraw your interest or participation in the study at any time without having to give a reason.</u>

Complaints Procedure
I hope that you will enjoy participating in this project. If you do have any complaints, you can contact Dr Paul Camic (Clinical Research Director) either by writing to him at the Department of Applied Psychology Canterbury Christ Church University, Broomhill Road, Tunbridge Wells, Kent, TN3 0TG, by emailing paul.camic@canterbury.ac.uk or telephoning him on 01892 507 773.

Thank you for your time in reading this letter.

Best wishes,

Naureen Whittinger
Trainee Clinical Psychologist

APPENDIX 4.2: Participant Consent Form

The role of religion for parents of children with learning disabilities

CONSENT FORM

Thank you for agreeing to take part in this research study which aims to look at the role of religion in the lives of parents of children with a diagnosed developmental learning disorder. Please read the information sheet carefully and ask the researcher any questions you may have about the study. If you are still happy to take part, then I would be grateful if you could sign and date the form below.

CONSENT TO PARTICIPATE   *Please circle*

This study has been explained to me   Yes / No

I have been given an opportunity to ask questions   Yes / No

I understand that I have the right to withdraw my consent at any time   Yes / No

I agree to take part in this study   Yes / No

CONSENT TO AUDIO RECORDING

I agree for a recording of my interview to be made for research purposes   Yes / No

CONSENT TO PUBLICATION

I understand that in any paper that is submitted for publication the   Yes / No
responses that I give will be anonymised and I will be free to withdraw
my comments from the transcripts if I feel they could be used to identify
me or my family.

I give permission for the researcher to use direct quotes in any paper that   Yes / No is
submitted for publication, provided that these quotes are anonymous.

I would like to receive a copy of my interview transcript so that I can make   Yes / No
sure my family can't be identified by others

I would like to receive a copy of the findings of this study   Yes / No

Signed   _____

Please print name   _____

Date   _____

APPENDIX 5.1 : Demographic Questionnaire

The Role of Religion in Parents of Children with Disabilities

DEMOGRAPHIC QUESTIONNAIRE

Participant No. ____

Questions about you and your family

1. What is your relationship to your child/children (e.g. biological mother, adoptive father, foster carer etc.)?

   _____

2. How long have you been caring for your child/children with disabilities?

   ☐ Since birth   since _____

3. Please complete the following information for each child with disabilities:

Year born	Age (years)	Gender (male or female)	Disabilities/special needs (for children with disability only)	When diagnosed (year)

4. What is your current age? _____ years

5. How would you describe your ethnicity (place of origin)?

_____

6. How would you describe the ethnicity of your child/ children?

   Child 1 _____   Child 2 _____

   Child 3 _____   Child 4 _____

7. What is your current employment status?

   ☐ Full time   ☐ Part-time   ☐ Volunteer work   ☐ Not working

   Please state if this has altered as a result of your caring responsibilities.

   _____

Questions about your religion

1. How would you describe your religion? (e.g., Roman Catholic, Sunni Muslim)

   _____

2. How long has this been your religion?

   ☐ From birth   Since _____

3. How would you describe the religion of your child/children?

   _____

For the following questions, please mark whichever is closest to your usual practice:

4. How often do you attend a place of religious worship or another place where religious worship is scheduled to take place?

   ☐ Never   ☐ Occasionally   ☐ Monthly   ☐ Weekly   ☐ Daily

5. How often do you meet with others from your faith community?

   ☐ Never   ☐ Occasionally   ☐ Monthly   ☐ Weekly   ☐ Daily

6. How often do you engage in religious meditation or prayer?

   ☐ Never   ☐ Occasionally   ☐ Monthly   ☐ Weekly   ☐ Daily

7. How often do you read religious scriptures or study religious texts?

   ☐ Never   ☐ Occasionally   ☐ Monthly   ☐ Weekl   ☐ Daily

Thank you very much for completing this questionnaire. Please note that this will be kept separately from the information collected from you during your interview.

APPENDIX 5.2: Interview Schedule

The Role of Religion for Parents of Children with Disabilities

<u>Thank you</u> for agreeing to talk with me about the role religion plays for you in parenting a child with a developmental learning disorder. I am <u>interested in a range of different religious experiences</u>, including religious beliefs, religious practices, any participation you may have in your religious community, your relationship with others within your religious community and your relationship with God.

I will be interested to <u>hear as much as you would like to tell me</u> about your experiences. You might find the interview feels a bit like a <u>one-sided conversation</u> and the <u>answers to some of my questions might seem obvious</u> but that is because I'm trying to <u>discover</u> how you understand things. There are <u>no right or wrong</u> answers, and you can <u>take as much time as you wish</u> in answering.

<u>Sometimes parents find talking about some of their experiences upsetting</u>. You do not have to answer any questions that make you feel uncomfortable but if you find yourself feeling distressed, please <u>let me know</u>. You are <u>free to withdraw</u> from the study at any time, without having to give a reason.

Do you have any <u>further questions</u> about the study before we begin the interview?

Introductory Questions

1. I'd like to start by asking you to tell me a bit about (*child's name).*

2. What does caring for ___ means for you and your family?

Prompts:
What things are different about caring for ____ than for another child?
What things are the same?

Role of religion in daily life

3. Can you tell me a bit about the role religion plays for you in your daily family life?

4. What role does religion play for you as an individual?

Prompts:
Religious beliefs, religious practices, participation in your religious community, relationship with others within your religious community, relationship with God.

<u>How much is that what people do within your culture, how much is determined by religion?</u>

Role of religion in parenting

5. Could you tell me about a time recently when you felt religion/your faith impacted on your experiences of parenting?

Prompts:
What happened? How did you feel?

6. How does your religion affect how you make sense of your role as a parent to _____?

Prompts:
Does it change the meaning of what you are doing or why you are doing it?

Parenting a disabled child

7. How does your religion affect how you make sense of _____'s difficulties?

Prompts:
How have your faith or your religious beliefs altered how you make sense of his/her difficulties? How does that make you feel?

Coping with difficulty

8. Thinking about your role as a parent, how has your religion affected how you and your family get through the difficult times?

Prompts:
What is different about being a parent with faith?
In what ways has religion been helpful? In what ways has religion been less helpful?

Relationships
I now want to ask you about your relationship with your religion and with your child. Specifically I am interested in the effect of one on the other.

9. How has your relationship with your religion changed as a result of your experiences of parenting _____?

10. How has your faith/religion affected your relationship with -----?

Possible prompts:
How do you feel about the changes?
How do you see things changing in the future?

Less stressful times

12. What role does religion play for you, when things are going better?

APPENDIX 6: Participant Demographics

ID	Parental Role	Age	Ethnicity	Marital status	Employment status	Religion
1	Biological mother	49	Nigerian	Married	Part-time	Pentecostal Christian
2	Biological mother	49	Jewish	Married	Full-time	Judaism
3	Biological mother	24	Afro-Carribean / English	Single	Not working	Christian (with muslim views)
4	Biological mother	44	White British	Married	Part-time	Church of England
5	Adoptive mother	54	White British	Single	Part-time	Baptist Christian
6	Biological mother	44	Nigerian	Married	Not working	Islam
7	Biological mother	49	White British	Married	Part-time	Christianity
8	Biological father	55	White British	Married	Full-time	Methodist Christian

Table 1: Parent Characteristics

ID	Disability	Year of birth (age)	Year diagnosed with LD	Gender	Ethnicity	School status*
1	Child 1 – Autism Child 2 – Autism	1996 (13) 2003 (7)	1998 2006	Male Female	Nigerian/British Nigerian/British	Special Special
2	Autism	1991 (18)	1993	Male	Jewish	Special
3	GDD/ Epilepsy/ Visual impairment	2007 (3)	2007	Male	Mixed	N/A
4	Autism/Language disorder	2001 (9)	2008	Male	White British	Special
5	DS/Diabetes	1992 (18)	1992	Male	White British	Special
6	Autism	1995 (15)	2000	Female	Nigerian	Special
7	DS	1996 (15)	1986	Male	White British	Special
8	Autism	1992 (18)	1995	Male	White British	Special

Table 2: Child Characteristics KEY: GDD = Global Developmental delay; DS = Down's Syndrome; *Special denotes that child is attending a specialist school for children with special needs as opposed to mainstream education.

APPENDIX 7.1: Feedback Cover Letter to Ethics Panel

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APPENDIX 7.2: Research Summary Letter for Parents

The role of religion for parents of children with learning disabilities

SUMMARY OF RESEARCH

Background to the study
Previous research has shown that some parents of children with disabilities identify religion as a strong source of support. However, little research addresses how parents in the UK make sense of their experiences of caring for a child with a learning disability. This study aimed to explore the role religion plays for parents of children with learning disabilities. Religion was defined as the beliefs, practices and relationships that are commonly shared between followers of one of the world religions.

What I did
Eight parents who identified themselves as having a religious faith were interviewed in South East England. These parents came from a range of backgrounds. They were following Christianity, Islam or Judaism. Parents were asked questions about how they made sense of having a child with a learning disability and what role religion played in their family life. All interviews were recorded, transcribed and analysed for themes common across them all.

What I found
The key findings summarised below represent the views of most parents, although some other views were also held by parents.

<u>Making sense of the disability</u>
Most parents felt God gave them their child for a reason. Most saw the experience of parenting their child had been a journey of personal and spiritual development. Some felt difficulties were part of life and presented opportunities for spiritual growth.

<u>Value of the child</u>
Most parents felt that their child was just like any other, and mothers all felt fortunate to have been given the opportunity to parent. Many parents had attempted to understand their child's spirituality. Some felt their child had an independent relationship with God, whilst others felt it was difficult for their child to understand God and religion.

<u>What it means to have faith</u>
All parents felt their religious faith was part of who they were, and as such it guided many parents in their parenting. Many parents felt that their faith gave them hope that things will get better. However, some parents admitted there were some times when it was difficult to hold onto this hope.

<u>Relating to God</u>
All parents felt they had a personal relationship with God, which for many had changed since their child was born. Most parents felt God gave them the strength to cope during difficult times. All parents believed that God answers prayer and many gave examples of prayers for their child that they believed God had answered.

<u>The family and religious community</u>
Some parents felt religion was central to their family. A few felt isolated in their faith which they felt had impacted on their religious practice. All parents received practical or emotional support from their religious community which was very important to them. Most parents felt their religious community reacted positively to their child, although some members did not always show acceptance to their child. Many parents struggled to take part in community activities.

Conclusions
Religion plays an important role for some parents of children with a learning disability. Parents with religious faith reported that religion helped them make sense of having a child with a disability and helped them cope with the task of parenting. The religious community was important to these parents, although they experienced some difficulties in participating.

I am currently in the process of writing up this project and am hoping to submit a report to an academic journal later this year. Please contact me if you would like a copy of this.

Thank you once again for taking part.

Naureen Whittinger
Trainee Clinical Psychologist

APPENDIX 7.3: Research Summary for Services

The role of religion for parents of children with learning disabilities

Background to the study

Some parents of children with disabilities identify religion as a strong source of support. However, little research addresses how parents in the UK make sense of their experiences of caring for a child with a learning disability. This study aimed to explore the role religion plays for parents of children with learning disabilities by asking parents who identified themselves as having a religious faith.

Key Findings

Most parents saw the experience of parenting their child as a journey of personal and spiritual development.

Most parents felt their child was just like any other and felt fortunate that God had given them an opportunity to parent.

Parents felt their religious faith was who they were and that it guided their parenting.

Many parents felt their faith gave them hope that things will get better. Sometimes though, it was difficult to hold onto this hope.

All parents felt they had a personal relationship with God but that this had changed since their child was born.

Religion was central to family life for some parents but others felt isolated in their faith.

The practical or emotional support parents received from their religious community was very important to them. However, many struggled to take part in the activities of their religious community.

Method

Eight parents from different religious and ethnic backgrounds were interviewed in South East England. They were asked how they made sense of having a child with a learning disability and what role religion played in their family life. All interviews were recorded, transcribed and analysed for themes common across them all.

Conclusions

Religion plays an important role for some parents of children with a learning disability. Parents with religious faith reported that religion helped them make sense of having a child with a disability and helped them cope with the task of parenting. The religious community was important to these parents, although they experienced some difficulties in participating.

Implications of research

We know that religion is important to some families who are parenting children with a disability. Services should be designed to meet the needs of parents of religious faith, some of whom might experience isolation within their families or the loss of their religious community. Opportunities for parents of children with disabilities to come together to celebrate their faith or to talk about religious issues could help in supporting such parents.

Naureen Whittinger
Trainee Clinical Psychologist
nw99@canterbury.ac.uk

APPENDIX 8: Research Diary (Abridged)

<u>March 2009</u>
Met with my internal supervisor to consider potential projects on spirituality and mental health. Based on a literature search, I have come up with several areas which I discussed with my supervisor; he provided me with references for further exploration of the literature in:
Religion and coping with difficulty
Religion and spiritual issues within the therapeutic process
Issues around services attempting to meet the needs of religious service users
What a relationship with God means for an individual
Changes in religious expressions and relationships in people with mental health problems

<u>April 2009</u>
I am still finding it difficult to come up with a specific research idea. Spoke with a fellow trainee who encouraged me to think about my clinical work. This led me to think back to a mother I worked with a few years ago who was parenting three children with Autism. I remember being struck by her efforts to engage her children in religious activity and educate them in her faith through religious stories, music and reading them holy books. Such efforts seemed to provide her and her children a sense of peace.

A brief literature search highlighted an American study which looked at the experiences of parents who have sought to find formal religious education for their children with special needs or disabilities. The parents mostly experienced clergy and members of faith communities as failing to recognise the spirituality of their disabled children. However, those parents whose children were welcomed into a spiritual community reported feeling sustained support and strengthened faith. Professionals were not perceived to have an awareness of or interest in spirituality within families of children who have special needs. I wondered about the experiences of families in the UK who are religious.

<u>May 2009</u>
I emailed my internal supervisor some ideas related to spirituality in parents of children with LD:
How spirituality impacts on coping with the demands of parenting a disabled child
How parents attempt to meet the spiritual needs of their children, and/or how they experience mental health services in relation to helping them to meet these needs.

Spoke with another member of the staff team who advised me where I could recruit participants.

<u>June 2009</u>
Met with a psychologist working in South London to seek her advice on shaping my research question. Discussed differences between spirituality and religiosity and spoke about some issues relevant to the sample. She suggested targeting an area where I should be able to find families of different faiths.

<u>August 2009</u>
First meeting with a potential external supervisor. Went well and she has agreed to supervise the project! She has given me lots of advice on places I can find my sample.

<u>September 2009</u>
Feel there is no time at the moment to give my full attention to the project but have begun some reading around the topic area. Mainly I have been looking at overviews of literature on spirituality and mental health research. There is not a lot of UK research!

<u>October 2009</u>
Meeting with internal supervisor to discuss my proposal. Was really helpful to think through definitions of spirituality and religion. Have decided it will be easier to focus on religion since it is easier to measure and also most existing research looks at religion rather than the broader concept of spirituality.

<u>November to December 2009</u>
IRP proposal finalised... and then my proposal review. Despite feeling unprepared, this seemed to go well.

<u>January 2010</u>
Further to the review, I have refined my research question to fit better with IPA and put in place a contingency plan for if I do not get the required sample within the timeframe for this project.

<u>February to March 2010</u>
I have been looking for a measure of religiosity but there is not really a standard one that is used across studies. I will therefore ask parents how often they attend religious institutions, pray, read religious scriptures and meet with others of their community. Have also refined my interview schedule according to the guidance in Smith et al.'s book on IPA.

<u>April 2010</u>
Have handed in my ethics form. The panel is due to meet in approximately two weeks.

<u>May 2010</u>
Ethics approval received!

<u>June 2010 to July 2010</u>
My recruitment drive has started. I am posting an advert in a charity newsletter, concentrating on multicultural areas of South London as the target region. This fits with my desire to speak with parents from a range of religious and cultural backgrounds. Since it is also the area my external supervisor works in, she has a good working knowledge of services and voluntary sector organisations that exist in the area should any of my participants make a request for support. At my meeting with my internal supervisor, he recommended widening the recruitment net as far as possible and we discussed dates for me to send him a copy of my Part A draft.

<u>August 2010</u>
Met with external supervisor to get her thoughts on my interview schedule. She suggested asking parents for a specific time when religion impacted on their parenting to get richer information about their emotional experience. She also felt the word religion was too formal and suggested using the words faith and belief.

17 August: Pilot interview with A, who has two young children. It was harder than I thought trying not to read from the script. A however thought I had a nice interview style and made some helpful suggestions for introductory/rapport building questions. She told me that she came away feeling she really wasn't that religious but acknowledged that she also wouldn't have been likely to respond to an advert for a study on religion. I came away feeling the need to keep practicing so that my interview style improves.

27 August: Spent another morning calling various organisations to ask them if I could advertise in their newsletters. Received a mixed response – some people very interested in my research, some reluctant to give me space. After several phonecalls, I spoke with a lady who herself has children with disabilities and she has agreed to participate!

<u>September 2010</u>
1 September: Pilot interview with H, who is a mother of a 8yr old boy and 6 yr old girl and a practicing Muslim. H was very open with me and shared a lot of information. She said she hadn't meant to go into such personal detail, but it just felt like we were having a conversation and she felt comfortable sharing what she had. Some of the questions had felt a bit similar to her, so I'll tweak the schedule somewhat.

Already I am able to draw out common themes for these parents from the two pilot interviews:
Being a parent changes things; brings religion to the forefront.
Life becomes about doing your best for the child and that includes giving them spiritual guidance.
Religion provides guidance on how to live your life.
Your children become the focus of your prayers.
God puts you with the child and the child with you

8 September: I have received three emails from potential participants this week. Things are looking up! Spoke with one of them on the phone this afternoon; a young mother of two disabled children. She listed a number of disabilities her son experiences. She expressed how difficult it was that there was not a label for his disabilities, nor a known cause. This led me to wonder about the differences between potential participants: differing diagnoses, differences in the ages of the children, different faiths. I hope that making a comparison between these parents will produce valid data.

15 September 2010
First research interview
I was pleased that my questions elicited interesting and relevant information. It feels exciting to have some data and for the project to be getting up and running. I was fascinated to hear about the mother's experiences and grateful for her openness in sharing them with me. She promised to pass on my information sheet to other families that might be interested in taking part and also agreed that I could come to speak to her parent's group to talk about my project to see if any other mothers would wish to take part.

October 2010
Received another email about someone responding to my advert on the research line! However, whilst this gentleman was keen to take part, he did not meet my criteria. He felt religion was unhelpful and a non-religious account would be useful to include in my write-up. I explained that unfortunately due to the methodology I had chosen, I was unable to consider people for whom religion was not important.

I am in the middle of writing up Part A but really struggling with the amount of research literature there is to digest. I am finding it hard to organise it since many studies overlap with respect to their research questions and their findings. This is all taking so much longer than I had hoped!

I have begun transcribing the interviews. It is also taking a long time!

Meeting with internal supervisor to discuss my draft of Part A. I discussed the possibility that my literature review would impact on my interviews. My supervisor advised me to bear it in mind especially if when listening back to the transcripts I notice myself looking for specific answers.

21 October 2010
Second research interview
Interview with a young mother of two children with learning disabilities and complex health needs, which took place in a High Dependency Unit upon the request of the participant. Whilst the location was not perfect, this mother had been hard to reach. Carrying out an interview here gave me the chance to see what parenting a special needs child could entail. I was aware that she was at times distracted by the machines around us and this meant that the focus of her interview sometimes shifted. However, I think despite this, I was able to get useful data. Two themes stuck in my mind as being particularly salient. Firstly, this mother felt having her children had saved her from where her life was going previously. Secondly, she combined ideas and practices from two religions, Christianity and Islam. My demographic questionnaire does not really pick up subtle distinctions between people who might choose to tick the same boxes. However, personal beliefs and experiences should be reached through IPA.

28 October 2010
Third research interview
Interview with a Jewish mother, who spoke strongly about tradition and ritual. This is in contrast to the Christian mothers who I have interviewed who spoke more about their beliefs. This mother only started to tell me about her beliefs once the interview had ended, so I asked her consent to turn on the recorder again! I wondered if my interview questions had not been specific enough to capture such data. I felt that due to the emphasis of tradition and religious practice within Judaism, this mother regarded any beliefs that did not stem directly from religious teachings to be irrelevant to the interview. Perhaps at the beginning of the interview I could let parents know I am interested in both religious beliefs that they have been taught and those they have come to themselves throughout their journey as parents?

I have also begun to consider the personal reasons why people might respond to my advert. I got a sense that this participant felt isolated in her family in terms of her religion. Parents of children with disabilities are busy people, so I am conscious that whilst many others who have read my advert may also hold religious beliefs, the participants I am meeting with are a self-selected minority for whom my research questions hold personal relevance.

November 2010
I thought it would be useful to note which themes I remember from the interviews and which themes come up when I study the transcripts. From memory, the following themes have so far emerged in all the interviews so far:
A child (with disabilities) is a blessing or gift from God.
Having a child with a disability gives an opportunity to parent
Being a parent puts one in a better position than those people who have not had children.

25 November 2010
Fourth research interview
Interview with a Christian mother who placed much emphasis on the power of prayer. She told me many stories about her son's own spiritual faith which seems to provide her with great joy. She spoke about her son being able to have 'pure faith', something she felt most people lack. As a child of God, her son was special regardless of his disability and continued to grow and develop in spiritual terms like the other members of the family.

December 2010
I have just spoken with another mother who has agreed to take part in the study. Our interview which will take place in the New Year will be the sixth interview, which is the minimum number of participants I have been aiming for.

16 December 2010
Fifth research interview
Interview with a Christian mother who has two adoptive children with Downs' Syndrome. She told me that she felt parenting such children was important as they were very valuable to God. She spoke about the Christian community as providing her with a network of friends and helping her to cope with being different.

5 January 2011
Sixth research interview
Interview with a Muslim mother. It seemed for her, religion provided a great sense of hope. There were some possible inter-relations between religious and cultural issues for this mother; for example, she felt her religion teaches parents to take ultimate responsibility for childcare and that if she is later unable to fulfil this role she will feel guilty at her failure (e.g. if her child goes to live somewhere else). I wondered if this would be something that might prevent her from accessing services and therefore something that services might need to consider when thinking about why people from non-Western backgrounds do not always access help.

February 2011
Meeting with internal supervisor. First attempts to begin coding some data. I will start with Interview 4 because this mother communicated a positive world view and the interview has stuck in my mind.

March 2011
I spoke with a gentleman who is the father of an adult child with a learning disability. He explained how religion had been important to him throughout his experience of parenting his son with Downs' Syndrome, now 36 years old. As a father, he felt it had been very important he was committed to church life, he had taught the Sunday school children and he told me he still had a strong belief in Jesus Christ. He told me he was thrilled that he had a child and that his son's disability did not colour his attitude towards religion in any way. Instead, he remained thankful to his Maker to this day. I explained that because he did

not fit my research criteria I could not interview him for my study, but I would be happy to send him the results if they would be of interest to him. He consented for me to include his comments in this diary.

Met with a fellow trainee to think through issues relevant to data analysis. I am hoping that the comments I have included in this diary will help in the process of bracketing and I also plan to look over the interview schedule before I begin data analysis properly. Our conversation also highlighted the following questions for me, some which have already sprung to mind over the course of my research:
How do my definitions of religion compare to the definitions of my participants?
What do people hope to gain from taking part in the project?
What are the non-religious beliefs that provide meaning for my participants?

8 March 2011
Seventh research interview
Interview with a mother who felt she had lost touch with her faith. She expressed guilt about this and reported that she attempted to avoid such negative emotions by not thinking about religion. On a positive note, she felt God was with her and kept her from being alone in her faith.

31 March 2011
Eighth research interview
Interview with a father of a teenager with severe Autism. This made me reflect on the role of gender and of being a secondary caregiver. This father tended to seek many of his answers from academic/scientific models rather than his faith. He felt his son was "non spiritual" but this was linked to his own understanding of faith which required a relationship with God, which he felt his son was incapable of. It will be interesting to see which themes this father brings that overlap with the other parents as the interview itself felt to be bringing in some completely new perspectives.

May 2011
Having begun the process of coding, I can't help feeling that my comments are entirely subjective and I'm anxious about not really understanding how to do IPA. I thought that before continuing, I should do some reading around ensuring quality of analysis using qualitative analysis but this left me even more perplexed. I read a very interesting paper on bracketing (Fischer, 2009) but this only highlighted how even very experienced researchers can fail to bracket adequately.

I decided to return to Smith, Flowers and Larkin's chapter on data analysis for clarification of how to carry out the analysis. I have also emailed my supervisor and we have arranged for a meeting in a couple of weeks to look at the data. In the meantime, I have some study leave arranged for next week and am now looking forward in immersing myself in the data!

I have now finished analysing my first interview. It has taken a long time and I think I produced way too many codes. However, I was interested to note how the same themes came up throughout the course of the interview and I am confident that the method has enabled me to get close to this participant's experiences. There are still another seven interviews to get coded and analysed - I'm hoping I'll get faster at coding!

June 2011
Have finally completed my analysis of the data. This was actually quite an enjoyable process and I feel confident in what I have done. Met with my internal supervisor to discuss the themes. This helped me to think about and interpret the experiences of individual parents and how this information could also be brought out in the analysis. This has been a busy month! Parts B and C written. Part A restructured. It's strange to think this project is now finally reaching an end after so many months of hard work.

July 2011
Making final changes and putting together Part D.

APPENDIX 9.1: Interview Transcript (Coded Example)

This has been removed from the electronic copy.

APPENDIX 9.2: Super-ordinate Themes (Example)

Transcript 4 Themes

Parenting a child with LD is difficult
Can be draining to parent child
Sometimes hard work to parent child
Can't do what you might do otherwise as a parent to a child with additional needs
Getting help was a stressful experince
Unanswered questions

Isolation as a caregiver
Isolation in parenting tasks
Hard to find time as a couple
Hardest thing is isolation
Knowledge of things can be different for the main caregiver
Uncertainty around parenting

Child with LD as spiritual
Child has independent relationship with God
Child spontaneously prays
Children express faith
Child puts trust in God
Child has pure faith
Child gets strength from God
Child has sense of right and wrong
Child's spirituality is an example
Child's faith encourages mother
Mother is wowed by child's spirituality
Gives confidence when times are hard

God has a purpose for X
God has a purpose for my child
My child will be an example to others
My child will use God's gifts
God is developing my child
My child's gifts are developing
God helps children blossom

God is with me
Not alone in parenting
God is with you always
Can sense that God is there
God is in my life
God really was there
Not alone
Can always talk to someone
Can always ask for help
Pass on worries to God
Present issues to God
Praying is more of a conversation
Praying at different times of the day

God answers me/ helps me
God answers your questions
Looking back and finding answers
God answers your questions
God answers prayers bit by bit
God answers prayer
God certainly answers questions
God has answers I don't have
God helps
God gives reassurance

X is one of God's children
My child is a child of God
My child is the same
God loves my child
My child is truly special to God
My child belongs to God first

X is gifted in a different way
We are all different
God creates difference
Development different for different people
Child is gifted in different ways
Different gifts are given to different people
God gives gifts to people with disability
My child is developing in his character which is the most important thing

This is a preparing ground
These are times of testing
This is a time of preparation
This is a preparing ground for the next life
Having X was a testing time
We are developing through our experiences
Having X part of our process of development
God provides experiences for learning
God is using my child to develop me
God puts you in situations where you have to develop
God gives opportunities
God strengthens me
God is teaching us

God as a model
Aim to develop a Christ-like character
Lord as a model
God is all loving
God is all forgiving
God knows all
People are weak but God does not fail

X is a blessing
My child is a blessing
Recognition that X is a blessing affects parenting

Good comes out of suffering
Difficulty can bring you closer to God
Good comes out of suffering
Learn most from the worst situations
Have learned through struggles
Difficult situations as opportunity for dev
Struggles enable development
God helps me to help others
My difficulties will help others
Know there will be a positive outcome
Know things will get better

Life is a journey
This is a journey
Faith is a journey (process)
Journey of faith and parenting interlinked
Children with us for a short time only
Growing as people in our faith
Family can be at different stages of the journey
At the end of the journey you will get to heaven

God puts things in place
God works in many ways
God has a purpose for us all
God puts things in place
Child is in God's hands
There's a pattern of events
God knows best
Gradually see things unfolding in life

Prayer is important
Prayer enables relationship with God
Prayer as much as possible is important
Pray for assistance
Pray for X to know God
Pray for X to acknowledge his gifts
Praying with X when he asks questions
Pray for wisdom

Faith is who you are
Faith becomes who you are
Must be hard without a faith
Don't know what it is like not to have a faith
Hard to pick a significant event
I have God in my life
Religion impacts on a daily basis
Internalisation of what God gives you
Feel lost without faith

Life is not plain sailing
Difficulties are to be expected
Life is a struggle
Life is not meant to be plain sailing

Wisdom in religious teaching
Bible gives pointers
Bible gives wisdom and parental guidance
Readings from the Bible relevant to my life
Feel encouraged by religious readings
Reading Word for Today gives me wisdom
Reading Word for Today relevant to my life

Other people's stories inspiring
Examples of how others keep going
Inspired by how other Christians have dealt with things
Inspired to do difficult things
Other people's stories encourage me
Examples of others helps me keep going
Christian radio is inspiring

Community as a place for help
Christian community is supportive
Community focus on helping others
Rejoice and share in good times
God helps me to help others

Parental role
Our role is to care for our child
Child needs to be looked after
Child needs support
Right way to bring up children
Sharing of religion with the children

Religion and the family
Religion changes family relationships
Shared family view
Great love within the family
We are loved by God unconditionally

Journey takes time
Perseverance is important
Process of waiting for an answer
Process of development is long

Unused codes
Guidance
Religion gives clear focus
Source of support
Forgiveness as part of our faith
We are loved by God unconditionally
Thankfulness
Love God and love others