Faith, Spirituality and People with Autism

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Abstract

All people have the right to fulfil their emotional, physical and spiritual needs yet it appears that people on the Autism Spectrum tend to lack support in relation to their spiritual needs (Swinton, 2001).

Aim - The aim of this dissertation was to conduct a policy and literature review on spirituality and faith in people with autism to fill the gap in this area of research.

Research question - The research question was: How do policies and scientific literature in the United Kingdom approach the spiritual needs of people with autism? The review included research into how policies refer to the spiritual needs of people with autism. The findings of scientific literature into the spiritual needs of people with autism were also reviewed.

Results – The paper identified four policies and eight articles which met the inclusion and exclusion criteria. It was found that the policies reviewed did not address the question of spiritual needs and people with autism directly but did refer to the rights and guidelines that all people with or without conditions, such as autism, can follow to obtain the fulfilment of their needs. In the eight articles, it was possible to generate three themes related to self-awareness, relationships and experiencing spirituality.

Total word count: 9374

Declaration

I confirm that this dissertation is my own original work except where I have acknowledged the use of other people's ideas or words by referencing the material as outlined in the course handbook. I have not submitted this dissertation or any part of it for any other academic award. I have read and understood the definition of plagiarism in the course handbook.

Signature   **Date** 22/08/2017

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1   Introduction

1.1   Spirituality and faith

Spirituality may be regarded as a way of living rather than a static belief. Gottlieb (2012) suggests that spirituality is an erratic procedure beginning with suffering to produce a new understanding of our lives and achieve fulfilment in defiance of difficult demands. It can be a deeply personal aspect (Speck 2005), in other words, a purpose of life in an individual´s heart and how it is put into action (Campbell, 2003).

The terms 'spirituality' and 'religion' are defined in different ways. Hill et al. (2000) define spirituality as "*a connection between a person and something sacred, an object or a feeling";* and religion as *"a conviction or tradition of something according to a system*" (Hill *et al*., 2000, p.60). Religion comes from the Latin word 'religare' which means 'bind together'. A religious life involves connecting to the object of someone or something superior to the self through the meaning that one holds regarding the emotional and cognitive aspects of this object, through a spiritual path or not (Schaap-Jonker, Sizoo, Van Schothorst, & Corveleyn, 2013). Spirituality, on the other hand, gives meaning to everything else in a person´s life, it is what gives a reason for functioning, as the word "spiritus', also derived from Latin, means 'air, life, breath or courage'. Therefore spirituality is much more in depth to the purpose and direction one has in life to overcome any barriers, differences, struggles they may come across (Baker, 2003).

Faith may be defined as the hope that someone holds for the thoughts and actions of their life, it is an important part of their character and personality (Fowler, 1981). It can also decrease negative feelings and consequently results in better mental health (Hill & Pargament, 2003).

According to Hill et al. (2000) spirituality is a central function of religion, therefore they can co-occur. Although it is important to understand that spirituality can function without religious concepts; it is activated by the individual´s search for the sacred, and a more personal account and experience with a higher power. Similarly, spirituality is not defined by religion; it gives humans their humanity (Swinton, 2001). It is believed to be more personal, subjective and experiential than religion (Thoresen, 1998).

The meaning of spirituality has changed over the past 20 years, in both theology and human sciences (Rovers & Kocum, 2010). Reducing it into a small definition would likely limit its perception (Hill et al., 2000). Spirituality belongs in all of us, suggests Narayanasamy (1999); the non-religious person also has spirituality within them, it is the capacity to search for meaning and purpose within one´s self.

On the contrary to this, Rovers and Kocum (2010) say that spirituality does not exist on its own, it exists between people. With this in mind, Moberg (1986) conceptualized spirituality in two dimensions: vertical, the relationship between self and a higher power (God); and horizontal, the relationship between the individual and others.

Spirituality is the possibility or the want of connecting with someone or something else greater than ourselves (Palmer, 2003). Spirituality is a need for a relationship (Emmons, 2005) in which individuals seek to maintain a sacred relationship with the transcendent and a daily commitment to a higher being. It is being intimately connected with the supernatural (Koenig 2010).

Spirituality expresses itself in meaning, purpose and morally fulfilling relationships, which include biological, mental, social and spiritual aspects (Rovers & Kocum, 2010). It is also a multidimensional space and each individual has their own location within it (Larson, Swyers, & McCullough, 1997). People with a developed spirituality look for meaning, purpose, hope, faith, love, forgiveness, prayer, meditation, and worship, beyond their current situations (Kuhn, 1988).

Massoudi (2003) argues that spirituality is a form of compassion, nonviolence, truthfulness, loving kindness, being connected to the whole, and living a peaceful harmonious life. Mayes (2001) agrees that spirituality is a way of compassion and service and the pursuit of transpersonal and transtemporal reality. As a whole, spirituality is the mainstream of life (Dickinson 1975; Stoll 1979), therefore values, beliefs, thoughts, decisions, and behaviours are centred as the artery of all dimensions (Brewer, 1979).

An important factor raised by the World Health Organization is that spirituality is seen as the self-wholeness and stability for an individual (WHO, 1993). It refers to becoming fully human, connecting self, others, the world and the Divine (Daly, 2004). It is also linked to quality of life, in terms of emotional, physical well-being, relationships and social inclusion (Johnstone, Glass and Oliver, 2007).

In comparison, the spiritual struggles that individuals may face due to the questions they have about the image of God or a higher power can lead a person to fear and/or disillusion. In other words, questions and doubts can result in outcomes such as stress, anxiety and depression (Hill and Pargament, 2003). Despite these measures of spirituality and health, it is believed that the positive outcomes prevail due to spiritual growth and development. Not only do people in the general population benefit from this, but so do people with medical illnesses and struggles in life. The use of spirituality as a coping strategy is known to provide immense strength, (Hill and Pargament, 2003), comfort and boost self-confidence (Koenig 2010). Spirituality may not take any obstacles or difficulties away but it does provide support and the capacity to enjoy life and to deal with situations and negative experiences (Brady, Peterman, Fitchettc, Mod, & Cella,

1999), diminishing negative thoughts of hopelessness and helplessness (Cotton, Levine, Fitzpatrick, Dold, & Targ, 1999). Furthermore, these struggles also contribute to the spiritual growth of an individual (Hill and Pargament 2003).

Galek, Flannelly, Vane and Galek (2005) researched the spiritual needs of patients, distinguishing seven categories, in the order they considered most important, as seen in the table below:

Table 1

Spiritual needs of patients in order of importance (Galek et al., 2005).
1- Meaning and purpose;   2- Love and belonging;   3- Hope, peace and gratitude;   4- Prayer, religious services and guidance from a higher power;   5- Death concerns and resolution;   6- Appreciation of art and beauty;   7- Moral and ethical issues;

Therefore having meaning and purpose in life is considered to be the most important aspect for these patients. Secondly being loved and having a sense of belonging are two critical needs among people who are suffering or have an illness (Galek et al., 2005).

According to Bogdashina (2013) the most influential model of spiritual growth is that of James Fowler. His theory in the 1980s relates to the stages of faith in human development, but that not necessarily every person will go through each stage of spirituality, some may stay on one stage all their life, others will go through the stages at a different pace. Therefore the spiritual needs of the patients in Galek et al. (2005) study above may be interlinked or may be different for a different population of patients. Fowler´s model of spiritual growth can be considered simultaneous to Piaget´s theory of child development (Bogdashina, 2013). A description of each stage is provided in table 2.

In the most sacred texts of the world´s greatest religions, there are three commanding domains of spirituality; they are faith, hope and love. Faith in the presence of God/transcendent, hope and meaning for a purpose in life, and love expressed by family and community (Rovers & Kocum, 2010).

Table 2

Fowler´s stages of faith in human development (Bogdashina, 2013).

Stage 0	Primal faith	Developed before language, with an awareness of being disconnected from others and from the environment.
Stage 1	Intuitive projective faith	Developed with language in early childhood.
Stage 2	Mythic literal faith	The person can interpret literally some myths and symbols. To make progress on the spiritual development at this stage it is necessary to become unattached to conditioned aspects such as those learnt from the person´s family.
Stage 3	Synthetic-Conventional faith	Reflection on past experiences. The concern for future vocation, career, personal relationships, and identity, become important.
Stage 4	Reflective faith	The person now takes on the responsibility of their own beliefs and values.
Stage 5	Conjunctive faith	People become more tolerant and diplomatic to others beliefs and views.
Stage 6	Universalizing faith	The wholeness, when the individual is mature, selfless, they become content with their spiritual values, being grateful, trusting, kind, compassionate, being tolerant and accepting limitations

Spirituality is the total process of life and human development (Canda, 1990) developed across the lifespan (Hill et al., 2000), through the fulfilment of primary needs (Donahue, 1985). The focus on spirituality, during a child´s educational years, is fundamental towards their self-identity, interrelationships and purpose in life (Miller, 2000). It is part of their formation and essential to their development (Crompton, 1998). For instance, cognitive aspects, emotions and personality are developed through spirituality and help promote personal growth (Hill et al., 2000).

There are five interconnected dimensions in the human experience, physical, biological, psychological, sociocultural and spiritual (Bogdashina, 2013). The spiritual dimension connects every part to the whole (Culliford, 2007). Coles (1990) conducted research into spirituality in children and confirmed that spirituality is a universal feature. Some people seem to be more spiritually aware or gifted than others; these include children, who are also known as 'innocent',

because they are not yet fully restricted to cultural conditions, people who have suffered a tragedy or loss, individuals with mental deficiency or mental illness, and people with autism (Bogdashina, 2013).

Subjective well-being is assessed by the responses one gives about their happiness, satisfaction, utility and welfare, influenced by culture, mental capacity, education and temperament (Costanza et al., 2007). With this in mind, to attain the highest quality of life, an individual requires not only basic human needs such as security, affection and freedom but also spiritual well-being. In other words, spirituality is not only a human right, essential for well-being (Swinton, 2002) it is also a basic human need (O´brien, 1982; Ross, 1995). Before considering the spiritual needs of people with autism spectrum, a brief description of the characteristics and underlying mechanisms of the spectrum condition is provided.

1.2   Autism

Autism spectrum disorder (ASD), according to the Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-V), is a neurodevelopmental disorder, considered to be a life-long condition (Hill & Frith, 2006). The main characteristics are deficits in social communication and interaction, and restricted, repetitive and/or obsessive behaviours or interests (American Psychiatric Association, 2013).

The condition was first described by Leo Kanner in 1943, although Frith (2003) explains and considers that evidence existed long before this. The inability to relate to others, self-sufficiency, acting as though others are not present, language impairments, excellent rote memory, despair in changes of routine, a fascination with objects, and good cognitive potential were described by Hans Asperger in 1944 (Frith, 2003). Additionally, since the 1980s autism has become known as a spectrum disorder (Wing, 1996).

This spectrum of disorders describes the presence of developmental and behavioural features (Lord, 2004). Some examples of these are the presence of rigidity, insistence on sameness, obsessive or narrow interests, and difficulty in shifting attention, exceptional rote or visual memory, unusual or precocious ability with numbers, repetitive behaviours and literal understanding. Additionally, the repertoire of behaviours includes the appearance of a lack of interest in other people, difficulty in recognizing faces and facial expressions, failure to develop joint attention and pretend play, failure to develop adaptive strategies, language impairments such as a delay or absent and poor motor coordination (Lord, 2004).

There is also an extensive list of co-occurring conditions that may be present alongside autism, some of which are neuropsychological conditions (e.g. ADHD, dyspraxia or sensory processing problems), learning disabilities and difficulties, neurological disorders (e.g. epilep-

sy), health problems (e.g. bowel problems and skin allergies), psychiatric disorders (e.g. anxiety and depression) (Hill & Frith, 2003; Gilberg, 2011).

The latest diagnostic tool, DSM-V, describes autism as a dyad of impairments, comprising impairments in social interaction and communication coupled with restrictive and repetitive repertoires of behaviour. It also included sensory sensitivities into the diagnosis, as well as removing autism spectrum disorder (ASD) subgroups and Rett Syndrome (American Psychiatric Association, 2013). The spectrum means individuals included in this diagnosis can have different levels of intelligence, language and social skills (Hill & Frith, 2003).

The underlying mechanisms of autism have slowly developed but still, none of them completely explain the spectrum, even though the condition was recognized as a brain functioning disorder in the 1960s (Geschwind, 2009). Research continues to focus mainly on genes, brain and mind (Hill & Frith, 2006). There are four main types of neuropsychological theories that try to explain it: executive function theory, information processing theory, social motivation theories and social cognitive theories (Williams, Goldstein, & Minshew, 2006).

Executive function theories explain the key cognitive skills a person has. Executive dysfunction explains the issues around planning, and flexibility or difficulties with change. This explains the features observed in autism, the restricted interests and stereotyped or repetitive behaviours (Ozonoff, Roger, & Pennington, 1991). Executive function theory does not, however, explain the strengths that people with autism have, which can be better described in the weak central coherence theory.

The weak central coherence theory in ASD is an information processing theory that describes the lack of global processing, and inability to see the bigger picture (Pellicano, Gibson, Maynery, Durkin, & Badcock, 2005). However, even though the name of this theory suggests a weakness, it refers to the strength in focusing on detail, a potentially high skill people with autism have (Frith, 1989). Other strengths are that people with autism can be highly knowledgeable about specific areas of interest, systemizing, visual memory, focus in repetition, precision and accuracy.

One of the social cognitive theories is the theory of mind. The inability to understand thoughts, beliefs and feelings of others, are impairments in the theory of mind also described as Mindblindness by Baron-Cohen (1994). This does not however explain the sensory sensitivities.

The biological basis of autism has also been studied; the structural abnormality, functional abnormality and genetic abnormality. However it is still much of a mystery as is the cause (Bailey et al., 1996). According to Hill and Frith (2006) most of the anatomical studies on the brain are difficult to be done regarding the link between behavior and brain functions.

People with autism tend to require a variety of interventions and support, yet families and carers report significant lack of support in many different areas (Kuhaneck & Watling, 2015). The following section outlines how we might understand the spiritual needs of people with autism.

1.3   Spiritual needs of people with autism

In the Journal of Special Education, Ault (2010) explains that little research has been done into children with disabilities and spirituality. Even though spirituality is an important dimension in the lives of this population, spirituality in young people with disabilities is often forgotten (Ault, 2010).

A survey conducted in 2010 by the Kessler Foundation and the National Organization on Disability provided the knowledge that, regardless of disability, faith was somewhat or very important to people. Spirituality is also a support towards self-worth and self-esteem (Nosek, 2001) and can support the feeling of connectedness and wholeness independent of disability or lack of disability (Baker, 2003). Spiritual care and support are arguably critical for children with special needs, and could be more important than other forms of interventions. The devotion to developing spirituality is crucial (Ault, 2010). The spiritual dimension is part of a holistic approach which should be given to all, with or without disabilities, in their developmental stages (Nosek, 2001).

There is a lack of support for people with autism however, in addressing their spiritual needs and search for fulfilling their own spiritual quests (Swinton, 2001). In light of this, the spiritual needs of people with disabilities are often overlooked by care staff and support workers (Swinton, 2001). Despite these concerns, spiritual needs are starting to be addressed in person-centered care plans as a holistic practice (McCance, McCormack, & Dewing, 2011). If spirituality is an essential domain in life, as has been mentioned above, then people with care needs should also have the support to fulfil their spiritual needs, be it going to a religious practice or having accessibility to experience spirituality as a subjective matter (Hill et al., 2000). Although we know that spirituality does not only consist of religious practices, the fact remains that there are more than 40,000 churches in the United Kingdom yet it would appear that little attempt is being made to respond to the spiritual needs of people with learning disabilities (Potter, 2002).

Considering the diagnosis of autism can often be stressful for the family due to diagnostic confusion, uneven and unusual course of development, attractive appearance, behavior in public, professional 'turfism', fads and unproven theories (Frith, 2003), the need for the family of a person with autism to receive additional support for their needs is also required. Especially if spirituality helps develop a number of positive aspects resulting in more positive behaviours and lifestyles, such as finding psychosocial support in dealing with stress, negative emotions, anxie-

ty, fears, angers and frustration, and is known to be used as a coping behaviour in relation to mental health factors (Koeing, 2010).

Although autism is not a sub-culture in itself, it has been argued that it functions as one, since people with autism behave, understand and communicate with the world in a different way to those without the condition (Murray, 2008). Their internal language or sensory perceptual images draw them closer to the original vision of spirituality, where it is developed before linguistic experiences (Bogdashina, 2013). Therefore it is nonlinguistic, an experience felt, sensed and/or perceived (Hay & Nye, 2006).

Some people, according to Bogdashina (2013), believe that people with autism do not have spiritual awareness. That they are not aware of anything external to themselves and understand in such a literal way that it is not possible for them to grasp abstract features. However, it is an error for people who are not on the autism spectrum to interpret the feelings and/or emotions of those with autism according to their own experiences. All things considered, people with autism can be spiritually sensitive and gifted (Bogdashina, 2013), especially children who are the purest of innocents as they have not yet been conditioned to not experience spirituality (Stillman, 2006).

Stillman (2006), when describing the story of Sally Siegel´s loss of voice in his book 'Autism and the God Connection', describes Sally as *'The person confined within the prison of the body. The Spirit is free' (Stillman, 2006, p.64).* The author recalls the experience of nonverbal individuals, and how it may not be possible for them to express their needs, wants and pains, but on the other hand, questions how much time can be spent in silence and in deep thought, reflecting and contemplating the world around them. Some spiritual visionaries explain that the divine is found within the silence of ourselves (Stillman, 2006).

Autistic sensitivities are divided into four categories: sensory, cognitive, emotional, and spiritual and these factors are what make people with autism more open to spiritual opportunities. Although it is important to remember that not all people with autism present these sensitivities (Bogdashina, 2013).

The meaning of child-like is having a sense of curiosity and openness to the world. Many people with autism maintain this child-like manner (Bogdashina, 2013). Different to the view that autistic people experience differences in sensory, cognitive and linguistic development, the spiritual experiences are often developed as spiritual giftedness, which Stillman (2006) calls the 'God-Connection'.

2   Method

- Purpose of project - This project is scientifically relevant as there is little research in this area. To contribute to faith, spirituality and people with autism is to open a new field of study. There is previous research about specific religions and their interpretations and views on autism but little on spiritual needs per se. The exploration of the literature in this study was: How do policies and scientific literature in the United Kingdom approach the spiritual needs of people with autism?

- Aim - The aim of this paper was to conduct a policy and literature review based on spirituality/faith and people with autism.

- Objective - The objective of this study was to learn about the connection between spirituality and people with autism, how policies that address the spiritual needs of people with autism were examined, and the findings of scientific literature into the spiritual needs of people with autism were reviewed.

This study followed a protocol and development which searched through the databases such as University of Kent Library search, Cochrane Library, Psycinfo, Medline, Scopus, Pubmed, Embase, Prospero. Using the following keywords:

1. Autis* OR ASD OR ASC;
2. Faith OR Spirit* OR Religio*
3. Spirit* needs OR Spirit* Care
4. Numbers 1 and 2; vice-versa
5. Numbers 1 and 3; vice-versa

Assessing the studies for eligibility in criteria and for methodological quality is essential (Hemingway & Brereton, 2009). Therefore the inclusion and exclusion criteria for this study were as follows:

2.1   Inclusion eligibility criteria

- Participants of the studies must have a diagnosis of autism. In order to make sure the criteria were specific, participants in the studies included had a diagnosis of one of the following: autism spectrum condition (ASC), autism spectrum disorder (ASD), high functioning autism, asperger's syndrome, classic (or kanner autism) or severe autism, developmental disorder or disability;

- Literature written only in English was included criteria. Therefore, we can generalise the findings to English speaking countries and there will be no misunderstanding through translation;

- The time limit of published studies was a 20 year period, ranging from 1996 to 2016, for the reason that the meaning of spirituality has changed over the past 20 years, in both theology and human sciences (Rovers & Kocum, 2010).

- The study design of the published papers included could be either observational or experimental. Additionally the methodologies could be quantitative, qualitative or mixed-methods;

2.2   Exclusion eligibility criteria

- Studies that did not include the diagnosis of autism spectrum condition were excluded;
- Non-English literature was excluded;
- Studies not published between the years 1996 and 2016 were excluded.

A total of 68 relevant articles were identified. To refine the search, the inclusion and exclusion criteria were assessed on title and summary of each paper. The studies that did not agree with these factors were excluded. Once this was done, papers were read in more detail. Based on the full inclusion and exclusion criteria a further 21 papers were excluded. Therefore the selection was drawn on those meeting the clear and full criteria. Eight studies (see Figure 1) remained and were read in full.
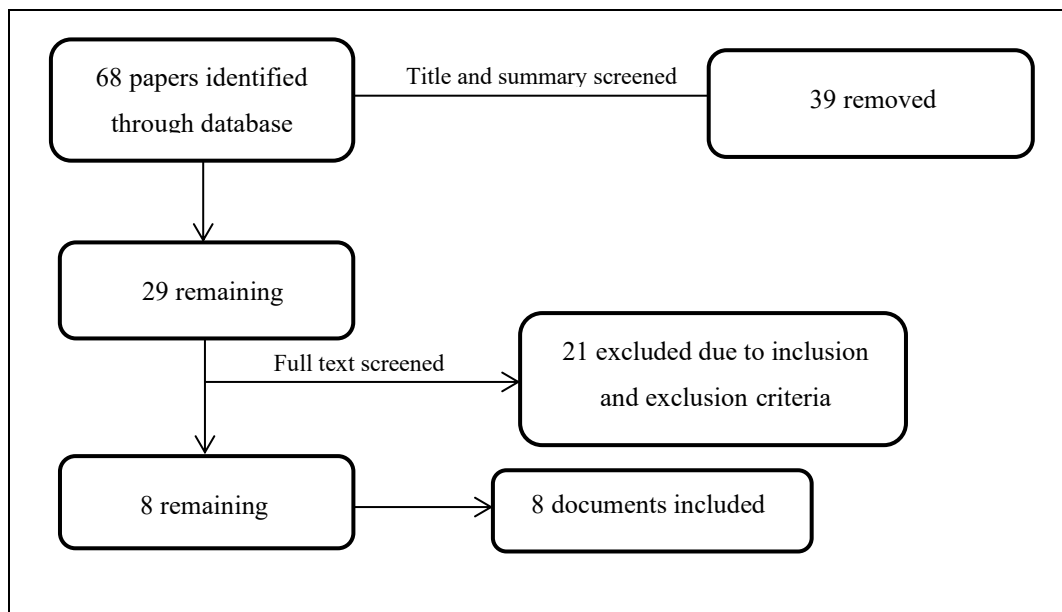

Figure 1 Flow diagram of the selection process for the Literature Review

The government documents and policies used for this review were retrieved from the following electronic databases: legislation.gov.uk, and Department of Health and Directgov (also known as gov.uk), using the same keywords mentioned above for the literature search. The Inclusion criteria were the following:

- Type of government document, policy or guideline: Government Acts, White papers, Green papers that address the spiritual needs of people on the autism spectrum in the United Kingdom;

- Publication dates: between the years of 1948 and 2016 (1948 the year when NHS took over the care provision in the United Kingdom);

- Electronically available documents;

Documents were excluded if they did not meet these criteria. In other words, if they were published before 1948, if they were not United Kingdom policies, and/or if they did not meet the reference to spiritual needs of people with autism. A total of 22 policy documents relevant to the study were identified; four of these were within the full inclusion criteria (see Table 3).

Table 3

Policies and Guidelines on Spiritual Needs and People with Autism

Title	Year	Country	Population	Summary
Autism Act	2009	UK	People on the autism spectrum	The Autism Act is a provision for the needs of people on the autism spectrum and is the first ever disability specific legislation to be passed in the United Kingdom (Legislation.gov.uk, 2017).
Care and Support Statutory Guidance	2014	UK	People with care and support needs	A guidance of promoting well-being for people with care and support needs in the United Kingdom (gov.uk, 2017).
Human Rights Act	1998	UK	People with and without autism	This Act is a United Kingdom law passed in 1998. It defends a person´s rights in United Kingdom courts and compels public organisations to treat everyone equally, with fairness, dignity and respect (Legislation.gov.uk, 2017).
Equality Act	2010	UK	People with and without autism	The Equality Act 2010 legally protects people of all age, race, gender, religion or belief from discrimination (Legislation.gov.uk, 2010).

- *Dissemination* - To communicate the outcomes of this research, this paper could be presented in conferences and/or be published, so that colleagues or any person interested in this area can have access to the findings.

3 Findings

3.1 Policies and guidelines review

Only four government papers met the inclusion criteria for this study. Notably only one document was specific for people on the autism spectrum. The remaining three government documents reviewed are regarding all people, with or without autism.

The Equality Act 2010 states that all people have the right to religion and/or belief and that no discrimination can be made against this. In this instance, all people are those with or without disabilities, with or without autism. The same applies to the Human Rights Act 1998, which implies that all people (as mentioned above all people including those with autism) have the right to freedom of thought, conscience and religion.

Although these two Acts do not refer directly to spiritual needs, they specify that no one person can discriminate against or treat another less favourable because of their religion or belief. The Equality Act continues by explaining what direct, indirect and combined discrimination upon religion or belief is (Equality Act, 2010). Article 9 of the Human Rights Act (1998) also states that all people have the right to change religion or belief publicly or privately.

> *"[…] Everyone has the right to freedom of thought, conscience and religion; this right includes freedom to change his religion or belief and freedom, either alone or in community with others and in public or private, to manifest his religion or belief, in worship, teaching, practice and observance […]" (Article 9, HRA, 1998).*

The Care and Support Statutory guidance from the Department of Health also does not specifically talk about people with autism, but it is regarding people who need care and support, and defines well-being by stating that it covers a wide range of features depending on each person, as all individuals are different and have different needs and preferences.

As stated in paragraph 1.8 of the guidance, the local authority can support the person´s well-being in many ways but most importantly by considering what the person wants to achieve. Taking this into account, the guidance focuses on meeting the needs and desires of the individual and supporting them to achieve fulfilment and meaningful targets in life and not simply providing them with services they fit into. Therefore the Care and Support Statutory guidance emphasises the importance of what matters most to the individual.

The guidance provides some key principles and standards which local authorities must take account for. Most of these are related to the importance of the individual participating as much as possible in their care and support plans, and that local authorities should work to understand and fulfil the needs and goals of each person. The individual´s choice of views, desires, feelings

and beliefs (including religious beliefs as stated) should be respected and supported in their life and care, as this is crucial to a person-centered system.

The Care and Support Statutory guidance also mentions that the approach should look at the person´s life holistically. Reflecting the fact that all people are different, their choices and what matters most to them will vary accordingly. For some people spiritual or religious beliefs will have great significance. The guidance says that local authorities should consider on a case-by-case basis how to fully support each individual to provide the best outcome and well-being in their lives. Giving people this power and control over their personal lives is essential for well-being and to maintain independence (The Care and Support Statutory guidance, 2014).

The Autism Strategy from the Autism Act 2009 is the only government document in the UK that refers specifically to people with autism. It does not mention spiritual needs specifically, nonetheless it does address the fulfilment of wishes and adjustments that services need to make for more accessibility. For instance paragraph 4.4 explains that it is important that all people related to someone with autism, get access to information about the choices they can make and what kind of support they can receive. The support they receive to fulfil their needs should be addressed locally and this is overseen by the health and wellbeing board. The health and wellbeing board should also raise awareness in the local community about reasonable adjustments that need to be made to promote access to people with autism. Autism affects the individual in different ways and additional measures may need to be put in place to best support them. Health and social care services should already recognize this and put these adjustments in place.

The Autism Strategy declares a point under the Care Act from April 2015 which says local authorities must integrate social, health and any other service that influences health and quality of life to help prevent or delay the development of additional needs. According to the Autism Strategy, people with autism have the same rights as any other person to have their needs met. It also states that it is the local authority's responsibility to listen and consider the wishes, feelings and beliefs of people with autism and that of their carers. It could be argued that some adjustments need to be made to meet these needs for many people with autism. Mainstream services can be hard to access, and adjustments need to and should be made and individualized as all people have different needs, such as communication adjustments, an increased need for planning and preparation, or increased time to become familiar with a setting or service. Under the Equality Act 2010, all public services or organizations are required to make the necessary adjustments to ensure accessibility for all people, including people with disabilities and people with autism.

All things considered, the Care and Support Statutory Guidance and Autism Strategy appear to focus on meeting the needs (not specifically spiritual) of an individual taking into account the

person´s wants, feelings and beliefs. Furthermore, these personal views should be supported and taken into account when addressing the person-centered plans of individuals who are in need of care. Similarly if the individual's preferences and needs are to be met in a community facility then required adjustments should be made in order for inclusion to be attained.

3.2 Literature review

Critical Appraisal

After the selection process, eight articles were extracted. In terms of assessing the quality of the papers reported, only one (Schaap-Jonker et al., 2013) conducted an empirical research consisting of 78 participants who completed questionnaires associated with the God image. However, the limitation of that study was stated by the authors as a small sample of participants and in addition to this, these participants were from a specific religious group, providing the difficulty of generalizing the results. Participants knew the aim and objective of the study so blinding was not applied, neither was randomization. Another key factor to the small sample in this study was that it was strictly separated from therapy or care, therefore the response rate of questionnaires returned to participate in the research was 46.4%.

Six of the studies were published in the Journal of Religion, Disability and Health. Although all submitted papers were peer-reviewed, it is important to consider the influence and direction these papers have from being published as part of this Journal. Since the Journal of Religion, Disability & Health understands that a fundamental factor for human experience is spirituality. It also advocates for health not being the opposite of disability but rather a state of physical, mental, social and spiritual well-being (Journal of Religion, Disability and Health, 2017).

The bias in three of the papers should be taken into account for, as they included personal accounts of people on the autism spectrum, in other words, their opinions and views on spirituality and faith. Although it is important to understand each person´s perspective, especially providing the opportunity for people with autism and their families to have a voice to express and share their experiences, views and beliefs, a larger sample of this would have been of greater value for research purposes.

The trustworthiness of the findings are dealt with to varying degrees, however all studies conclude by reflecting on the challenges that this topic of research has, the understanding that each person with autism spectrum disorder is unique and individual, and how more studies in this area are needed.

It was possible to identify three relevant themes within the published papers that generated three questions about the spiritual needs of people with autism. They were:

- Does an individual need self-awareness in order to address their spiritual needs?

- Is relationality a core concept in supporting spiritual needs?
- Can people on the autism spectrum fulfil their spiritual needs by experiencing spirituality?

3.2.1 Does an individual need self-awareness in order to address their spiritual needs?

Gordon (2009) suggests that to encounter spirituality a person must have a sense of self-awareness. Furthermore, the person must give significance to the other over themselves. The same author then contradicts this concept with what Frith (2003) explains as an absent sense of self for people with autism and the implications and difficulties of interrelatedness between people with autism and others. Frith (2003) suggests that awareness of self and awareness of others are linked, although for individuals with autism, all of their awareness is inputted into the self, not in an egocentric manner but in an innocent way.

People with autism, according to Gordon (2009) have a different sense of self, compared to those without the condition, therefore they don´t necessarily fit into any other community or group when reflecting on spirituality, structures of thoughts, or faith communities. But, the author continues to say that this should not be a reason for exclusion or a lack of acceptance into spiritual groups. Differences should not separate and/or limit the validity of their experiences. Some religious practices may believe that a cognitive basis and intellectual understanding is required to obtain spirituality. Resulting in the exclusion of people with learning disabilities, autism and other conditions (Swinton, 2002). Brock (2009) however, evokes the idea that each person with autism is different from another, so in this case, some may be more 'absent self' and others have self-awareness, some may have a learning disability and others not, each individual has unique characteristics, lifestyle, beliefs and understanding.

Regarding the difficulties and differences with the sense of self in people with autism, and the way people with autism often experience their emotions and feelings in different ways (Vermeulen, 2005), Gordon (2009) believes that an understanding of spirituality and how people on the autism spectrum encounter it, is questionable. Subsequently, Gordon (2009) questions whether an absent sense of self in autism would contribute to a less selfish way of being, which in turn would allow a deeper level of spirituality and sense of God or a higher being.

3.2.2 Is relationality a core concept in supporting spiritual needs?

Barber (2011) explains that to be human, a person has to be in relationship with others. The same author, as well as, Schaap-Jonker et al. (2013), reminds us that such relationships can be qualitatively different for people on the autism spectrum, who show impairments in social communication and interaction. By no means does this suggest that people with autism are not human. The theory that a person has to be in a relationship with others to be human is therefore

questionable. On the other hand, Brock (2009) stresses the point that people with autism see the world differently and denies that they are non-relational.

Gordon (2009) queries the link between spirituality, relationality and people with autism, including how it can be possible to say that relationality is a core concept and defines one´s spiritual potential and capacity. Deeley (2009) suggests the fact that people with autism deposit so much time and interest into a specific topic, object or feature but rarely in someone in order to form an interpersonal relationship.

Schaap-Jonker et al. (2013) mention other conditions that can affect a person with autism when it comes to relationships, like anxieties and uncertainties due to experiencing the world in fragments and weak central coherence, as explained above. These impairments also contribute to feelings of anxiety not only towards other people, but towards God/ Higher being, reflecting on Him as judgmental.

Hill and Meteyard (2013) describe the way that people without autism see those with autism. The way they treat them, reflect upon their differences and the value they have to offer. The authors suggest that when there is a difference, it is then that we stand aside from our personal self-focused, egocentric ways and enter into a new community, a new understanding, a new communal treasure. The authors continue by saying that disabilities are still often viewed in a pitiful way and still the current approach to any life challenge, difference, or anything considered a problem, is to immediately look for answers and solutions. They advocate that differences should not be considered less than or inferior, instead of seeing the person with any kind of special needs as different, inferior in any way, the authors suggest that we see them as people on their journey of life, and then we can contribute not only to them but to ourselves too. Brock (2009) says that every human being is here to be known and loved and we find our identity through others. Not to mention that we are all different, independent of having a disability or not (Tammett, 2006).

In light of these differences, religious or faith communities can adapt to the needs of each person, with or without autism, so that the needs of every person can be met (Kramer-Mills, 2010).

3.2.3 Can people on the autism spectrum fulfil their spiritual needs by experiencing spirituality?

God image, according to Schaap-Jonker et al. (2013) is made through a process that is impaired in people with autism, the impairment of imagination that results in more rigid, inflexible relationships. However, Barber (2011), who is on the autism spectrum, describes a personal account of spirituality and believes people with autism do make a connection with God.

Barber (2011) believes that people without autism often assume that people with autism cannot have a spiritual experience or connectedness with God due to their social impairments and because they assumedly struggle to connect with people. On the contrary, he defines connectivity as a dimension of humanity.

Barber (2011) believes that spiritual connectedness is different for each person and each individual has their unique way of following and experiencing the process. Wiseman (2006) defines the experience of spirituality as becoming lost in something much larger than one´s self. Barber (2011) continues to explain that this could be something like a storm, snowflake, music, rain or art; in other words, transcendence experiences. Another way to help an individual to experience the divine within themselves is by supporting them in naming and identifying their feelings, which helps them know and identify the divine within themselves and in others throughout their faith formation (Swanson, 2010). Swanson (2010) says we experience God through our senses and identify and give meaning to these senses. Although for people with autism knowing and identifying feelings can be a difficulty. Swanson (2010) considers how attaining bodily wisdom can be difficult for people with autism but also addresses the fact that with the right support people with autism can experience the growth and deepening of a sense of self and spiritual formation (Swanson, 2010).

Like all people, those with autism also go through processes of life such as connections and disconnections, be they physical, psychological or spiritual. To connect in these ways, a disconnection may need to take place, and this could be the disconnection with others, to be alone. Making connections is fundamental to our personal development, but disconnecting can have its advantages too (Barber, 2011).

Barber (2011) demonstrates the different types of connectivity as he explains these are multi-layered. A person connects with God and God with them. A person connects with others and vice-versa. Also, God connects through the person to others and to the world. It is a spiritual connection. Connecting with God can happen through different methods, such as prayer, questioning, anger, conversations, or meditation; it is a personal experience (Barber, 2011). It is not possible to fully know how someone experiences their spirituality as it is unique and personal to each person (Barber, 2011). Swanson (2010) refers to the Bible passage Genesis 1:27 *'So God created mankind in his own image, in the image of God he created them'* (Holy Bible New International Version, 2003), and defines being made in the image of God as part of the faith formation, with an individual coming to understand their self and the divine within us.

Barber (2011) talks about the difficulties through the horizontal and vertical dimensions of spirituality for people with autism, in connecting with God and with others. Furthermore, people with autism may articulate their experience with God and their spirituality in a different way,

but this should not be considered less valid than other people´s ways of experiencing the divine. The issue with understanding the spirituality of an individual who has an impairment with imagination and how they connect to someone or something that cannot be seen with the physical eye, but instead with the emotional and psychological features, does not mean it is less or devalued (Barber, 2011). Hills and Meteyard (2013) agree with this aspect, people cannot be considered less valued and less a reflection of the divine due to their differences.

Barber (2011) gives a description of his personal understanding and vulnerabilities comparing them with Jesus as a new born vulnerable baby. How He, as a vulnerable outcast, made such reflections of uplifting and liberating experiences, when He has the need of acceptance and love too. The author gives a personal account of his difficulties, and how he finds open meditation hard, but that more structured faith based strategies can work and do help him in his spiritual needs. Although Hills and Meteyard (2013) say that to analyse autism and spirituality is a challenge to faith communities because of such differences and social impairments.

Barber (2011) cites Feely and Long (2009) who suggest that we should acknowledge not only people´s social, psychological and emotional needs but also spiritual needs too by journeying with them as they make connections and sense of their own worlds. Hills and Meteyard (2013) also mention how people with autism also have spiritual needs and how challenging it is for them to address those needs, the need of love, hope and divine comfort. Gordon (2009) says that if the definition of spirituality brings such implications for people with autism, then the definition needs to be broadened so that the understanding is clearer. It will, therefore, be easier to address the needs of this population and will not infer in any way that people with autism do not have significant dimensions of human experience. Gordon (2009) addresses the fact that each person´s spirituality is different and believes that it comes down to a theological challenge to make sense of the implications that this causes.

In the study conducted by Schaap-Jonker et al. (2013), it was found that people with autism attribute more negative traits to the God image than positives, including feelings of anxiety and punishment. Furthermore, the authors suggest that difficulties in social domains contribute to difficulties in the spiritual domain too. Additionally, spirituality could be a negative factor in some people´s lives due to uncertainty, fear and rigidity (Schaap-Jonker et al., 2013).

In the same study (Schaap-Jonker et al., 2013) it is said that the God image for people with autism has a less reciprocal nature than for those without autism. Deeley (2009) emphasises the fact that we should be very cautious when considering spirituality of those with autism, due to the vast variability of the spectrum condition, and that each person with autism has different characteristics, difficulties and impairments that cannot be generalised.

Deeley (2009) considers the impairment of theory of mind, weak central coherence and executive function and how this may affect understanding of religious statements rather than the experience of spirituality itself. Difficulties with meta-representations, cognitive flexibility and empathizing may influence the way people with autism experience things (Deeley, 2009). Experiencing God through sensations and feelings can have several sensory and emotional attributes, therefore, this can be very challenging for those with autism. Metaphors best explain spiritual experiences (Schaap-Jonker et al., 2013) and as known in the underlying mechanisms of autism this could be impaired. Lewis (2009) agrees that these characteristics may contribute towards difficulties with spiritual experiences and understanding in those with autism.

Faith formation for people with autism, needs to be experience-based and facilitated through others and interpersonal supports, because to fully know God we must experience Him. It is not only a cognitive process but an experience (Swanson, 2010). Knowing is not just a cognitive process, it is also a sensory, perceptual, and emotional process (Swanson, 2010). Swanson (2010) explains the faith formation for children and those with autism, an individual needs to understand and know God through an experience first, rather than knowing about Him in a more cognitive style. Brock (2009) believes that people with autism are ideal models for experiencing spirituality due to their restrictive patterns of interest; following the Descartes model, the best way to fully experience something is to withdraw from everything else and have full, clear, particular interest in one specific experience. Meyer (2008) says that the highest form of education that any one person could have is spiritual training. Hills and Meteyard (2013), cite a passage from the Bible John 9:3: *'Neither this man nor his parents sinned, said Jesus, but this happened so that the works of God might be displayed in him'* (Holy Bible New International Version, 2003), which describes that people with disabilities or differences are the way they are, so that God´s work can be shown through them.

4 Discussion

All people with or without autism have the right to freedom of thought, conscience, religion, belief and values without discrimination as set out in the government Acts mentioned above. However, not only are there no government documents or guidelines that address what the spiritual needs of people with autism are, neither are there documents that provide any guidelines on how to support a person´s spiritual need in general. All people also have the right to quality of life, which is the merit given to human values that the individual pursuits, it is the very essence of human existence and as Schalock et al. (2002) explain, to live a life considered of quality will require support.

This paper shows the importance and understanding that government documents and guidelines provide, on nondiscrimination against religion, thoughts and beliefs. These documents have also outlined the importance of including these personal values into support and care systems. Yet, there are no guidelines on how this should specifically be done in order to address the spiritual needs of an individual.

Spirituality and spiritual development are addressed in highly significant global documents like the United Nations Conventions on the Rights of the Child (1990). Hills and Meteyard (2013) also list authors who have researched the topic of disability and spirituality, like Nancy Eiesland (1994), John Hull (2003), Stanley Hauerwas (1986) and John Swinton (2007). Notwithstanding, the topic of autism and spiritual development is still very rare in the scientific field (Schaap-Jonker et al., 2013).

Brock (2009) denies that people with autism are non-relational as relationality goes beyond the basic meaning of interpersonal relationships. The amount of time and interest put into a specific topic, object or feature for some people on the autism spectrum is a personal experience of relationality and connectedness with that particular item. Although this relationality is rarely experienced in the form of interpersonal relationships with others (Deeley, 2009), it is important to remember that spirituality is the possibility or the want of connecting not only to someone but also to something beyond one´s self (Palmer, 2003).

Some people on the autism spectrum may have a different sense of self as stated by Gordon (2009), however it is not possible to evoke this idea, as each person on the autism spectrum has their own unique lifestyle, characteristics and beliefs (Brock, 2009). Even if it is said that people with autism have an absent self, Gordon (2009) does challenge this and says people with autism could be considered to constitute a less selfish way of being, in other words, having a deeper spirituality.

The difficulties that people with autism have, and the barriers they face in participating in groups or faith communities, because of the impact of impaired social interactions is explained by Baron-Cohen (2001). Although to have spirituality is different from religious organizations and faith communities, participating in a church or other religious organisations can be found to help increase the development of friendships, self-concept and awareness, a sense of belonging and value for people with disabilities (Howell & Pierson, 2010). In contrast to this, Schalock et al. (2002) believe that the presence of a disability is often associated with negative aspects when considering the participation in a community or group facility, in other words this means that people with autism are in danger of being excluded from many community settings including faith and religious based communities.

Kramer-Mills (2010) introduced the Autism and Faith Task Force, which combined lay people and leaders from different faith traditions to prepare a survey about the spiritual needs of families with autism. The Task force was then renamed as Special Needs Accessibility Project (SNAP). The name changed as there was a high prevalence and need to address people not only with autism but with other developmental disabilities and special needs too. As Speck (2005) suggests, everyone has spirituality and it is a transcendent experience (Bento, 2000). In other words, it is the connection between the individual and something beyond themselves. Therefore it should be addressed to fulfil the whole of an individual´s quality of life (Speck, 2005).

Spirituality is different for each person and every human being journeys their own unique process of experiencing it, as seen in Fowler´s stages of faith in human development, each person moves onto the next stage in their own time. Therefore no one person´s (with or without autism) experience of spirituality should be considered less valid than that of another person (Barber, 2011). One of the characteristics held by some people with autism which could influence their spirituality in a positive manner is an ability to withdraw or disconnect from everything else and have full, clear, particular interest in one specific experience, in line with the Descartes model explained above (Brock, 2009).

The right of having spiritual needs addressed is a new field of study and according to Lewis (2009), Article 12 of the United Nations Convention on the Rights of the Child (1989) mentions that children should have a voice in decisions being made about them and their provision, including meeting spiritual needs. Lewis (2009) explains the ethical issues on considering a child´s opinion on spirituality if they have autism. Furthermore, questions arise due to the lack of research into spirituality and children with disabilities or additional needs, as can be seen in the papers reviewed in this study. Usually, there is evidence on spirituality and children but possibly due to the difficulties and ethical issues, disabilities are not mentioned, therefore, it is not clear whether they are omitted (Lewis, 2009).

As mentioned above, the meaning of spirituality has changed over the past decades, in both theology and human sciences (Rovers & Kocum, 2010). However, it not only continues to be a total process of human life and development (Canda, 1990), it is also a personal and intimate experience, which, through different dimensions, gives meaning, stability and purpose in life (Reed, 1992). By embracing the biblical understanding of knowing God it is done so, in a whole bodily experience therefore this is beyond the cognitive understanding of who God is (Swanson, 2010). A cognitive understanding of God / the divine is based on what has been learnt about Him (Schaap-Jonker et al., 2013). Therefore creating opportunities for people with autism to know who God is, experiencing it in a way that is best for each one of them, is a faith formation process (Swanson, 2010). It is also important to remember that autism not only affects the individual on the spectrum but their family and support network too (Walsh, 2008), in this case providing support and care for all who are involved with the individual could be of great value (Walsh, 2008).

All in all, the understanding of spirituality is a critical component of human development and well-being (Bone, 2005), particularly due to interpersonal connectedness, which is found to increase emotional well-being (Grimm, 1988). The core principle of Schalock´s et al. (2002) quality of life domains is based on the individual´s needs. The subjective experience, living conditions and personal values are the key factors that determine one´s quality of life. Spirituality is part of a holistic practice, notably body, mind and spirit. Therefore, these factors influence a person´s need which will then reflect on their quality of life (Grimm, 1988).

Reflective Paragraph

It can be said that the spiritual beliefs of the author and the passion of working with people on the autism spectrum influenced the decision to reflect on this aspect and may have slightly affected the analysis of discussion. The topic of spirituality and people with autism was chosen because, given the time and effort required to produce this dissertation, the author felt there was a need for it to serve a wider purpose than just attaining a Master´s degree. Considering the apparent gap in literature, and the reason behind addressing it, the author believed that to explore and develop the understanding of this topic and to discuss the findings of this research, had the potential to impact not only herself and the population referred to (people with autism spectrum disorder) but also their families, carers, multidisciplinary teams and the government.

5 Conclusion

Schaap-Jonker et al. (2013) explain that to investigate the relationship between autism and spirituality, knowing the difficulties of rigid and literal interpretation is important. The results of the literature search for this paper, showed the lack of empirical studies on the topic. Therefore further research is required to better understand and review this essential theme as it has a major impact on the quality of life of people with autism. Additionally there is a need for more empirical research and would be well placed to provide it with a wider population, including those of different religious, faith and spiritual affiliations, backgrounds and beliefs.

Despite the lack of literature and policies, this study demonstrated the importance of supporting the spiritual needs of people on the autism spectrum. Spirituality is more than the sum of religious practices and/or a particular tradition or experience. It is a personal account, of an individual with the beyond, which gives them purpose, fulfilment and meaning in life, it is the individual´s air, life, breath and courage to overcome any barriers, differences or struggles they may come across (Baker, 2003).

Above all, people on the autism spectrum may have a different sense of self, a different way of connecting or disconnecting, a different perception of the world and that within it, but this does not in any way mean they or their faith and spirituality is considered of less value compared to people without the condition. Each person has their own unique way of living, believing and being which contributes to the learning and experiencing of others.

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