

**Spiritual care for people with intellectual and developmental disability: an exploratory study.**

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**Background:** A faith-based (pseudonym, Adam's House-AH) and a non-faith based care service (pseudonym, Greenleaves-GL) were explored to find out if and how spiritual support was provided for people with intellectual and developmental disabilities (IDD).

**Method:** Six months were spent volunteering within each service and a mixed-methods approach was utilised including applied and ethnographic methods to explore and describe if and how spirituality was embedded within the two services.

**Results:** Themes found included community of value; homely functional care; and barriers to spiritual care. GL staff tended to provide what we termed "religious spiritual care" whilst AH staff administered both "religious" and "non-religious spiritual" based support. This difference may be related to the type of training found only at AH which included spiritual dimensions.

**Conclusion:** Services could benefit from acknowledging the importance and significance of spiritual care training and education for effective and varied spiritual care for people with IDD **who desire such support.**

**Keywords:** Intellectual and Developmental Disability, Spirituality, Spiritual care, Health care professionals, Faith and non-faith based care services.

## Introduction

Spirituality is defined as faith in the “sacred”; a personal relationship with a supreme power (Baker, 2003), while religion implies an adherence to institutional beliefs and practices (see Argyle & Beit-Hallahmi, 1975). In this paper a multidimensional working definition of spirituality, informed by relevant literature (see Hill et al., 2000; Sango, & Forrester-Jones, 2014) is used to define spirituality as belief in supernatural phenomena. This multidimensional approach (see Figure 1), consists of three dimensions (as depicted in the circle section of Figure 1): “transcendence” (i.e. supernatural existence); “connection and relationship” (with self, others, nature, the supernatural); and “meaning and purpose” (making sense of life, striving for answers). These dimensions are rooted in either one of two categorical aspects of spirituality: 1) “religious spirituality” and 2) “non-religious spirituality” (the two rings around the circle in Figure 1). The first refers to the social practice and expression of belief in the supernatural (church attendance, worship or prayer). The latter, denotes adherence to belief in the supernatural without necessarily socially practicing this belief (not engaging in, or observing religious practices).

## PLEASE INSERT FIGURE 1. MULTIDIMENSIONAL WORKING DEFINITION OF SPIRITUALITY

Literature on older people; people with intellectual and developmental disabilities (IDD), and people with mental illness suggests that spirituality and religion can provide meaning and purpose to life, support during stressful life events, and comfort at particular times such as when a bereavement occurs (e.g., Forrester-Jones 2013; 2014; Koenig, 2010; Narayanasamy et al., 2004; Stancliffe et al., 2016; Wiese et al., 2015). Recent government policy in the United Kingdom (UK) also stresses the need for individual’s beliefs to be recognised and respected within social care (Care Act, 2014) **where appropriate**. Nevertheless, little research concerning spirituality and people with IDD exists, the few relevant studies (Minton & Dodder, 2003; Narayanasamy, 2007; Swinton, 2001, 2002; Shogren & Rye, 2005; & Turner, Hatton, Shah, Stansfield & Rahim, 2004) suggest that spiritual and religious support mediates social and psychological well-being, especially if the person with IDD is involved with a religious or spiritual community (Gaventa, 1993; Swinton, 2001). Even less research concerns people with severe and profound IDD, though Bassett, Perry, Repass, & Silver, (1994) and Sango & Forrester-Jones, (in press) found the role of prayer to be reported as important to the well-being of these individuals. McEvoy, MacHale and Tierney (2012) and Forrester-Jones (2013; 2014) also demonstrated the merits of spiritual and religious explanations of dying or death and funeral rituals to individuals with IDD.

Swinton (2001) argues that to deny people with IDD the opportunity for spiritual support limits their quality of life. To date though, limited evidence exists which demonstrates how paid support workers can and do cater for the spiritual needs of people with IDD. The aim of this paper is to report on an exploratory study of spiritual care provided in two different UK care services: a faith-based service (pseudonym Adam’s House-AH), and a service with no stated basis of faith (pseudonym Greenleaves - GL). The main research question was, to what extent and how was spiritual support **offered and** provided to individuals in two different IDD services?

## **Methods**

### **Study design**

The study design was exploratory using a mixed-methods approach given the complexity and “fuzzy” nature of the phenomenon of spirituality, which cannot be easily explored using a single research method (Sandelowski, 2000). Quantitative and qualitative data were collected simultaneously, analysed independently and combined to gain an understanding of participants’ perspectives around spiritual and religious matters, and whether or not, and how they operationalised this through their care practice (Creswell, Klassen, Plano Clark, & Smith, 2011). Pragmatism was the philosophical underpinning of this methodological triangulation (Tashakkori & Teddlie, 1998).

### **Ethics**

The study was approved by the UK’s National Health Service South-East Ethics Committee (Ref: 13/LO/0594). Each participant received an information sheet explaining the nature, reason and voluntary nature of the study, as well as a consent form to sign. Participants were assured that anonymity and confidentiality would be maintained.

### **Sampling and recruitment**

A purposive sampling method was used, with the aim of recruiting 50 IDD support workers (ideally 25 participants in each service). All staff (total of 35 in GL; 57 in AH) were invited to participate by their respective managers via hard copy information sheets and consent forms following managers’ consent for the research to take place. The first author visited each service to explain the research to staff, providing opportunities for questions and/or concerns to be raised. It was made clear that participation was voluntary and that non-participation would not affect anyone’s employment or social status within the service. Of the 92 staff approached, 42 people (21 in AH; 21 in GL) agreed to participate by returning signed consent forms.

### **Setting**

The study sites were purposefully selected to explore how staff in a stated “faith-based” service (AH) and another service stating “no-faith” (GL) perceived and operationalised spiritual or religious aspects of care to people with IDD. Both services were situated in the South East of England and regulated by the same local authority and so provided a comparative base from which to explore the two different service models. Both services had similarities and differences (no two services are ever identical in nature), therefore direct comparisons as regards service provision could not be made. The purpose of this study however was not to compare the services de facto, but rather to explore how spiritual support was being provided in two services offering different models of spiritual support.

The residences of both services were located across both rural and urban areas. AH included nine supported living houses (between 3 and 6 residents with IDD living in each house) with 24 hour care provided by both “live-in” and “live-out” paid staff and volunteers. None of the staff had a predominant role for the provision of spiritual care. Two participants had been paid staff and were now volunteers, sometimes assisting with general activities (e.g., “trips out” with residents). GL consisted of three houses (between 3 and 11 residents with IDD living in each house) with a 24 hour care system. All members of GL staff were paid and none lived in the houses.

AH’s written care philosophy centred on “sharing”, “relationships”, and “simplicity” and supporting individuals to “explore their spiritual lives”. GL’s mission statement focused on Valuing People (2001) with an emphasis on meeting the social and physical needs of

residents through individual Person Centred Plans (PCP). Entry to AH was generally through service users' relatives, who "had heard about AH" via their social networks. Once approached, AH provided the prospective residents with IDD an opportunity of a "trial period" (a day's visit or an extended stay for up to three months) in order to decide if they wanted to live there, and which house they preferred to live in. The decision for a service user to live at GL was made by themselves in conjunction with their family or care provider, or Local Authority. A companion paper to the current study which reports on the views of the residents of both services demonstrates how the total sample were very similar as regards their level of IDD and support needs (Sango & Forrester-Jones, in press).

### Materials and procedure

The first author spent six months in each service performing participant observation (PO). In AH, this included supporting residents in their domestic and social activities including daily chores, communal meals, horse riding, dance, music, football, and enabling individuals to attend church, participate in monthly house meetings and "community gatherings" (social, spiritual or religious events organised by both staff and residents). At GL, PO meant participating at meal times, weekly staff meetings, shift-handovers, and at various social clubs held at local pubs and church halls, and college classes such as cooking.

A semi-structured interview was developed using questions from the Spiritual Care Competence Scale (SCCS) (van Leeuwen, et al., 2007) and the Spiritual Care Perspectives Scale (SCPS) (Amenta, Highfield & Taylor, 2000). These scales aim to capture staff self-assessment of their own "spiritual competence" (i.e., how equipped they feel regarding their knowledge and skills to provide spiritual care) and their attitudes towards providing spiritual care to individuals with IDD. **The SCCS 13 items' Cronbach's alpha was 0.82 and according to Nunnally (1978) reliabilities of 0.7 or higher will suffice. The SCPS 6 items' Cronbach's alpha was 0.64; a respectable reliability that can be justified by the number of items (i.e., 6) on the scale (Cortina, 1993), as well as the fact that lower thresholds have been found in the literature (Santos, 1999).** Interviews commenced midway through data collection to enable researcher-participant rapport to be established. To enhance the credibility of findings (Maxwell, 1992), all interviews were audio-recorded and transcribed verbatim with field notes written up immediately post each PO session.

### Analysis

Quantitative data were subject to descriptive analysis using SPSS V22. NVivo V10 (QSR International, 2012) helped manage and sort the qualitative data which was then analysed thematically by the first author following Braun and Clarke (2006) with the second author independently analysing half of the transcripts. Codes and themes were compared and cross-checked between the authors until theme descriptions were saturated and agreed upon.

### Results

To avoid risk of directly comparing two non-identical services, only descriptive statistics and qualitative findings are reported here. The focus is therefore on exploring the differences in the spiritual care models of AH and GL.

### Sample

The total study group (n=42) included individuals from Europe, Africa, and Asia. Participants were mainly female (n= 9 males) and aged between 18 and 53 years old. Forty-five percent had worked for their respective services for more than five years. Fifty-seven percent had been educated up to secondary school or further-education level, 26% had

undergraduate qualifications and 17% had postgraduate qualifications.

### **Religious and spiritual background**

Eighty-six percent of AH and 52% of GL staff reported they were Christian. Thirty-eight percent of GL and 5% of AH staff said they had “no religion”. Of those who said they were “Christian”, 22% from AH and 36% from GL reported family traditions as a major influence on their current belief, stating that their Christianity was derived from having: “been christened”; “raised in the Christian religion”; or “my parents encouraged me to attend Christian events”.

Eighty-one percent of AH and 24% of GL staff reported that their own spiritual beliefs were influenced by the importance of spiritual matters in the lives of residents, as illustrated below:

**G:** ...I think because without...[residents] I wouldn't be dwelling so much about what the meaning of our lives is... (AH female paid staff).

Most AH (81%) staff also reported that their Christian belief and religious background influenced their daily lives and approach to work:

**P:** ...so as challenging as it [the job] is...you...ask guidance from God. I tend to say these sorts of things whenever I go to work...”He is the one leading you, guiding you...” (AH female paid staff).

Such spiritual influence also involved believing that a higher order (God) was watching how they carried out their work:

**Y:** ...if I am asked to do something [at AH], I try to do it even if no one is watching me because I believe that someone else is watching me, who is God of course. (AH male paid staff).

62% of GL staff who had a religious belief also said that it influenced their lives and jobs especially during difficult times:

**HP:** I turn to my religion and spirituality when I need it most, when I go through tough times. (GL female paid staff).

Others at GL felt that their work was influenced more by a “*code of practice and conduct at work*”.

## Spiritual care competence and experience

There were no mean or median differences between GL and AH participants as regards their attitudes towards spiritual care (e.g., being positive about residents' spirituality), perspectives of spiritual care (e.g., whether or not enough attention was devoted to residents' spiritual care), or their own spiritual care competence and experience. During PO, all of the AH staff provided examples of when they supported residents in a religious or spiritual context, as illustrated by two participants below:

**P:** Every day before we have supper we sing Praise - it's part of spiritual care. One of them [resident] asks us to pray for their Mum or Dad who [have] passed away. It makes him feel better... (AH female paid staff).

**Ss:** [Resident] doesn't go to church but always asks us to "pray, pray" for her family before she goes to bed. (AH female paid staff).

The importance of spiritual practices in helping residents **who want to engage in them** to "feel better" is also highlighted in a companion paper by the authors in which service users report the significance of prayer in the context of hope, healing, meaning and purpose (Sango & Forrester-Jones, in press).

## Church attendance

All of the participants recounted moments of providing religious spiritual care in the context of supporting residents to attend church. Seventy-one percent of GL and 48% of AH staff felt that Sunday Class activities such as colouring images of biblical characters, singing hymns and choruses, and socialising during refreshment breaks were the main attractions:

**MC:** They [the residents] sing hymns, colour pictures of [Biblical] stories and discuss different things about the story. They play instruments, have a cup of tea and a biscuit. They see their friends each week. (GL female paid staff).

AH staff also highlighted an additional spiritual element to attending church:

**Ss:** ... I think they have always gone to church since they were young. They can think about God if they go to church, and be reminded of God. (AH female paid staff).

AH staff also helped residents to engage in monthly "community gatherings" and yearly "pilgrimages" at various Cathedrals in the UK (and occasionally in Europe):

**M:** We have pilgrimages. We walk together, support each other and have prayer and meal times. We sing and walk...different distances, different places. They enjoy it, especially when we sing and pray together. (AH female paid staff).

### **Education and training in spiritual care**

AH staff (62%) reported that they received specific training in spiritual care as part of “formation”. This was provided in-house and included general support worker training such as manual handling, PCP, health and safety, and information about IDD. ‘Formation’ also included sessions on “exploring the spirituality of people with IDD” and “spiritual care for people with IDD” as described below:

**J:** ...I have never seen any training offered by any organisation on how to support people’s spiritual needs, so we are lucky in [AH]. It helps you understand how to support people. It entails things like prayer, the history of [AH], Makaton, person centred approach and learning disabilities. (AH female paid staff).

Ninety percent of GL staff reported that they had no specific spiritual care training, with the rest (10%) stating that their training consisted of general instruction in healthcare, managing challenging behaviours, and PCP.

### **Qualitative findings**

Three themes were derived from the qualitative data gathered via PO (see Figure 2 below).

### **PLEASE INSERT FIGURE 2. THEMES FROM ADAM’S HOUSE AND GREENLEAVES**

#### **Community of value**

This theme was unique to AH and related to “non-religious spiritual care”. It included two categories: “*shared lives*” and “*informalised care relationships*”.

#### **Shared lives**

Care in AH seemed to be submerged within a sub-culture of norms which enabled staff and service users to share daily life experiences. For example, staff and service users shared meals together whereby food was laid out in the centre of a table, and after saying grace (during which everyone held hands) everyone served food to each other (rather than staff serving residents their food individually), as described below:

**E:** How we sit and eat and serve one another says something about [AH], that people are included rather than excluded. And in a way, its deeply Christian. From reading the gospel, Jesus often ate and drank with people no one else wanted to be with. There is something intimate about sharing. (AH male paid staff).

Eating together reflected “sharing” in a tangible way which went beyond staff making sure residents were being fed. The above quote by E typified the views of most AH staff; that the tradition of eating together was derived from and embodied a sense of the spiritual, informed by the Christian value system. According to staff, this habit fostered spiritual intimacy between them and the service users, enabling individuals (both people with and without IDD) to disclose their spiritual needs which often included requests for prayers for their loved ones or themselves. “Doing things together” with both residents and staff taking on an equal role also extended to everyday tasks such as cooking, washing the dishes, and Hoovering:

**J:** The most precious moments in the day are washing up with P because we put on the radio and sing along. It’s the presence of them [residents with IDD] and the time we spend with them. Social care is a human service, it’s not just about delivering a service... (AH male paid staff)

Participants also reported that “sharing” led to valuing individuals on an equal footing, which moderated any potential power imbalances between staff and service users:

**Hg:** ... so I think that the living together experience actually teaches new assistants how to treat [service users] and how to respect them and how they make equal relationships.... (AH male paid staff).

Through these shared experiences, religious and non-religious spiritual support appeared to be provided as a matter of course for service users **who requested it**, and staff were able to create opportunities and space for people to be supported through life experiences including periods of emotional instability:

**Sk:** When [residents] are not stable I try to give them some calm and peace (AH female paid staff).

Participation at religious events (e.g., funeral services) were not compulsory, but neither were service users excluded from them as shown below:



[Field note: funeral church ceremony 10. 09.2014] I stopped to chat with T [resident] who attended the funeral [of another resident]:

**R:** Hello T, how are you?

**T:** Good thanks, I'm not staying, going home (T speaks and signs the word 'home').

I later discovered that T chose not to attend the funeral because she was tired from the day's activity (card making etc.) but wanted to say 'hello' to people.

### **Informalised care relationships**

Staff-service user interactions were observed to be respectful, caring, and reciprocal to the extent that attachments appeared to be familial in nature. These types of interactions may be typical of other non-faith based services which offer similar less institutional settings (see Emerson et al., 2000) suggesting that the benefits of a faith-based setting like AH may be due more to the social support provided rather than to specific religious or spiritual practices **on offer**. In the current study however, for most AH staff, these informalised care relationships also personified a dimension of spiritual community:

**J:** We are all members of the community, a flat structure of equal people. I think you have relationships with people not because you are paid for it but because you are fond of them. (AH male paid staff).

Durable relationships were also evident, where staff-service user relationships continued even when one party had left the service:

**E:** There was a resident who came to [AH] in 1974. We were quite close and she got Alzheimer's and had to move into a nursing home. I visit her every week and take some music as she always liked music and singing (AH male paid staff).

### **Homely Functional Care**

This theme characterised GL and described supporting residents to live in a "homely" atmosphere with an emphasis on the daily processes and practicalities of care. Here, prominence was placed on individuals' physical needs, promoting empowerment and their independence, and respecting and supporting their choices:

**MC:** They are all happy, healthy looking, get a good meal and drinks each day, and toileting. The home is homely. Their bedrooms are suited for them and they can bring things from home to make things more homely. (GL female paid staff).

In the authors' companion paper (Sango & Forrester-Jones, in press) some GL residents expressed interest in and requested spiritual and religious activities yet whilst every resident had a personal daily "activity planner" which included a range of activities (e.g., social clubs, day centres, cooking and wood work) activities of a spiritual nature were absent. Nevertheless, GL staff reported that they provided practical support to individuals who had suffered a bereavement, by organising transport or accompanying individuals to attend the funeral. K's quote below exemplifies how some staff felt ill equipped to provide effective spiritual support during grief, as also suggested by Stancliffe et al. (2016) and Wiese et al. (2015):

**K:** I have got one who is going to his first funeral. He has basic understanding but to him it's like "I am just saying goodbye aren't I" and I'm like, "yeh you are pretty much just saying goodbye". (GL female paid staff).

### **Barriers to spiritual care**

Obstacles to providing religious and spiritual care were highlighted by over 50% of staff at both services. Three categories formed this theme: "*communication issues*", "shortage of staff" and "staff perceptions of spiritual understandings":

#### **Communication issues**

AH staff used a mixture of Makaton (a multimodal communicative approach using speech, signs and graphic symbols) and other alternative, and augmentative communication strategies to communicate with service users. Where individuals with IDD could not speak, religious and spiritual pictorial images were used to facilitate prayer and praise sessions. There was concern from some staff that there was a tendency to assume that non-verbal individuals were enjoying religious activities because they "looked happy" at these events:

**G:** It's tricky with people who are not communicating verbally because it's a bit of a guessing work. For example one individual goes to church but doesn't speak. She never said "I want to go to church", but she is smiling and seems quite happy there, so we think she wants to go there. S [service user] says 'prayer, prayer', so we have the board [pictures and symbols] and we give it some structure. S puts the pictures on the board. (AH female paid staff).

GL staff also felt that the lack of communication skills of some residents was a barrier to their spiritual needs being met:

**SH:** Sometimes our patients are unable to communicate with us...spiritual needs in consultation with the client is not always possible. (GL female paid staff).

#### **Shortage of staff**

Shortage of staff was also reported as a difficulty for both sets of participants. Although staffing

levels per resident were similar across both services, AH staff shortages were either due to limited funding or administrative or general care tasks taking up “too much time”. New staff who had not yet received “formation” training were often not “confident” enough to provide religious or spiritual support (e.g., accompanying residents to church) and this could lead to less attention devoted to spiritual care:

**G:** It’s [religious and spiritual care] the first thing that gets cut, when we are short staffed (AH female paid staff).

**Y:** There are times when you can’t take people to church. You don’t have a driver or you have new people and they are not confident enough to go...(AH male paid staff).

GL participants stressed the need for additional staff so that “more time” could be devoted to “one-to-one” holistic care, otherwise functional aspects of care (e.g., personal care, medication) overshadowed opportunities for spiritual support:

**LD:** Because there are a lot more physical things that they need - bathing, medication, you don’t really have time to sit down and talk about spiritual things (GL female paid staff).

### **Staff perceptions of spiritual understandings**

Over 50% of GL staff suggested that residents “might not have a spiritual need” or did not understand spiritual matters due to their “mental capacity”:

**BL:** I just feel like they do not have the mental capacity to understand real beliefs. I mean if they had it, then yes there would be lots of attention. We have the understanding, but they don’t (GL female paid staff).

Some GL staff also said that they felt “uncomfortable” trying to provide religious or spiritual care in the face of their own lack of knowledge or belief in, “spiritual things”:

**RJ:** I have actually requested not to take them [to church], not because I do not want to encourage them to believe, but because I don’t believe and I don’t want to be put in a situation where I feel uncomfortable (GL male paid staff).

**SH:** We have had staff here saying that they are atheist and so do not want to go to church. But it is an activity, the same as swimming (GL female paid staff).

Such refusals to accompany residents to church may be a conundrum for a service which is short-staffed.

Around 50% of AH staff reported feelings of “doubt” and “fear” in relation to preparing prayer sessions and talking about religious or spiritual matters with residents:

**E:** There can be a fear about forcing religion on people. Certainly in recent years, Christianity has become marginalised in Western Europe and our society has become more secularised. (AH male paid staff).

## **Discussion**

Two different models of spiritual care were delineated from the study. On the one hand, in GL spiritual support was provided through religious spiritual care, by helping individuals to attend church and other religious activities. This supports previous empirical studies (e.g., Minton & Dodder, 2003; Swinton, 2002; Shogren & Rye, 2005; Turner et al., 2004). AH staff on the other hand provided both religious spiritual care (church attendance, prayer), and non-religious spiritual care (sharing spiritual experiences and discussing the meaning and purpose of life); the latter of which, arguably, relates to the concept of positive social support (Emerson et al., 2000; Forrester-Jones et al., 2006; 2014). It has however been suggested (Swinton, 1997; Watts, 2011) that spiritual care can also take the form of close relationships and spending time together, particularly for individuals with profound IDD. Characteristics of the non-religious spiritual care provided by AH staff form part of the multidimensional working definition of spirituality (Figure 1). In the current study, the context in which non-religious spiritual care was provided, and the meaning ascribed to that support by participants was what made the support spiritual rather than simply social.

### **Religious and spiritual background, attitude and spiritual care provision**

Both AH and GL staff reported personal spirituality. For AH, this was generally rooted in the religious spirituality category, contextualised within the three dimensions of spirituality as discussed in the introduction (Figure 1) and results section of this paper. The spirituality of GL staff was more grounded in the non-religious spirituality category; contextualised within transcendence, and connection and relationship dimensions. Previous literature has intimated that health and social care staff who have some form of religious affiliation tend to identify spiritual needs in “patients” compared to those claiming no religious affiliation (see Amenta, Highfield & Taylor et al., 1994; Narayanasamy & Owens, 2001; Narayanasamy, Gates & Swinton, 2002; Ross, 1994; Stranahan, 2001; Soeken & Carson, 1986). Musgrave and McFarlane (2003) further suggest that social care staff may sometimes allow their personal beliefs to influence the way they carry out their roles at work in relation to spiritual and religious care. Some of the GL staff perceived residents to be lacking in awareness or understanding of spiritual matters due to their IDD, or that they had no spiritual needs. These perceptions were in contrast to those of AH and this attitudinal difference might explain in part, why both religious and non-religious spiritual care were provided in AH compared to GL (e.g., Soeken & Carson, 1986).

### **Education and training in relation to spiritual care**

Attitudes and practice towards spiritual care demonstrated by AH staff may also be related to the specific spiritual care training (formation) they received. Piles (1990) argued that spiritual care training determines the level of spiritual care support offered by staff. Studies of general nurses (Baldacchino, 2006) and health care workers (Amenta et al., 2000; Balboni et al., 2013; Pesut 2002; Van Leeuwen, et al., 2008) have also associated limitations in spiritual support with a lack of education on the topic. Our study therefore provides further valuable insight into the positive influence such training can have on IDD support workers' spiritual care competence. Diverse perspectives remain as to whether or not spirituality and spiritual care should be "taught" to health care professionals, or if spiritual care competencies are and should be something that are "picked up" whilst on the job (e.g., Bradshaw, 1997). Others (e.g., Amenta et al., 2000; Narayanasamy, 2001) stress the importance of spiritual care training and education to avoid the risk of spiritual awareness not being developed.

The themes identified in this study exemplify the ways through which non-religious spirituality and non-spiritual support related to the types of care provided in both services. In the context of the "community of value" theme, (non-religious spiritual care) qualitative data showed how the two categories were entrenched in AH's core values, based on the proposition that we all have spiritual aspects to our being which ought to be cared for (see Tanyi, 2002) and highlighted the importance of the spiritual dimension within effective holistic care. Overlooking such spiritual needs may result in a more "functional care" model, as depicted generally by GL. Burkhart and Hogan (2008) reported that in their study of nurses, explanations given for not engaging in spiritual care included "time constraint", "busyness," or "the speed of things" (p. 932) which were similar to our findings. Studies of health care services (Balboni et al., 2012; Fletcher, 2004; Van Dover & Bacon 2001) found that staff unavailability led to spiritual care being "passed on" to pastoral care departments (e.g., chaplains). Since staff in both services reported similar shortages, the additional time AH staff spent concerning themselves with spiritual aspects of residents' lives should not be underestimated. Nor can it be explained as a consequence of structural or systemic issues (since both were regulated by the same LA). Rather, it is more likely that the differences in spiritual care was due to staff attitudes, training, and the particular ethos of the services.

Communication challenges found in both services were also noted by Swinton and Treevett (2009) who described how religious narratives (the Christian belief that Jesus Christ is living inside of you) could be confusing for individuals with autism. Deeley (2009) described how "mental deficits and non-social restricted interests" of individuals affect their spiritual understanding, interest and sensibility. However, the heterogeneity of IDD traits in general means that we need to be cautious about essentialist and reductionist generalisations concerning the spiritual aspects of people's lives, especially in the absence of adequate research on the topic (Deeley, 2009). Rather, our research indicates that individuals with IDD can and do have the ability to relate to the "unknown" and appear to experience religious development independent from their level of cognitive development (Dubin & Graetz, 2009; Sango & Forrester-Jones, in press).

### **Limitations of the Study**

The small sample size of the study, which includes more women than men, makes generalisation of findings difficult yet the small nature of our study reflects the limited number of faith-based services catering for people with IDD available within the UK. It was our initial intention to recruit 100 participants across four services (25 in each) including two faith-based and two non-faith based services to allow for statistical comparisons. However, whilst a Jewish service was recruited, it withdrew part-way through the study due to "staffing issues". A UK

Islamic community service for people with IDD was also sought, but personal communications between the authors and this community led to a decision that such a service could only be found outside of the UK (and there was no additional funding to expand our study in this way). On the one hand our findings are therefore arguably restricted in terms of their transferability to other faith-based and non-faith based settings. On the other hand, transferability of our findings were enhanced through the detailed descriptions of the research context and purposeful sampling method (Bitsch, 2005: 85). Since we are only reporting on one situation, those wishing to “transfer” the results of our study to a different context can make their own judgment regarding how sensible the transfer is (Bitsch, 2005:85).

It could be suggested that the Christian belief of the first author (who collected the data and analysed most of it) might have biased the interpretation of findings to positively portray the faith-based service. This risk was resolved by the authors taking descriptive and interpretive validity steps recommended by Maxwell (1992). Descriptive validity relates to the factual accuracy of the researcher’s account of data such as observations and interviews. In our study, all interviews were recorded and field notes made after each observation. The recorded interviews were transcribed verbatim; creating an accurate, unbiased account of what respondents said. As regards interpretive validity (how well participants’ perspectives rather than the researcher’s perspective are understood, described and represented), the first author was able to approach the thematic analysis process with knowledge of each interviewee’s vocal inflections, speech modulation and in some cases body languages since she transcribed all of the interviews, thereby enabling a correct understanding and description of each participant’s perspective. In subsequent analyses, interpretive validity was ensured by staying close to the transcripts at all times and grounding interpretations in direct quotes and phrases capturing respondents’ words.

Finally, the study was non-experimental (with no randomised participants or services and no control) since the services were purposefully selected for being either stated faith-based or having no stated basis of faith, and staff were approached by the service managers. Nevertheless, the quantitative measures used provided a structure to the research and guided the interview data collection process, with more qualitative methods enabling a “deep-dive” into participant’s perspectives. These methods allowed themes to emerge in relation to the notoriously difficult topic area of spirituality.

## Conclusions

The findings presented in this paper suggest that practice changes within care services for people with IDD as regards appropriate spiritual care training and education for staff may help to foster positive spiritual awareness, attitudes and care so as to mediate religious and spiritual experiences of individuals with IDD **in line with their personal desires.**

### Recommendations for Practice and Research:

- We advocate that spiritual care is incorporated into health and social care professionals’ training and education, especially given the recent Care Act (2014) which advocates the need for individuals’ beliefs to be recognised and respected **where appropriate.**
- Mindful that our study was restricted to an exploration of a Christian faith-based service, we suggest that future studies should explore services operating from different religious backgrounds as a logical extension of our research.

## References

- Amenta, M., Highfield, M., & Taylor, E. J. (1994). Attitudes and beliefs regarding spiritual care: A survey of cancer nurses. *Cancer Nursing*, 17, 479-487. Retrieved from <http://journals.lww.com/cancernursingonline/pages/default.aspx>
- Amenta, M., Highfield, M., & Taylor, E. J. (2000). Preparation to Care: The Spiritual Care Education of Oncology and Hospice Nurses. *Journal of Hospice & Palliative Nursing*, 2, 53-63. Retrieved from <http://journals.lww.com/jhpn/pages/default.aspx>
- Argyle, M., & Beit-Hallahmi, B. (1975). *The social psychology of religion*. London: Routledge.
- Baker, D.C. (2003). Studies of the inner life: the impact of spirituality on quality of life. *Quality of Life Research*, 12, 51-7. Retrieved from <https://www.ebscohost.com/>
- Balboni, M. J., Sullivan, A., Amobi, A., Phelps, A. C., Gorman, D. P., Zollfrank, A., Peteet, J.R., Prigerson, H.G., VanderWeele, T.J., & Balboni, T. A. (2013). "Why is spiritual care infrequent at the end of life? Spiritual care perceptions among patients, nurses, and physicians and the role of training." *Journal of Clinical Oncology*, 31, 461-467. doi: 10.1200/JCO.2012.44.6443
- Baldacchino, D. R. (2006). Nursing competencies for spiritual care. *Journal of Clinical Nursing*, 15, 885-896. doi: 10.1111/j.1365-2702.2006.01643.x
- Bassett, R. L., Perry, K., Repaso, R., Silver, E., & Welch, T. (1994). Perceptions of God among persons with mental retardation: A research note. *Journal of Psychology and Theology*, 22, 45-49. Retrieved from <https://www.ebscohost.com/>
- Bradshaw, A. (1997). Teaching spiritual care to nurses: an alternative approach. *International Journal of Palliative Nursing*, 3, 51-57. Retrieved from <https://www.ebscohost.com/>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101. doi: 10.1191/1478088706qp063oa
- Burkhart, L., & Hogan, N. (2008). An experiential theory of spiritual care in nursing practice. *Qualitative Health Research*, 18, 928-938. doi: 10.1177/1049732308318027
- Care Act. (2014), c. 23. Retrieved from <http://www.legislation.gov.uk/ukpga/2014/23/enacted>
- Cohen, S., Underwood, L. G., & Gottlieb, B. H. (Eds.). (2000). *Social support measurement and intervention: A guide for health and social scientists*. Oxford University Press.
- Cortina, J. M. (1993). What is coefficient alpha? An examination of theory and applications. *Journal of Applied Psychology*, 78, 98-104. doi: 10.1037/0021-9010.78.1.98**
- Creswell, J., Klassen, A., Plano Clark, V., & Smith, K. (2011). *Best practice for mixed methods research in the health sciences*. Bethesda, MD: Office of Behavioral and Social Sciences Research, National Institutes of Health. Retrieved from [https://tigger.uic.edu/jaddams/college/business\\_office/Research/Best\\_Practices\\_for\\_Mixed\\_Methods\\_Research.pdf](https://tigger.uic.edu/jaddams/college/business_office/Research/Best_Practices_for_Mixed_Methods_Research.pdf)
- Deeley, Q. (2009). Cognitive style, spirituality, and religious understanding: The case of autism. *Journal of Religion, Disability & Health*, 13, 77-82. doi: 10.1080/15228960802581479
- Dubin, N., & Graetz, J. E. (2009). Through a different lens: spirituality in the lives of individuals with Asperger's syndrome. *Journal of Religion, Disability & Health*, 13, 29-39. doi: 10.1080/15228960802505213
- Emerson, E., Robertson, J., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., ... & Netten, A. (2000). Quality and costs of community-based residential supports, village communities, and residential campuses in the United Kingdom. *American Journal on Mental Retardation*, 105, 81-102. Retrieved From: [www.scholar-google-co-uk](http://www.scholar-google-co-uk)

- Fletcher, C. E. (2004). Health care providers' perceptions of spirituality while caring for veterans. *Qualitative Health Research*, 14, 546-561. doi: 10.1177/1049732303262509 Kingsley Publishers.
- Forrester-Jones, R. (2013). The road barely taken: Funerals, and people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 26, 243-256. doi: 10.1111/jar.12022
- Forrester-Jones, R. (2014). Loss and people with autism. In Read, S. (Ed) *Supporting People with Intellectual Disabilities Experiencing Loss and Bereavement*, London, Jessica Kingsley Publishers.
- Forrester-Jones, R., Carpenter, J., Coolen-Schrijner, P., Cambridge, P., Tate, A., Beecham, J., ... & Wooff, D. (2006). The social networks of people with intellectual disability living in the community 12 years after resettlement from long-stay hospitals. *Journal of Applied Research in Intellectual Disabilities*, 19, 285-295. doi: 10.1111/j.1468-3148.2006.00263.x
- Gaventa, W. (1993). Gift and call: recovering the spiritual foundations of friendships. In A. Amado (Ed.) *Friendships and community connections between people with and without developmental disabilities*. (pp. 41-66). Baltimore: Brookes.
- Hill, P.C., Pargament, K.I., Hood, R.W., McCullough, J.P., Swyers, D.B., Larson, D.B., & Zinnbauer, B.J. (2000). Conceptualizing Religion and Spirituality: Points of Commonality, Points of Departure. *Journal for the Theory of Social Behaviours*, 30, 51-77. doi: 10.1111/1468-5914.00119
- Koenig, H. G. (2010). Spirituality and mental health. *International Journal of Applied Psychoanalytic Studies*, 7, 116-122.
- Loynes, B., & O'Hara, J. (2015). How can mental health clinicians, working in intellectual disability services, meet the spiritual needs of their service users? *Advances in Mental Health and Intellectual Disabilities*, 9, 9-18. doi: 10.1108/AMHID-10-2014-0035
- Maxwell, J. (1992). Understanding and validity in qualitative research. *Harvard Educational Review*, 62, 279-301. Retrieved From: <http://www.msuedtechsandbox.com/hybridphd/wpcontent/uploads/2010/06/maxwell92.pdf>
- McEvoy, J., MacHale, R., & Tierney, E. (2012). Concept of death and perceptions of bereavement in adults with intellectual disabilities. *Journal of Intellectual Disability Research*, 56, 191-203. doi: 10.1111/j.1365-2788.2011.01456.x
- Minton, C. A., & Dodder, R. A. (2003). Participation in religious services by people with developmental disabilities. *Mental Retardation*, 41, 430-439 doi: 10.1352/0047-6765(2003)41<430:PIRSBP>2.0.CO;2
- Musgrave, C. F., & McFarlane, E. A. (2003). Oncology and oncology nurses' spiritual well-being and attitudes toward spiritual care: a literature review. *Oncology Nursing Forum*, 30, 523-527. doi: 10.1188/03.ONF.523-527
- Narayanasamy, A. (2001). *Spiritual care: A practical guide for nurses and health care practitioners*. 2nd Edition. Quay Publishing, Wiltshire.
- Narayanasamy, A. (2007). Palliative care and spirituality. *Indian Journal of Palliative Care*, 13, 32. doi: 10.4103/0973-1075.38897
- Narayanasamy, A., & Owens, J. (2001). A critical incident study of nurses' responses to the spiritual needs of their patients. *Journal of Advanced Nursing*, 33, 446-455. doi: 10.1046/j.1365-2648.2001.01690.x
- Narayanasamy, A., Gates, B., & Swinton, J. (2002). Spirituality and learning disabilities: a qualitative study. *British Journal of Nursing*, 11, 948-957. doi: 10.12968/bjon.2002.11.14.10467



- Narayanasamy, A., Clissett, P., Parumal, L., Thompson, D., Annasamy, S., & Edge, R. (2004). Responses to the spiritual needs of older people. *Journal of Advanced Nursing*, 48, 6-16.
- Nunnally, J. C. (1978). *Psychometric Theory* (2nd Edit.) McGraw-Hill. Hillsdale, NJ.
- Pesut, B. (2002). The development of nursing students' spirituality and spiritual care-giving. *Nurse Education Today*, 22, 128-135. doi: 10.1054/nedt.2001.0664
- Piles, C. L. (1990). Providing spiritual care. *Nurse Educator*, 15, 36-41. Retrieved from <http://journals.lww.com/nurseeducatoronline/pages/default.aspx>
- QSR International. (2012). NVivo 10 (Version 10) [Computer software]. Doncaster, Australia QSR International Pty Ltd.
- Ross, L. (1994). Spiritual aspects of nursing. *Journal of Advanced Nursing*, 19, 439-447. doi: 10.1111/1365-2648.ep8537606
- Ross, L. (1995). The spiritual dimension: its importance to patients' health, well-being and quality of life and its implications for nursing practice. *International Journal of Nursing Studies*, 32, 457-468. doi: 10.1016/0020-7489(95)00007-K
- Sandelowski, M. (2000). Focus on research methods-whatever happened to qualitative description? *Research in Nursing and Health*, 23, 334-340. doi: 10.1002/1098-240X(200008)23:4<334
- Sango, P. N., & Forrester-Jones, R. (2014). Spirituality and learning disability: a review of UK Government guidance. *Tizard Learning Disability Review*, 19, 170-177. doi: 10.1108/TLDR-01-2014-0005
- Santos, J. R. A. (1999). Cronbach's alpha: A tool for assessing the reliability of scales. *Journal of Extension*, 37, 1-5.
- Sango, P.N., & Forrester-Jones, R. (in press). Spirituality and social networks of people with Intellectual and Developmental Disability. *Journal of Intellectual & Developmental Disability*. doi: 10.3109/13668250.2017.1310820
- Shogren, K. A., & Rye, M. S. (2005). Religion and individuals with intellectual disabilities: An exploratory study of self-reported perspectives. *Journal of Religion, Disability & Health*, 9, 29-53. doi: 10.1300/J095v09n01\_03
- Soeken, K. L., & Carson, V. J. (1986). Study measures nurses' attitudes about providing spiritual care. *Health Progress*, 67, 52-55. Retrieved from <https://www.chausa.org/publications/health-progress/current-issue>
- Stranahan, S. (2001). Spiritual perception, attitudes about spiritual care, and spiritual care practices among nurse practitioners. *Western Journal of Nursing Research*, 23, 90-104. doi: 10.1177/01939450122044970
- Stancliffe, R. J., Wiese, M. Y., Read, S., Jeltos, G., & Clayton, J. M. (2016). Knowing, planning for and fearing death: Do adults with intellectual disability and disability staff differ?. *Research in Developmental Disabilities*, 49, 47-59. doi:10.1016/j.ridd.2015.11.016
- Swinton, J. (1997). Restoring the image: Spirituality, faith, and cognitive disability. *Journal of Religion and Health*, 36, 21-28. Retrieved from <https://www.ebscohost.com/>
- Swinton, J. (2001). 'A Space to Listen: Meeting the spiritual needs of people with learning disabilities'. A report commissioned by the Shirley Foundation in conjunction with the Learning Disabilities Foundation, London.
- Swinton, J. (2002). Spirituality and the Lives of People with Learning Disabilities. *Tizard Learning Disability Review*, 7, 29-35. doi: 10.1108/13595474200200037
- Swinton, J., & Trevett, C. (2009). Religion and autism: initiating an interdisciplinary conversation. *Journal of Religion, Disability & Health*, 13, 2-6. doi: 10.1080/15228960802606193

- Tanyi, R. A. (2002). Towards clarification of the meaning of spirituality. *Journal of Advanced Nursing*, 39, 500-509. doi: 10.1046/j.1365-2648.2002.02315.x
- Tashakkori, A., & Teddlie, C. (1998). *Mixed methodology: Combining qualitative and quantitative approaches*. Thousand Oaks, CA: Sage Publications.
- Turner, S., Hatton, C., Shah, R., Stansfield, J., & Rahim, N. (2004). Religious Expression amongst Adults with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, 17, 161-171. doi: 10.1111/j.1468-3148.2004.00192.x
- Vance, D. L. (2001). Nurses' attitudes towards spirituality and patient care. *Medsurg Nursing*, 10, 264-268. Retrieved from <https://www.ebscohost.com/>
- Van Dover, L. J., & Bacon, J. M. (2001). Spiritual care in nursing practice: a close-up view. In *Nursing Forum*, 36, 18-30. doi: 10.1111/j.1744-6198.2001.tb00245.x
- Van Leeuwen, V. R., Tiesinga, L.J., Jochemasen, H. & Post, D. (2007) 'Aspects of spirituality concerning illness'. *Scandinavian Journal of Caring Science*, 21, 482-489. doi: 10.1111/j.1471-6712.2007.00502.x
- Van Leeuwen, R., Tiesinga, L. J., Middel, B., Post, D., & Jochemsen, H. (2008). The effectiveness of an educational programme for nursing students on developing competence in the provision of spiritual care. *Journal of Clinical Nursing*, 17, 2768-2781. doi: 10.1111/j.1365-2702.2008.02366.x
- Watts, G. (2011). Intellectual disability and spiritual development. *Journal of Intellectual and Developmental Disability*, 36, 238-245. doi:10.3109/13668250.2011.617731
- Wiese, M., Stancliffe, R. J., Read, S., Jeltos, G., & Clayton, J. M. (2015). Learning about dying, death, and end-of-life planning: Current issues informing future actions. *Journal of Intellectual and Developmental Disability*, 40, 230-235. doi:10.3109/13668250.2014.998183

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## Figures

**Figure 1. Multidimensional working definition of spirituality**

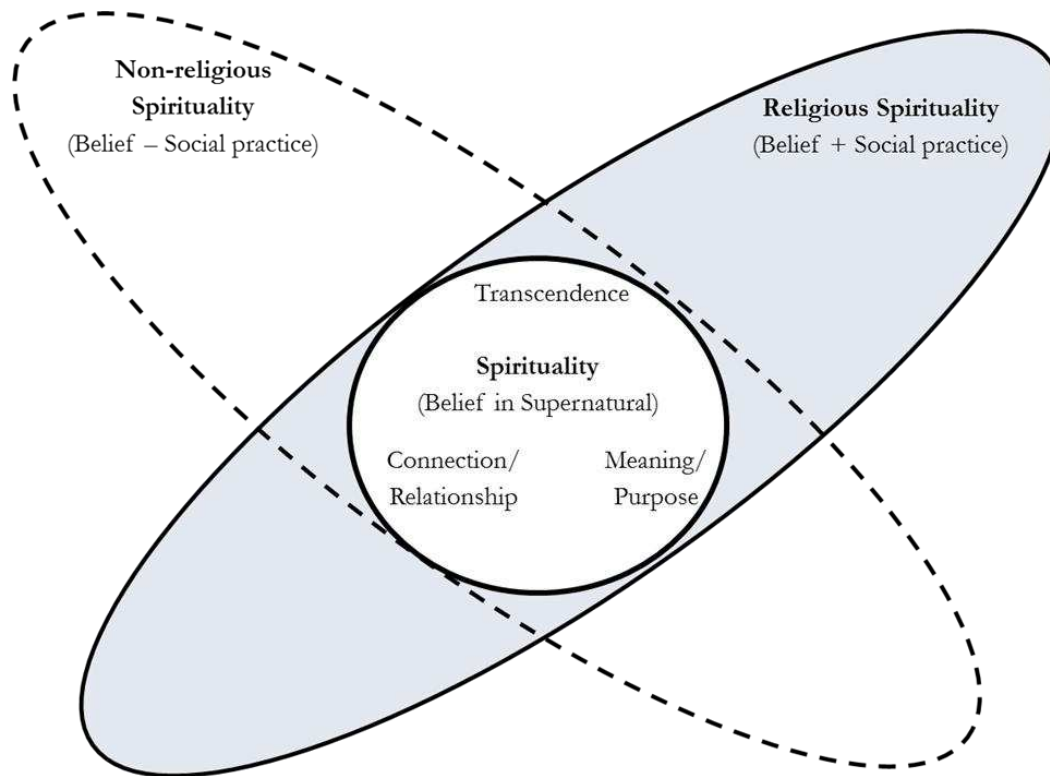


Figure 1 is from the first author's doctoral dissertation: Sango, P. N. (2016). Spirituality and People with Intellectual Disabilities: Comparing the Significance of Spirituality in Faith and Non-Faith Based Care Services (Doctoral dissertation, University of Kent).

**Figure 2. Themes from Adam's House and Greenleaves**

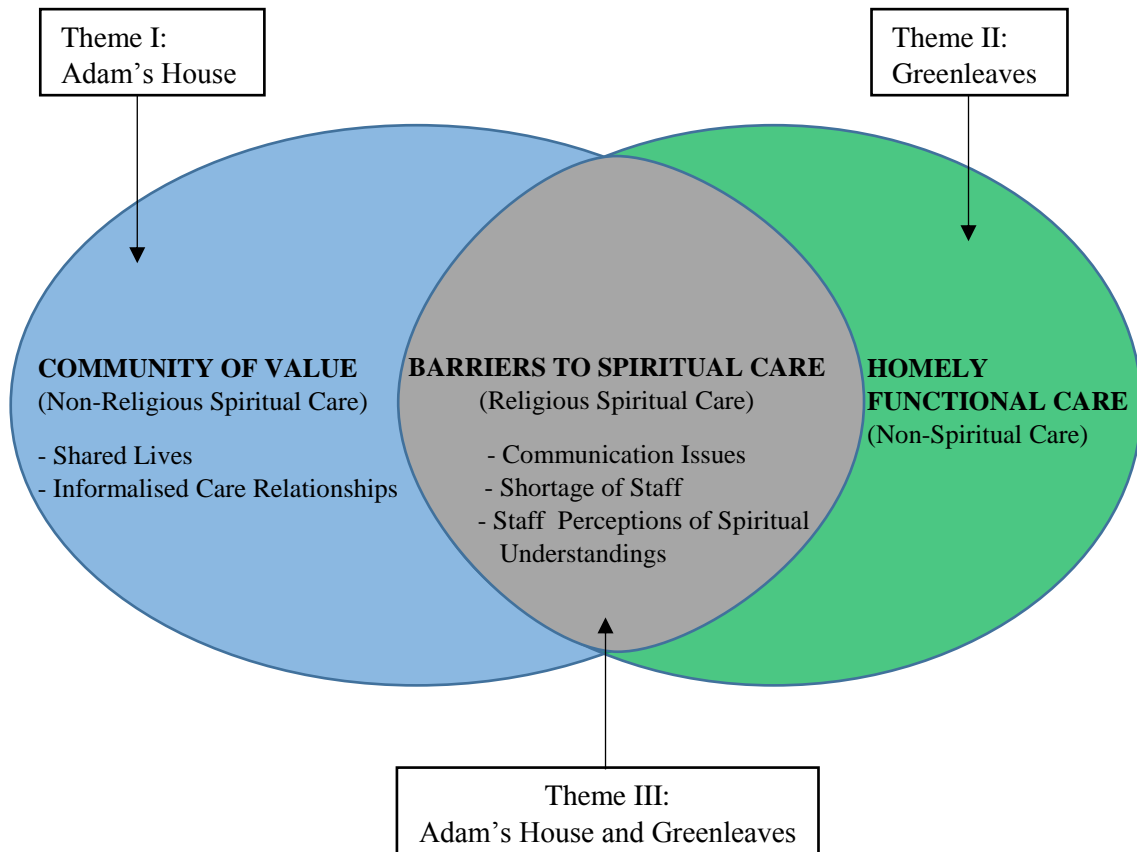


Figure 2 is from the first author's doctoral dissertation: Sango, P. N. (2016). Spirituality and People with Intellectual Disabilities: Comparing the Significance of Spirituality in Faith and Non-Faith Based Care Services (Doctoral dissertation, University of Kent).