Spirituality and social networks of people with intellectual and developmental disability

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***Background*:** Researchers contend that religious/spiritual communities may provide a conduit to friendship for people with IDD. This research explored the interface between social networks and spirituality for individuals with IDD living in either a faith or non-faith based service.

***Method**:* A mixed-methods approach was used including semi-structured interviews, the Social Network Guide and the Spiritual Belief Inventory-15R with individuals with IDD (or staff members who provided their opinions of what individuals who lacked capacity to consent would say if they had capacity). These findings were corroborated with extensive field notes generated from participant observation.

***Results**:* The faith-based group had a higher network size (*m*= 78) compared to the non-faith based group (*m* = 44). Those with larger social networks also reported higher SBI-15R scores.

***Conclusion**:* Findings highlight the possible role of social, spiritual/religious activities for expanding individuals' social networks.

Keywords: intellectual and developmental disability, spirituality, spiritual/religious activities, social networks, faith and non-faith based care services.

Introduction

Spirituality and religion are generally used interchangeably, yet spirituality may be defined as faith in the “sacred” and/or finding a personal relationship with God or a supreme power (see Baker, 2003) whereas religion can denote a state of adherence to specific institutional beliefs and practices (see Argyle & Beit-Hallahmi, 1975). Spirituality is increasingly viewed as an important aspect of holistic and person-centred care (Potter, 2002) and features as a variable in the World Health Organization Quality of life assessment (see Group, 1998). Studies have shown however that the religious/spiritual aspects of the lives of people with intellectual and developmental disability (IDD) tend to be ignored in care services, because the spiritual needs are unacknowledged, or carers feel unprepared to constructively deal with them (see Swinton, 2002).

It has been suggested that faith-based communities can create environments in which individuals including those with IDD feel accepted and experience self-worth (Swinton, 2002). Such environments have also been shown to help people with IDD overcome feelings of stigma, low self-esteem with spiritual/religious activities providing social and psychological support (McNair & Leguti, 2000; Culliford, 2002). Faith-based organisations are defined as “*any organization that refers directly or indirectly to religion or religious values and functions as a welfare provider or as a political sector*” (Dierckx, Vranken & Kerstens, 2009, p.1). In Walls and Zarit’s (1991) study of 98 older adults without IDD from African American churches in urban Pennsylvania, 50 per cent reported that their closest friends were family members whilst 40 per cent considered church members to belong to this category. Social networks which facilitate participation in spiritual/religious activities have also been shown to be important aspects of quality of life for people with IDD (see Forrester-Jones et al., 2006).

Alternatively, religious communities can create barriers to integrating people with IDD due to the abstract nature and discourse of some beliefs. For example, Scientology assumes a cognitive basis for spirituality with an intellectual response required to certain verbal formulations which may serve to exclude people with IDD, not because they are less spiritual, but because of the ways in which spirituality is defined (Swinton, 2002). Nevertheless, it has been proposed that access to a religious/spiritual community may provide a conduit to developing and maintaining friendships for people with IDD (Gaventa, 1993) since such communities operate in a way which recognises the spiritual needs of ‘all’ individuals forming an integrated community, which wider society may lack (Swinton, 2002).

Aim and Research Question

The aim of this paper is to report on a study which explored the interface between social networks and spirituality for individuals with IDD living in a faith-based (pseudonym, Adam’s House (AH)) and a non-faith based (pseudonym, Greenleaves (GL)) service. The main research question was: To what extent does the opportunity to exercise religion/spirituality mediate the social lives of individuals with IDD?

Methods

Study design

The study was exploratory. Mixed-methods were chosen since spirituality is a complex phenomenon which cannot be explored using a single research method (Sandelowski, 2000). Quantitative and qualitative data were collected simultaneously, analysed independently and combined to gain a deeper understanding of participants' perspectives (Creswell, Klassen, Plano Clark, & Smith, 2011); pragmatism being the philosophical underpinning of this methodological triangulation (Tashakkori & Teddlie, 1998).

Ethics

The study gained ethical approval from the United Kingdom's (UK) National Health Service Ethics Committee (Ref: 13/LO/0594). No funding was available to pay participants; their participation was voluntary without inducement. Each participant received either a plain English or easy read information sheet explaining the nature, reason and voluntary aspect of the study, and an assurance of anonymity and confidentiality. The first author also visited each service to explain the research and answer questions. For those who lacked capacity to consent (17 service users), the Mental Capacity Act (MCA) 2005 applied. Managers identified either a personal consultee (e.g. family member or advocate) or a nominated consultee (e.g. care manager or other professional or lay person who knew the potential participant well and who had no connection with the project). Personal and nominated consultees' roles were to consider the risks and benefits of the individual participating in the research and whether the participant would want to participate if they were able to consent in line with section 32 (4) (a) and (b) of the MCA 2005. The voluntary nature of the research was made clear to all potential participants, consultees/nominated consultees and that non-participation would not affect residency, care provision or staff status and that no reason was required for declining the invitation to participate.

Sample

A purposive sampling method was used, the aim being to recruit 40 individuals with IDD (20 in AH; 20 in GL) so that statistical comparisons could be made. After agreement was gained from managers of both services, all residents (19 living in GL; 22 in AH) were invited to participate. Of the total number of service users approached (*n*= 40); 36 (*n*=18 in AH; *n*=18 in GL) agreed to take part. All had a diagnosis of IDD; case files revealed that more individuals in AH had moderate to severe IDD whilst GL mainly had individuals with either mild or profound IDD (see Table 1). The total group were predominantly male (*n*=11 females; 25 males) with ages ranging from 21 and 71. The whole group were White British and just under 40% had lived in their respective service for over 10 years.

PLEASE INSERT TABLE. 1 SERVICE USERS' (*N*=36) DEMOGRAPHIC DATA

Setting

AH and GL were both located in Southern England, UK and regulated by their local authority (LA). The services were purposefully selected to explore both a stated faith-based service (AH) and a service stating no faith (GL). AH consisted of nine supported living houses (with a total of 22 service users; between 3 and 6 residents with IDD in each house) with 24 hour care provided by "live-in" paid staff and volunteers. A couple of the houses had "live out" staff, helping individuals when necessary. According to in house policy documents and discussions with service managers, AH's care philosophy centred around notions of "sharing", "relationships", and "simplicity"; specifically setting out to support individuals to explore their spiritual lives. Service users' access to AH was mainly via their local social networks. For those with more severe or profound IDD, family members together with the LA care manager would decide on whether AH was an appropriate environment.

GL consisted of three residential houses (between 3 and 11 residents with IDD living in each house) with a 24 hour care system. None of the staff lived in the residence. GL's mission statement was based on "Valuing People 2011" with a focus on Person Centred Plans. The decision to reside at GL was generally made by family members or the LA.

Both AH and GL had residences located in rural and urban areas. Whilst the two services were not identical in nature and direct comparisons could not be made, the purpose of the study was not to compare the services *de facto*; rather, to explore the interface between religion/spirituality and social networks. The study was also non-experimental; the sample of care organisations and participants being non-random. Therefore, causal inferences from the quantitative data could not be made and care ought to be taken when interpreting the findings. Nevertheless, the explorative mixed-methods approach chosen, offered a more holistic picture to emerge as regards a rather "fuzzy" topic. The quantitative measures provided a structure to the research and guided the interview data collection process, while qualitative methods enabled an in-depth comparison of participant's perspectives.

Materials and procedure

The first author engaged in participant observation (PO) for six months in each service; joining in with daily activities; aiding volunteers and staff to support service users in various social and spiritual/religious activities including dance, music, monthly house meetings, communal lunches/dinners, church, and "community spiritual gatherings" (organised by staff and service users) in AH and helping out at meal times, social clubs (usually taking place in local pubs and church halls), woodwork, and cooking classes at a nearby college in GL.

Quantitative methods included the Adaptive Behaviour Scale (ABS) short form (Hatton et al., 2001) to measure individual's adaptive and social behaviour using three factor scales: personal self-sufficiency; community self-sufficiency; and personal social responsibility. This was completed by the researcher with each service user either alone or with support from their carer, depending on their communication abilities. The Cronbach's alpha for the three ABS factors was 0.86 indicating a high level of internal consistency, with high construct validity. The Social Network Guide (SNG; see Forrester-Jones, Jones, Heason & Di'Terlizzi; Forrester-Jones et al., 2006) was used to map individuals' social relationships including the structural (size and membership), interactional (reciprocity, frequency and duration) and functional (e.g. personal, household, material support) aspects of their social networks. The SNG invites participants to name or provide the contact's network membership (e.g. staff, friend, family etc) from 10 possible areas of life. In some cases, participants indicated the number of people they knew in the different areas of life by counting with their fingers, often pausing to think before giving a number.

The Spiritual Belief Inventory-15R (SBI-15R; Holland et al., 1998) measures Beliefs in a Supreme Being and Practices (Subscale 1, ten items) as well as social support gained from religious and/or spiritual affiliation (Subscale 2, five items) as a potentially mediating variable in coping with life conditions and quality of life. An example of questions about belief and practices being *"Religion is important in my day-to-day life"* and of social support being *"I enjoy attending religious functions held by my religious group"*. Responses coded from "strongly disagree" to "strongly agree" were adapted with smiley faces with questions simplified to aid understanding. An analysis of SBI-15R by Holland et al. (1998) found high internal consistency for data: Cronbach's alpha 0.93 (for all the 15 items); Cronbach's alpha 0.92 for Subscale 1; Cronbach's alpha 0.89 for Subscale 2.

The above applied measures were carried out via face-to-face interviews with 10 individuals with IDD from AH and 9 from GL who were verbally capable. For the other 17 individuals who lacked capacity, staff were asked to give their opinion based on what they knew about the individuals (following the MCA, 2005). Administered during the second month of fieldwork, these applied instruments were followed by semi-structured open-ended interviews concerning individual's beliefs during PO which not only maximised data corroboration but also allowed a good rapport and trust to develop between the researcher and participants. It also afforded the researcher with an extended understanding of the cultural context of the field. All interviews were audio-recorded and transcribed verbatim.

Whilst there was the possibility of "researcher bias" (i.e., the first author's Christian belief biasing data collection and analyses), descriptive and interpretive validity steps were taken to mitigate this risk. Descriptive validity refers to the factual accuracy of the researcher's account of observations and interviews by the audio recording of all interviews and the immediate writing up of field notes post-observations. Recorded interviews were transcribed verbatim, creating an accurate, unbiased account of what respondents said. To ensure interpretive validity, (i.e. how well participants' perspectives rather than researcher's perspective was understood, described and represented) the first author (rather than anyone else) transcribed audio recordings of all interviews, thereby approaching thematic analysis with knowledge of each interviewee's vocal inflections, speech modulation and in some cases body language. This process contributed to a more accurate understanding and description of each participant's perspective. The second author then independently analysed half of the transcripts, comparing/cross-checking codes and themes with those of the first author. A final discussion between both authors followed until themes were saturated and agreed upon. In subsequent analyses, interpretive validity was ensured by staying close to the transcripts at all times and grounding all interpretations in direct quotes and phrases capturing respondents' own words.

The self-report instruments used risked being prone to the social desirability effect (e.g. exaggerating responses regarding the number of members in a network) to portray themselves, or their care service in a positive light. It is hoped that the effective use of triangulation including interview responses being double checked with PO (Creswell, 2013) will have reduced this effect and increased data reliability.

Analysis

Using SPSS V22, quantitative data were subjected to descriptive analysis and a non-parametric Man Whitney U test. Spearman Rho correlation was used to test for any relationship between the SBI-15R and SNG data. The effect sizes for both significant and non-significant P values (Tables 3 & 4) were manually calculated using the non-parametric formula of r=Z/square root (N). Cohen's (1988 in Dunst & Hamby, 2012) effect size estimates were used to interpret the strength of the relationship/effect size, where "insignificant" was up to 0.19, "small" 0.20 to 0.49, "medium" 0.50 to 0.80, and "large" 0.80 onwards (see Dunst & Hamby, 2012).

NVivo V10 (QSR International, 2012) was used to manage and initially sort the qualitative data. This was followed by in-depth thematic analysis by the first author following Braun and Clarke's (2006) process of familiarisation with the data (via transcription, reading and re-reading transcripts and noting down initial ideas); generating initial codes across the entire data set; searching for and collating of codes into potential themes whilst gathering quotes relevant to each potential theme; and reviewing of themes by checking if the identified themes worked in relation to the coded extracts and the entire data set. This stage was facilitated through the generation of thematic "spider like" maps. As stated above, the second author independently analysed half of the transcripts, comparing codes and themes with the first author until saturation. In this final stage, identified themes were named and vivid, and compelling extract examples were selected and analysed in the context of the research and literature (see Braun and Clarke, 2006).

Results

Adaptive Behaviour Scores for Factors A, B and C

Statistical analysis for Factor A (i.e., personal self-sufficiency) revealed no significant differences between the two groups (see Table 2) indicating that individuals across the study had similar abilities in terms of self-care including the use of a knife and fork, toileting, bathing and dressing, and personal mobility. Similarly, no significant differences were found between the groups for Factor B (i.e., community self-sufficiency) or Factor C (personal-social responsibility including being aware and considerate and being able to interact and socialise with others).

PLEASE INSERT TABLE 2 ABS (SHORT FORM) DATA FOR BOTH SERVICES (*N*=36)

Participants' Spiritual Belief Inventory-15R (SBI-15R) Score

Table 3 shows the total sample scores for the SBI-15R (Holland et al., 1998) which simultaneously measured 'belief in a supreme being', 'practices towards such belief' and social support gained from religious/spiritual community. Significant statistical differences were found; individuals from AH reporting higher levels of spiritual beliefs and practice, as well as reporting the likelihood of gaining support from their religious/spiritual community compared to individuals from GL.

PLEASE INSERT TABLE. 3 SERVICE USERS' (*N*=36) SBI-15R SCORES

Qualitative Data: Emergent themes

Three interlinking themes were inducted from the qualitative data; corroborating the SBI-15R findings, especially the "belief and practice" SBI-15R subscale. The first two themes: "*perceptions of death*", and "*importance of prayer*" characterised over half of the total sample, while the third theme "*expressions of belief*" was unique to core members from AH.

Theme 1: *Perceptions of death*

This theme depicts individuals' understanding of what happens/where people go when they die. One person felt that the deceased were "*asleep*" as illustrated below:

> **S:** He doesn't mention him [Tyre's dead brother] but I know that if you talk about him or you are looking through photos he says "he's asleep". (GL staff)

Others understood death to mean that the deceased "had gone to heaven":

> **Katia:** …[I am] upset…because she is going to heaven and [I] am going to be by myself.
>
> **Researcher:** What will she do in heaven?
>
> **Katia:** She will be with my dad, my Dad is up there, they will be together. (Service user, AH)

Here, Katia expressed grief and also her conviction that heaven existed. Jethro, from GL also indicated a belief in an after life; describing it as 'up there':

> **Jethro: [prayer] -** yeh, very importabnt, so is my Dad….Dad is up there.

Theme 2. ***The importance of prayer***

Whilst this theme emerged from both services, AH service users appeared more able to express the importance of prayer in their lives than their GL counterparts; citing healing, buffering worry, and mediating hope. For example, Rose from AH, described how she believed that praying to “Jesus”, and the prayers of her family, friends and church members contributed to the healing of her epilepsy such that she no longer depended on medication, which improved her quality of life:

> **Rose:** I prayed to Jesus and said “oh could you heal me of my seizures?” … Mum and Dad prayed as well and I was at school one day and yeh I felt like I was going to go into one [a fit] and no I did not go into one and ever since then I have been like “wow” and coming off the medication I feel more brighter because before I was like really tired and exhausted …

The importance of prayer for helping loved ones, and providing comfort in difficult times was also highlighted by AH core members George, Katia and Rose:

> **Researcher:** What sort of things do you say to God?
>
> **George:** Friends, family… to help someone poorly**.**

> **Katia:** Make my Mum well. It helps, when [I] am down I go to the garden, sit there, talk to God by myself…I pray and pray, like a tunnel with a light going through the tunnel every day.

> **Rose:** I believe in God and that He can sort everything. If you got a problem you can pray to Him and He can sort that situation out and you do not have to worry about it and you can just sing to Him...
>
> **Researcher:** Does this help you?
>
> **Rose:** Yea, especially when I am stressed…

The importance of prayer was also noted in the context of aiding mental health and self-esteem:

> **Camille:** being confident in myself, I believe in myself, because I had that problem not believing in myself when I was younger and sometimes I still, but sometimes I don't get it now so much.. I ask him, I tell him, "God could you help me believe in myself, help me to be strong and grow in wisdom".

Camille also described how God helped her through daily challenges such as the absence of a favourite member of staff:

> **Camille:** with God and my needs, well if I say "[I] am finding this hard"…he will listen to me… I say "Oh God can you help me next week because [a staff that lives with Camille] is going to be away for a whole week" he will answer me...

Talking "to Jesus" also helped and guided Camille to make new friends:

> **Camille:** I pray three times a day. I ask him to help me to do this, or help me with this meeting tomorrow.
>
> **Researcher:** Give me an example?

> **Camille:** …I had a friend who didn't want to be friends with me, and I asked Jesus could He help me to be friends with this other person, and I kept asking and asking, it took a while but yeh…

The importance of prayer for individuals from GL (as shown below by Micah and Silas) appeared to be mainly rooted in the desire to pray for and longing to remain spiritually connected with their deceased parents:

> **Micah:** I pray sometimes.
>
> **Researcher:** Who or what do you pray to?
>
> **Micah:** Couple of years ago my Mum died… so something like that really.
>
> **Researcher:** Who do you pray to?
>
> **Micah:** My mum mostly.

> **Silas:** I pray.
>
> **Researcher:** what do you pray about?
>
> **Silas:** My dad, passed away.

Theme 3. *Expressions of belief*

This theme, unique to those living at AH, referred to individuals' expression of their knowledge of doctrinal aspects about God and church:

> **Researcher:** What else do you do when you go to church?
>
> **Clifford:** Holy Communion sometimes
>
> **Researcher:** What is Holy Communion?
>
> **Clifford:** wine and bread

> **Researcher:** What is Holy Communion?
>
> **Katia:** Like bread, you cut it up in pieces and give it to people

With some individuals demonstrating some understanding of what might be regarded as fairly sophisticated doctrinal understandings of Jesus as helper, and God and Jesus as One:

> **Researcher:** Tell me about God?
>
> **Paterson:** God [is] like Jesus (AH service user with moderate ID and limited verbal ability).

> **George:** Jesus
>
> **Researcher:** Who is he?
>
> **George:** Helper. Helps us (AH service user with moderate ID and limited verbal ability).

> **Camille:** I believe in God because He is Jesus as well, God is Jesus, God is not one man and Jesus is another.
>
> **Researcher:** Why do you believe this?
>
> **Camille:** [deep breath and smiles] It’s hard to say... you have to believe Jesus is God, you can’t say “no, Jesus is one man God is another”, it doesn’t work like that, other people think it works like that but I don’t. I believe Jesus is God and God is always there, whatever you do, God is always there, always. And if I go to college or do my laundry or my cleaning, or my room or I am eating, God is there. God follows you and in fact God is in your heart every day and night.

Such relative complex beliefs were illuminating especially in relation to individuals like Camille who required daily assistance with her personal care and domestic chores. This particular theme did not emerge from the GL data.

These themes contextualised the SBI-15R data, further contributing to an understanding of service users' spirituality.

Social Networks: Size

PLEASE INSERT TABLE. 4 SERVICE USERS' (N=36) SOCIAL NETWORK GUIDE

Mean social network size was significantly higher for the AH group (average =78) compared to those in GL (average = 44) (Table 4). A significant positive correlation was found between social network size, beliefs and practices (rho = 0.422; p = 0.01) and social support from a spiritual community (rho = 0.418; p = 0.01) indicating that individuals with larger sized networks reported more spiritual belief/practice and gained more social support from their spiritual community.

Social Network Membership

Staff made up the largest membership category of individuals' networks in both services (paid staff: GL = 303 (38.3%); AH = 384(27.3%)). Other membership groups included other people with IDD (GL = 231(29.2%); AH= 123(8.8%)), and other family (GL= 90(11.4%); AH =108 (7.7%)). Individuals in AH reported more social acquaintances (AH =335(23.8%); GL = 20 (2.5%)), other friends without IDD (AH = 233(16.6%); GL = 80(10.1%)), and employer/colleagues (AH = 97 (6.9 %); GL = 0 %) compared to their GL counterparts.

Social Support

The frequency of social support provided by network members was categorised either as “hardly” or “never” (score 0) and “always” or “sometimes” (score 1).

Personal support

No significant differences in personal support (e.g. washing, dressing) were found between services though GL participants received slightly more (27.5%) than those in AH (24.6%). Personal support was mainly provided by paid staff.

Household support

Overall, both groups received similar amounts of household support (HS) (around 27%), mainly from paid staff although (90% in AH vs 70% in GL) This difference may be explained via the fact that, as highlighted by Z (AH staff) and the field note below, household tasks (including cleaning of bedrooms, laundry, food shopping), were always carried out jointly between staff and service users:

> **Z:** Whether it’s one core member or two, you are doing activities with them, cleaning the house and their bedroom… they are helping.
>
> **Field note 07.11.2013**… an assistant asked me to help them with the weekly shopping…with Charlie, a core member and two assistants. Elise, another core member joined us… Charlie and Elise took charged of pushing the trolley and picked items from the shelves…we all unpacked the shopping at the residence…

Material support

Individuals living in AH received significantly (U=684,382.500; p=0.000) more material support (31% including provision of gifts) than those from GL (8%) which, for both groups was provided mainly by paid staff (AH = over 50%; GL = 80%), other friends without IDD; family and club/church members. Observations indicated that there were more opportunities for reciprocal gift giving in AH than in GL. For example, in AH, staff and service users' birthdays were always celebrated via jointly organised birthday parties.

Decisions and feedback

More network members (28.5%) provided decision-making and feedback for individuals in AH than for those in GL (23.9%). In AH this support was provided by paid staff (over 60%); "club/church" members; "household" members, "other friends" without IDD, "other family", and "visiting professionals". In GL, paid staff (over 90%) mainly provided this support.

Confiding

Confiding (concerning private matters, hopes and aspirations) was significantly (U=623,327.500; p=0.000) provided by more network members (28.8%) of those living in AH compared to GL (16.8%). In AH, confidants varied, including paid staff (over 40%); other friends without IDD (over 10%) and club/church members (over 10%). In GL, confidants were reported to be mainly paid staff (over 70 %).

Companionship

Most individuals with IDD (98.7% for both AH and GL) reported that they enjoyed/received companionship (including talking, shopping, group card making, group singing). GL participants reported having little company from neighbours, probably because they had little, if any contact with their local neighbours, apart from other people with IDD, whom they did not necessarily wish to associate themselves with.

Invisible

This related to people who may not have been physically present but whom individuals with IDD felt “watched out for” or “kept an eye” on them. More network members belonging to those living in AH (98%) significantly (U=709,677.00; p=0.000) provided invisible support compared with GL (29.5%). Invisible support was provided by over 40% of paid staff in GL versus around 20% in AH. Both study groups also reported that they obtained invisible support from club/church members; other family; other friends without IDD; day centre/evening club members and household members. Only those from AH received invisible support from social acquaintances (over 20%) and people from their place of work (a little below 10%).

Critical

None of the participants from AH reported that their social contacts were critical of, or upset them whilst around 3% of the total network members belonging to individuals in GL were reported as critical, including other service users and family members (circa 50% for both network members). Observations and interviews indicated that a few individuals with IDD in GL did not always get along with their colleagues, as illustrated in the quote below by a member of staff talking about Joshua who was non-verbal. The service users referred to by S, often argued with each other due to personal dislikes:

> **S (staff for Joshua):** He gets on with all the staff, [but] can have a few problems with some of the people he lives with… [they] don’t get on…. arguing, shouting at each other, [it] can become physical. They just have a dislike for each other.

As indicated below, a few individuals from GL sometimes felt that their families were critical of, and upset them. For example Saul had quarrelled with his sister, refusing to speak to her because she was critical of him:

> **Field note 04.07.2014** During the interview, **SH** (staff) intervenes asking Saul "have you made up with your sister yet?" **Saul**: "No I am not going to speak to her, she upset me".

Reciprocity

Reciprocal relationships were mostly evident in AH (AH =28.3% vs GL = 11.2%). Whilst in GL, reciprocal relationships were mainly between participants and paid staff (over 50%); other family (over 20%) and household members (over 15% fellow service users), in AH reciprocal relationships were more wide spread across members (staff only accounted for approximately 35% of reciprocal relationships). The type of reciprocal relationships evident within AH is illustrated below:

> **Researcher:** So you visit Tamar (another core member) often?
>
> **Camille:** Yeh, or Tamar comes here. She has been a good friend for years now.
>
> **Researcher:** How has she been a good friend?
>
> **Camille:** Because she always gives me stuff and I give stuff back to her…earlier this morning she put a hand bag outside the door. I said "oh is that for me?", She said "Yeh". And she will often do that - leave something outside the house, or ring my bell, or come in for [a] drink and watch telly with me.

Frequency of interaction

Individuals from GL interacted with their network members daily/weekly (69.3%) compared to those from AH (57.4%). In GL, these network members mainly consisted of paid staff (circa 50%), and other service users (over 20%). Individuals from AH mainly interacted daily/weekly with paid staff (40%) as well as club/church members (circa 20%). Individuals from AH often met up with their social acquaintances during community gatherings (monthly events celebrating various religious/non-religious occasions including Christmas, Easter or "family day" visits). This was emphasised by N, Z, Ht and J (staff from AH) stating:

> **N:** It's nice when we all come together…assistants from other houses. On community gathering, you see the whole community and it's nice to meet other people.
>
> **Z:** We have general community gatherings every month/two months. Either a little disco or the [plant garden] opening. Houses have their own parties so we frequent other houses.
>
> **Ht:** So within the system, they've got the opportunity to pray on Wednesdays and during the community gathering.
>
> **J:** Its quiet nice and there are some community gatherings sometimes devoted to prayer.

Such gatherings also potentially allowed service users opportunities to expand their social networks:

> **L:** … there is extra things happening in people's lives because of that, community events, the parties, the whole network of people which opens up to people being

part of [AH].

Duration of relationships

More individuals with IDD in AH had known their network members for more than five years (67.6%) compared to those in GL (26.5%).

Type of relationship

More participants from AH perceived various network members (7%) as their “best friends” (including staff; other core members, club/church members, other friends and family) than participants from GL (0.1%) who generally only considered family members to be their “best friends” (over 95%).

The combination of quantitative and qualitative data appears to highlight not only how the study group understood their spirituality/religion through their beliefs around death, and their ability to express doctrinal concepts such as prayer, Holy Communion and the Trinity, but also illustrates how spirituality/religion relates to the types of social networks participants had.

Discussion

Previous studies (e.g., Tuner et al., 2004; Swinton, 2002) did not report on adaptive abilities, only reporting the degree of individuals’ conditions (i.e., mild, moderate or severe). This study therefore provided a more detailed breakdown of group skills, showing no significant differences with both samples displaying generally lower than average levels of daily living skills (mean= 138.01; median = 157). This mean was slightly higher than for those living in residential campuses (mean = 103.9) in Robertson et al.’s 2001 study but lower than those living in village communities (mean = 195.4) or in dispersed housing (mean = 150.2) and also lower than those in Forrester-Jones et al.(2004) study where participants scored a total ABS mean of 269.5 pre-employment. This research has demonstrated that despite skills deficits, our sample could and did engage with spiritual activities to various degrees; service users in AH generally displaying higher levels of individual spiritual belief and being in receipt of more spiritual and social support from their care service than GL participants.

The average social network size for the two groups (AH=78; GL=44) was small compared to ordinary population studies which report around 124 network members (Hill & Dunbar, 2003). Compared to previous studies of the social networks of people with IDD using the same measure, our sample were faring. For example, O'Callaghan and Murphy (2002) found a mean network size of 20.6 for 60 adults with IDD residing in Kent and a London suburb and Forrester-Jones et al., (2006) reported a mean network size of 22 for people with an IDD living in services across England. Nevertheless, sharp differences between the two services were evident, with AH participants enjoying a much higher average number of contacts compared to their GL colleagues. One explanation for this is that individuals in AH were in paid and/or voluntary employment (e.g., card and candle making, etc) compared with those in GL. Employment may have provided avenues for AH individuals to acquire social contacts (Forrester-Jones et al., 2004). Alternatively, individuals in AH who attended spiritual/religious activities (e.g. regular prayer/group meetings and church attendance), may have been in a better position to gain more network members (see Bekelman et al., 2007).

The impact of spirituality on the social well-being of people with IDD has also been advocated by Swinton (2002); Minton and Dodder (2003) and Turner, Hatton, Shah, Stansfield and Rahim (2004) who all reported that if given the opportunity to participate, many individuals with IDD enjoy the accepting atmosphere at religious services as well as secondary outcomes of friendships and acquaintances including "other friends without IDD". The importance of participation in spiritual/religious events in addition to social and work-based (paid or voluntary) activities for providing effective opportunities to develop social relationships should therefore not be underestimated.

That residents in GL received more personal and household support from staff compared to their AH counterparts may have reflected more of a dependency model of care (Forrester-Jones et al., 2006) in GL despite the similar levels of adaptive behaviour of both groups. Support in AH was carried out in the spirit of “partnership” between staff and service users, presenting a picture of a more balanced staff role, which in turn could be more facilitating of individual independence; positively impacting on self-esteem and QOL (see Gabriel & Bowling, 2004). Such a “partnership-support model” also appeared to play an important role in facilitating social network development through the provision of spiritual/religious activities.

The emergent qualitative themes corroborated the quantitative data and highlighted how spiritual/religious practices can meliorate psychological well-being including reducing symptoms of worry, (see Young, Cashwell, & Shcherbakova, 2000; Meisenhelder, Schaeffer, Younger, & Lauria, 2013) as well as scope for improving self-esteem and confidence. The themes also rebut previous notions that people with IDD have no understanding of spiritual matters (see Bassett, Perry, Repass, & Silver, 1994; Swinton, 2002; Turner et al., 2004 for further discussion). Instead, they corroborate Forrester-Jones’s (2013; 2014) work depicting how individuals with IDD understand dying, death and funeral rituals in the context of spirituality. Similarly, the current findings clearly indicate that some people with IDD have spiritual beliefs which they will practice when provided with opportunities to do so. What differed between the study groups was only the level and intensity of expression of spiritual belief; with those from AH appearing to have a means and language in which to express their ideas and thoughts within an openly spiritual environment, compared to those from GL. It might also be argued that increased spiritual/religious participation may in turn, increase the communication/vocabulary of some individuals; consequently equipping them with the verbal tools to enter spiritual discourse with others, though this would need to be tested out with further research.

Study Limitations

In addition to those discussed within the methods section above, further study limitations are outlined as follows. The initial aim was to recruit 40 individuals with IDD (20 in each service) for statistical comparative analysis. Eighteen individuals in each service (36 in total) agreed to take part meaning that the sample is relatively small, mainly consisting of females, making generalisations difficult. Our study was also restricted to the Christian faith. After a long period of initial scoping, a Jewish service was recruited, but withdrew part-way through the study due to "staffing issues". An Islamic community service was also sought, but personal communications with this community in the UK during the research time-scale led the authors to decide that such a service for people with IDD could only be found outside of the UK (and funding was unavailable to expand the study in this way). Our findings are therefore not necessarily transferrable to other similar settings. Yet whilst transferability, is primarily the responsibility of the one doing the generalisation (Bitsch, 2005,) our findings, which were enhanced through the detailed descriptions of the research context and purposeful sampling method (see Bitsch, 2005, p. 85) may be applied to other settings. Ultimately though, individuals wishing to "transfer" our results to a different context are responsible for making their judgment regarding how sensible the transfer is.

Conclusion and recommendations for future research and practice

This research has shown that spirituality is at least as important as other quality of life dimensions for people with IDD, and also has implications for the development and maintenance of social networks. Previous literature on the topic has been generally philosophical or autobiographical than empirical; our study thereby makes important contributions to the field. The following recommendations aim to expand this area of study and practice:

Recommendations:

Practice:

- Health and social care organizations should facilitate spiritual support to individuals with IDD to enhance their quality of life.

Research:

- The current findings should be used to adapt and enhance existing measures of spirituality to be more relevant to people with IDD.
- The link between spiritual/religious practices and social relationships should be researched more widely within the field of IDD, incorporating services operating from different religious backgrounds.

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TABLES

Table 1. Service users' (*n*=36) demographic data

	Adam's house	Greenleaves	Overall
Sample number	18	18	36
Gender			
Male	9	16	25
Female	9	2	11
Age			
Mean	48.72	45.28	47
Median	54.00	49.50	51.75
Range	21-71	23-67	21-71
ID condition			
Mild	2	7	9
Moderate	8	2	10
Severe	6	5	11
Profound	2	4	6

Note: (n=36) is the total number of participants

Table 2 ABS (short form) data for both services (*n*=36)

	Adam's House	Greenleaves	Mann-Whitney U test
ABS Factor A: Personal self-sufficiency			
Mean	23.61	25.28	U=191.500 p=0.355
Median	26.00	30.50	
Range	0-33	10-33	
ABS Factor B: Community self-sufficiency			
Mean	22.00	28.67	U=214.500 p=0.097
Median	25.50	34.50	
Range	2-41	4-47	

ABS Factor C: Personal –social responsibility				
Mean	19.56	18.89	U=154.500 p=0.815	
Median	21.00	19.50		
Range	3-27	4-28		

Note: The two samples presented here generally show lower average levels of adaptive behaviour than the normative sample.

Table 3. Service users' (*n*=36) SBI-15R scores

	Adam's House	Greenleaves	Mann-Whitney U test	Raw effect size (r)
Beliefs & Practices				
Mean	21.22	11.28	U=69.000	-0.49
Median	20.50	8.00	p=0.003**	
Range	6-30	0-29		
Support from spiritual				
community	10.56	5.83		
Mean	11.00	4.50	U=69.000	-0.49
Media	5-15	0-14	p=0.003**	
Range				

Note: **Significant at the 0.05 level; (n=36) is the total number of participants

Table 4. Service users' (*n*=36) Social Network Guide

	Adam's House	Greenleaves	Mann-Whitney U test	Raw effect size (r)
Social Network Size				
Mean	78.00	44.06	U=19.500 p=0.000**	-0.75
Median	69.00	43.50		
Range	56-135	21-66		

Note: **Significant at the 0.05 level; (n=36) is the total number of participants