

Intellectual and Developmental Disabilities, Spirituality and Religion: A systematic review 1990-2015.

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Abstract

Over the past two decades research on religion/spirituality has begun to gain momentum. Nevertheless, to our knowledge, a systematic review of empirical research in the field of intellectual and developmental disabilities (IDD), social care services, and spirituality has not been carried out in the last 20 years. Six psychology, IDD, religion, and health related journals were searched in addition to two data bases. Published empirical papers on religion, religiosity, spirituality, spiritual and/or religious care and people with IDD and related terms between 1990 and 2015 were identified and examined. Of the 57 publications identified, only 8.9% met the inclusion criteria and were reviewed. The five empirical papers included in this review were thematically analysed, yielding four main themes in relation to spiritual/religious care: ‘understanding of spiritual/religious concepts’; ‘support to participate in spiritual/religious activities’; ‘spiritual/religious practices in relation to self-identity’; and ‘barriers to spiritual/religious care provision’. This paper concludes that more empirical and original research in relation to the spiritual care of people with IDD residing in IDD care services is needed.

Keywords: Systematic review, Spirituality, Religion, Spiritual Care, Intellectual and Developmental Disabilities

Introduction

The terms spirituality and religion are often used interchangeably to mean the same thing (Zinnbauer et al., 1997). The phenomenon can become complex though, since many social scientists argue that the two concepts are different (Poston & Turnbull, 2004; Zinnbauer, Pargament, & Scott, 1999; Canda, & Furman, 2010 p. 59, 74-75; Forrester-Jones et al. submitted). 'Religion' refers to social entities, differentiated by specific beliefs and practices, often requiring membership and characterised by additional non-spiritual aims (e.g., cultural, economic, political, social); whilst spirituality is understood more at an individual level (Miller & Thoresen, 2003).

Care should be taken when making distinctions between religion and spirituality (Hill et al., 2000; Reinert, & Koenig, 2013) for four reasons. Firstly, such polarization of concepts may neglect the fact that all forms of spiritual expression tend to take place in a social context, and all organized faith traditions are interested in personal affairs and spirituality (Pargament, 1999). Secondly, such distinctions can implicitly denote the simplistic and inaccurate view that spirituality is 'good' and religion is 'bad'. Thirdly, most people experience spirituality within an organized religious context and often do not perceive any differences between spirituality and religion (e.g., Zinnbauer et al., 1997; Forrester-Jones et al. submitted). Finally, such differences may lead to unnecessary duplication in concepts and measures, as some religious measures may cover both individual and institutional domains (Hill & Pargament, 2003).

It could therefore be argued that it is difficult to separate both concepts, which is perhaps why they are generally not distinguished in theory and research (Sinnott, 2002). This may also be due to the development of scientific and philosophical knowledge as well as historical events which continually affect society's perception of the Divine (see Hill et al., 2000). This includes the rise of secularisation and the growing disillusionment with religious institutions in western

20th and 21st century society as irrelevant or less socially useful (Davie, 2003). A recent example of secularisation is the emergence of the secular church in London, United Kingdom (UK), whose focus is on ‘doing good, living well and appreciating the wonder, and beauty of the world’ without belief in, or worship of the Divine. Nevertheless, although participation in organized religion in Europe may have decreased, there has been little decline in human interest in spirituality or religion.

Many individuals argue that they are spiritual but not religious; choosing their own constructed belief systems and participating in communal activities often to advance their personal agenda or support religious institutions (Taylor, 2007). Religion, religiosity, religiousness and spirituality may be used interchangeably at the individual level, since a person might describe themselves as being ‘religious’ by way of being devoted to a belief in a divine or supernatural power, and/or practice of worship or other rituals directed towards such a power and/or by having an allegiance to religious principles/teachings (see Argyle and Beit-Hallahmi, 1975, p. 1; Vaughan, 1991, p. 105; Freitas, 2015). Although spirituality may be defined in relation to religion, religion may or may not be rooted in spirituality. Traditionally the term religion was used to refer to all aspects of human relationship to the Divine or transcendent; that which is greater than us “the source and goal of all human life and value” (Meissner, 1987, p. 119). More recently (e.g., Wulff, 1997; Dudley, 2016, p.1); the definition of religion has been narrowed to refer to traditional systems of beliefs, world religions and denominations such as Christianity, Judaism, Islam, Hinduism, and so on.

Although not all conceptions of spirituality are associated with religion, all definitions of spirituality tend to include, but are not limited to, religious beliefs. In this paper, a multidimensional approach, informed by the religion/spirituality literature (see Hill et al., 2000; Sango, 2016; Sango, & Forrester-Jones, 2014; Forrester-Jones et al. submitted) is used to define spirituality as the belief in supernatural phenomena. This multidimensional approach consists

of three dimensions: transcendence (i.e., divine or supernatural existence), connection/relationship (with self, others, nature and the supernatural), and meaning and purpose (i.e., making sense of one's life, striving for answers). These dimensions are rooted in either one of two categorical aspects of spirituality which are 'religious spirituality' and 'non-religious spirituality'. The first includes the social practice/expression of one's belief in the supernatural (e.g., church attendance, worship or prayer etc). The second is an adherence to the belief in the supernatural without socially practicing such belief (e.g., not engaging in or observing religious practices etc).

Spirituality is increasingly being seen as an important aspect of holistic practice and person-centred care (Potter, 2002) and features as a variable in both general quality of life measures (e.g., World Health Organisation Quality of life Group, 1998), as well as those relevant specifically to people with Intellectual and Developmental Disabilities (IDD) (see van Loon, Claes, Mostert, Schalock & van Hove, 2015). Studies have shown however that the religious/spiritual aspects of the lives of people with IDD tend to be ignored in care services, either because support workers do not acknowledge the need for spiritual care, or feel unprepared to constructively deal with spiritual needs (Foster, 2000). It has been suggested that spirituality in general and for people with IDD in particular can create environments in which individuals feel accepted and experience self-worth (Vanier, 2000 in Swinton, 2002). Spiritual belief and practice has also been shown to help people with IDD overcome feelings of stigma, low self-esteem and social isolation (Stiemke, 1994), suggesting that spirituality and spiritual/religious activities can be a powerful source of social and psychological support (McNair & Leguti, 2000; Culliford, 2002).

A literature search of the previous twenty years yielded no systematic reviews of empirical research on spirituality/religion and IDD. We found an interesting paper by Ault in 2010, but

this related to spirituality/religion in relation to special education. Other systematic or meta-analysis reviews of spirituality/religion have concentrated on samples of people with mental health difficulties (Bonelli & Koenig, 2013; Barskova, & Oesterreich, 2009), cancer (Thune-Boyle, Stygall, Keshtgar, & Newman, 2006), and other health conditions (McCullough, Hoyt, Larson, Koenig, & Thoresen, 2000; Powell, Shahabi, & Thoresen, 2003). There may be several reasons for this gap in the literature Swinton (2001) and Sango and Forrester-Jones (submitted) have argued that carers may perceive spiritual care of people with IDD as non-essential compared with physical care. In the UK, this perception is unlikely to change given the evident policy gap of this area (see a literature review by Sango & Forrester-Jones, 2014 identifying gaps in UK policy and government direction on spirituality/religion and vulnerable adults). Religion/spirituality as a phenomenon has also traditionally been under researched within health and social care (Bergin, 1991; Hill & Pargament, 2008) perhaps because of the complexity or ‘fuzziness’ of the topic (Selway & Ashman, 1998; Forrester-Jones et al. submitted; Sango and Forrester-Jones 2014) or due to the belief amongst academics that religion and spirituality have receded in a more secularised age, despite evidence to the contrary (e.g., Bradley, 1992; Davie 1994; Hill et al., 2000). The aim of this review is to identify, describe and thematically synthesize the available empirical literature on the spiritual care of individuals in IDD social care services.

Method

Design

A systematic literature review was undertaken following the principles of Gough, Oliver and Thomas (2012), Bonelli and Koenig, (2013), and Lazaridou, Philbrook, and Tzika, (2013) who all advocate a structured process as outlined below:

Systematic search

The search stage began by accessing six on-line journals specifically relevant to the topic: Journal of Applied Research in ID (Vol3(1)-Vol 28(6) 1990-2015); Journal of Intellectual Disability Research (Vol34(1)-Vol 59(12) 1990-2015); British Journal of Intellectual Disabilities (Vol18(1)-Vol 43(4) 1990-2015); Health and Social Care in the Community (Vol1(1)-Vol23(6) 1993-2015); Journal of Disability and Religion (Vol1(1)-Vol 19(4) 1990-2015); and two search engines: PsycINFO; and SCOPUS. The journals were selected because they are known as the main national and international journals for including research on IDD. The search engines were chosen as sources which would most likely identify empirical articles not already found in the specific journals. Searches using the first five on-line journals utilised the 'advanced search' function, via the University's authorised access platform allowing for year of publication to be specified and key terms to be entered. The sixth journal (Journal of Disability & Religion) did not have an 'advanced search' function yet the general 'search' function was appropriate since the journal's first volume started in 1994. The search strategy for the identification of relevant articles consisted of using keywords related to spirituality/religion, and QOL, combined with IDD or related terms, as shown in the list below:

1. Learning Disab* OR Intellectual Disab* OR Mental* Retard*
2. Spiritu* OR Religio*
3. Numbers 1 and 2; vice versa
4. QOL OR Health OR Wellbeing (well-being)

5. Spiritual care OR religious care

The key words listed in numbers 2, 4 and 5 were all combined separately with those listed in number 1 (e.g., ‘numbers 1, 2 AND 4’ or ‘numbers 5 AND 1’). The terms used for spirituality were based on Bonelli and Koenig’s (2013) systematic review on mental disorders, religion and spirituality 1990-2010. Thus, the search term “religio” signified religion, religiosity, and religiousness, and “spiritu” referred to spiritual and spirituality. Similar key terms for spirituality and religion were used in Shaw, Joseph and Linley’s (2005) systematic review on religion, spirituality, and post-traumatic growth. Many of the papers found used spirituality and religion simultaneously as postulated by Hill & Pargament, (2008). The reference lists at the end of potentially relevant papers were also followed up. Saturation was reached when adding other keywords or further searching of the journals and databases produced no additional potentially relevant papers.

The next stage in the review process was to identify relevant papers to the topic of spiritual care and IDD in social care settings. To this end, the following inclusion and exclusion criteria were employed:

Inclusion criteria:

1. Type of study: published quantitative and/or qualitative primary research addressing spirituality/religion/spiritual care, IDD, QOL/health/well-being of people with IDD.
2. Publication dates: from 1990 to 2015, in order to review the most current literature (See Swinton, 2001 for details on a general literature review between 1990-2000).
3. Language: written in English
4. Sample: 18 years of age and over; individuals with IDD residing in any social care setting (i.e., faith or non-faith based/private/public) and/or support staff of people

with IDD. Rationale for sample and setting: to gather empirical research on the spiritual care of, and spiritual support, if any, provided by professional care staff to individuals with IDD in IDD social care services

Exclusion criteria- articles were excluded if they were:

1. non-empirical and unpublished
2. pre-1990
3. not written in English
4. carried out with individuals under 18, with and/or without IDD; not involving social care service settings, research only involving families of children with IDD

Screening of the literature

Following the method set out in the 'systematic search' section; the titles of each article found in the journals and databases were reviewed. Papers (a total of 22 articles from the journal search and 19 from the wider, database search) were initially identified as potentially relevant if the article title indicated a potential focus on spirituality/religion and people with IDD. The abstracts, main documents and reference lists of all 41 papers were skim-read. Sixteen additional articles were identified from the reference lists of the 41 articles as potentially relevant and were also skim-read. Of the 57 articles, 52 were excluded: 5 were duplicates; 7 had reported on ageing and end-of-life care specifically; 6 had used participants who were under 18 years old; and 12 did not include people with IDD and/or support staff, or included children with IDD and their families' perspectives about coping with having a child with disability. Other excluded papers were theoretical or conceptual rather than empirical (n=22). A total of five empirical articles therefore met the inclusion criteria to be reviewed (see Table 1). Our search outcome appears to have confirmed Swinton's (2001) more general literature

review on spirituality and IDD (from 1990 to 2000), similarly finding very few empirical studies on spirituality and IDD.

Appraisal of included studies

We based our appraisal of the five papers on the Critical Appraisal Skills Programme (<http://www.casp-uk.net>) which helps researchers to evaluate existing studies through comparison, and make judgements about the reliability, validity and relevance of their findings in a particular social context. The methodological quality of the included studies was variable (see Table 1). In some cases, there was no clear evidence of the number of participants utilised and although all of the five studies are heavily qualitative, only one (i.e., Shogren & Rye, 2005) measured participants' religiosity/spirituality. None of the studies used any conceptual framework. All of the included studies clearly stated their research aims. All of the studies also outlined research methods used, which appeared to be relevant for addressing the research aims. Three of the studies (i.e., Narayanasamy, Gates & Swinton, 2002; Turner et al., 2004; Swinton, 2002) did not state that they had received favourable ethical opinions, despite the fact that they were published in peer reviewed journals which state that they require authors to confirm approval from appropriate ethical committees. Given the increased scrutiny that funding bodies, higher education institutions, academic and practice based journals as well as health and social care providers are applying to ethical practices, it is reasonable to assume that ethical approvals were in place for all of the studies. Alternatively, most of the papers were published before recent calls (in the last few years) for more rigorous ethical considerations when researching people with IDD (and research on humans in general) (Forrester-Jones, Palmer & Izquierdo, 2016), so this might also explain the omissions. All but one of the studies (i.e., Swinton, 2002) did not clearly describe the data analysis process, yet all clearly presented and discussed their findings in relation to future research and/or practice and/or policy. Discussions on validity and reliability of the findings were mostly discussed by Minton &

Dodder (2003). Explanations for the lack of such discussions in the other studies might include the fact that issues of inter-rater reliability, sample selection/ randomization, and blinding are not necessarily relevant to the qualitative paradigm (see Katrak et al., 2004). Overall then, it was concluded that all five studies were relevant and valuable.

Data extraction and synthesis

Information relating to aim of study, sample, study design/data collection, and research setting were extracted from each included paper and their main findings summarised. The five empirical studies were analysed in terms of the contexts in which spirituality and/or religion were provided for people with IDD. Gough et al.'s (2012) and Thomas and Harden's (2008) three stages of thematic analysis were followed as described below:

- 1) The five articles that met the inclusion criteria were printed out and manually analysed by free' line-by-line coding using different coloured pens for different meanings and content of the text.
- 2) The 'free codes' were then categorised to construct 'descriptive' themes.
- 3) 'Analytical themes' were developed by moving 'beyond the content' of the original studies and using descriptions that emerged from the empirical findings.

Thematic synthesis was found to be appropriate for the current review since it enabled prominent themes to be unearthed inductively (Gough et al., 2012). Information extracted from the included documents is summarised in Table 1.

Findings

PLEASE INSERT TABLE 1. SELECTED STUDIES

Data description

The total study sample (n=137) across the reviewed papers included 95 people with IDD, 35 members of staff (4 of which were managers), 3 family members and 6 church leaders (see Table 1 for more study characteristics). One study (i.e., Swinton, 2002) was unclear as to their sample. Four of the studies (i.e., Swinton, 2002; Minton & Dodder, 2003; Turner et al., 2004; Shogren & Rye, 2005) directly involved participants with IDD, and one study consisted of IDD nurses (i.e., Narayanasamy, Gates & Swinton, 2002). All of the studies collected supplementary data from participants' families and support staff as well as church representatives (e.g. chaplains). All of the studies took place in social care and/or community care like settings such as group homes, supported living or day centres. Three of the studies were located in the UK, the remaining two were carried out in the USA. All were published between 2002 and 2005. Four of the studies used qualitative methods such as interviews, focus group and observation, and one, (Shogren & Rye, 2005) employed mixed-methods. Four main themes from the included papers were identified: 'understanding of spiritual/religious concepts'; 'support to participate in spiritual/religious activities'; 'spiritual/religious practices in relation to self-identity'; and 'barriers to spiritual/religious care provision'.

Theme I. Understanding of spiritual/religious concepts

Contrary to the conceived wisdom that people with IDD cannot understand spiritual/religious concepts (see McNair & Smith, 1998) Turner et al. (2004) and Shogren and Rye (2005) reported that their participants with IDD expressed a strong and clear sense of religious/spiritual identity. Study participants described their faith; were able to differentiate

their beliefs from other faiths and had appeared to have clear conceptions of religion; for example, some participants with IDD in Turner et al.'s (2004) study reported "I am a Catholic" and "It's a Catholic church", and "Protestant, I'm a Protestant". Others were able to identify symbols representing their beliefs, including the concept of God. Turner et al. (2004) also reported that the concept of prayer was almost universally understood, with only one service user not demonstrating any understanding of it. These findings indicate that complicated religious/spiritual notions should not prevent staff from supporting people with IDD to explore the spiritual aspects of their lives (Shogren & Rye, 2005).

Theme II. Support to participate in spiritual/religious activities

Three of the five studies (see Table 1) provided evidence regarding how service providers/staff provided spiritual/religious support to people with IDD. This mainly took the form of helping individuals to attend church services; the most frequent activities service users participated in after watching television, riding the bus, eating out, watching videos and listening to music. In Shogren and Rye's (2005) study, 76% of the 41 participants with IDD reported that they attended worship services, just under half (49%) attending on a weekly basis. Minton and Dodder (2003) also highlighted support for church attendance, stating that participants were 'always eager to attend', waking up early (i.e., 7 am) on Sunday mornings to leave at 9.00 am for the church service. Turner et al. (2004) also reported that participants engaged in a variety of religious practices including prayer.

Theme III. Spiritual/religious practices in relation to self-identity

This theme, which was interrelated with theme II referred to the importance of spiritual/religious practices to expressions of individual identity (e.g. Tuner et al., 2004). Involvement in spiritual/religious activities appeared to improve participants' reported quality

of life, providing opportunities for friendships through church attendance etc. Such relationships, embedded within spiritual/religious contexts, helped participants to find meaning to their lives and cope with life stressors such as the death of a parent (see Swinton, 2002; Turner et al., 2004). Participants also reported the importance of the Catholic doctrine of being able to pray for their deceased parents (Turner et al. 2004) and in Shogren and Rye (2005), prayer was related to increased positive affect and spiritual and psychological well-being. For some participants, prayer was practiced individually and informally, whilst for others, more corporate formal prayer was the norm (see Turner et al., 2004). Swinton (2002) further reported that belief in God or a higher power gave people with IDD a sense of security, love and acceptance.

Participants also reported feelings of personal fulfilment through participating in religious services, especially when provided with the opportunity to engage in worship activities through reading of scriptures and singing to God (Turner et al., 2004). This was corroborated by positive staff perceptions of service users enjoying participating in church activities (e.g., church summer camp) (Minton & Dodder, 2003). Service providers also suggested that participation in religious/spiritual activities helped people with IDD to understand moral issues such as distinguishing between right and wrong, and to remain calm in stressful situations (Shogren & Rye, 2005).

Participating in activities with church congregations also acted as a conduit to social support for people with IDD (Swinton, 2002). Church was viewed by individuals with IDD as a place where they were welcomed, recognized, and where they gained a sense of belonging (Minton & Dodder, 2003). Additional outcomes of such involvement included phone calls (Minton & Dodder, 2003; Swinton, 2002) and home visits from church members (Turner et al., 2004). Friendships made in church helped individuals with IDD to add and develop spiritual aspects to their lives, such as hope, meaning, purpose, value, relatedness and self-transcendence

(Swinton, 2002).

Theme IV. Barriers to spiritual/religious care provision

All five studies provided examples of barriers to staff providing spiritual/religious care. Although individuals with IDD enjoyed visits from church ministers, this excitement was tempered by the disappointment felt by participants who expressed a desire for phone calls and visits from the wider church congregation, some of whom held 'uncomfortable' attitudes towards people with IDD according to staff in Minton and Dodder's study. Here it was reported that some members of the congregation could react strongly to people with IDD who were deemed to be exhibiting so-called 'disruptive behaviour' (e.g., refusing to sit in assigned pews during church services, interrupting 'sunday school'/class sessions, or 'smelling' or wearing 'wrinkled clothes'). Such difficulties were confounded by the fact that staff would tend to leave service users in 'sunday classes' only to be supervised by untrained church members; apparently due to staff shortages during weekend shifts (Minton & Dodder, 2003). A lack of support by both parties (church and social care providers) sometimes led to congregations dealing with 'misdemeanours' of service users by telephoning staff to remove individuals from the church. Whilst these church reactions illustrate ignorance of IDD, as well as attitudes which clearly do not align to Christian doctrines of love and acceptance, they also signal a lack of staff support and training regarding expected normative social skills in church settings (Minton & Dodder, 2003).

Accessing transport and availability of staff to accompany individuals to places of worship could also be an inhibiting factor for supporting the spiritual needs of people with IDD (Shogren & Rye 2005). Underlining such structural issues appeared to be a lack of consideration by service providers and staff as to the importance of spirituality, and how their caring role might include support for this area of life (Swinton, 2002). Perhaps as a result of

training which had been devoid of spiritual care, some staff did not think of spirituality as relevant to their work role. Rather it was left to support workers who were individually spiritual or religiously oriented to help service users to express their own spirituality (Swinton, 2002; Narayanasamy et al. 2002).

Narayanasamy et al., (2002), who argued that such understanding is crucial for an effective provision of spiritual care, found that nurses who had a personal approach to spirituality (i.e., emotional feelings, the need to search for meaning and purpose; creating space, spending time with 'patients', showing them love and respect), were more likely to provide spiritual care, while those who had a procedural approach to spiritual care (i.e., acknowledgement of 'patients' expression of religious beliefs and practices), tended to address spiritual needs as religious in nature (e.g., whether they are 'Christian' or 'Muslim' or 'Jewish' etc). Turner et al. (2004) found that although some service users expressed wanting more religious/spiritual activities to take place at their residence, care services tended to be indifferent to such requests, some even showing hostility to service users expressing an interest in religion. Where this was the case, the only religious festival celebrated was Christmas, which was celebrated in a secular, rather than religious manner (Turner et al., 2004).

Shogren and Rye (2005) and Turner et al. (2004) also noted lack of awareness as to how religious congregations should and could efficiently accommodate people with IDD in church activities. This made participation difficult for both parties, and both studies found little evidence of religious organizations and communities fully including people with IDD into places of worship by, for example giving them a valued role or encouraging them to join church-related groups. At least in Minton and Dodder's (2003) study, individuals with IDD did participate in 'sunday class' activities (i.e., by singing hymns, reading out gospel stories etc).

Discussion

In line with the current review's inclusion and exclusion criteria, only five empirical studies (see Table 1) were relevant in relation to the provision of spiritual/religious care provided for people with IDD residing in social care services. Four themes were delineated from the five studies. The first theme described service users' understanding of spiritual/religious concepts; the second illustrated how the spiritual/religious care of service users occurred through support to participate in religious/spiritual activities; and the third portrayed the importance of spiritual/religious activities and practices for spiritual identity of people with IDD. The final theme concerned barriers to spiritual/religious care provision. These findings indicate the importance of participation in religious activities for enabling individuals with IDD to find meaning to their lives, derive value from a sense of connectedness and belonging, and cope with life challenges, such as the death of loved ones. Spiritual/religious activities also facilitated friendship relationships which in turn, enhanced their spiritual lives (Swinton, 2002).

Our synthesis also demonstrated how abstract spiritual/religious concepts are not the prerogative of ordinary populations. Rather, some people with IDD (e.g., Turner et al., 2004) can understand and explain their own faith/belief when supported to do so.

Nevertheless, Minton and Dodder (2003) observed a lack of deeper relationships between service users and church members, ascribing this to general negative attitudes towards people with IDD. The fact that in the UK, church members need to be checked by the Criminal Record Bureau prior to having personal contact with vulnerable adults may only further preclude the establishment of meaningful social contacts and relationships. That Minton and Dodder (2003) also found people with IDD being sent home from church services due to their bad odour or wrinkled clothes further highlights a lack of sensitivity and, arguably a fault of church congregations who are supposed to welcome anyone into the fold. This demonstrates that on the one hand, more needs to be done by service providers/staff to prepare residents to

attend church services in order to avoid stigmatization and enable ‘belongingness’, and on the other hand, churches may need to reassess and widen their approach to equality and diversity to try to understand intellectual as well as physical disability in relation to spirituality. It appears that empirical research into congregational attitudes towards disability as well as the church-service provider relationship is only just beginning to take place (Waldock & Forrester-Jones in preparation).

Barriers to spiritual care also related to shortages of resources including staff and transport (Minton & Dodder, 2003; Shogren & Rye, 2005). Such issues can be overcome with appropriate service plans (Mansell & Kent, 2013) and effective person-centred planning (PCP) (Mansell & Beadle-Brown, 2004; Sanderson, 2000) via which spiritual/religious dimensions of the lives of people with IDD could be identified and acted upon. Evidence (e.g., Ratti et al., 2016) indicates that PCP might have a positive effect on the lives of people with IDD, particularly community participation and participation in daily choice making and activities. Moreover, studies comprising other forms of individualised planning which share some characteristics with PCP (e.g., individual programme plans in IDD services) appear to indicate that in practice individual planning only reaches a minority of service users (e.g., Felce et al., 1998; Holburn & Cea, 2007). Unfortunately, individual plans are often created only as paper exercises which are either not put into practice or not well associated with the real lives of people with IDD (Shaddock & Bramston, 1991; Menchetti & Garcia, 2003; Mansell & Beadle-Brown, 2004; Unwin, Tsimopoulou, Kroese, & Azmi, 2016).

Limitations, reflections and conclusion

To our knowledge this is the first, if not the only existing systematic review on the spiritual care of individuals residing in IDD care services. The following limitations ought to be acknowledged. This review did not include unpublished literature or theses, so relevant empirical studies may have been omitted. In terms of limitations of the systematic review,

screening and data extraction were performed by a single reviewer, which may have reduced the rigour of the review.

Notwithstanding the above limitations; this review presents valuable insights into the spiritual/religious care of people with IDD residing in IDD care services, and how this potentially impacts on the lives of individuals. The review also illustrates the potential barriers to spiritual/religious care and how these might be overcome.

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