

# *Spirituality and the Lives of People with Learning Disabilities*

## ABSTRACT

*The spirituality of people with learning disabilities is under-researched and frequently misunderstood. Despite evidence to suggest that a focus on the spiritual aspect of the lives of people with learning disabilities can be health-bringing and life-enhancing, this dimension of people's lives is often overlooked or considered irrelevant. This paper seeks to explore some significant aspects of the 'forgotten dimension' of spirituality and to show that both the available research evidence and the experiences of people with learning disabilities suggest that it is an aspect of life which should be taken seriously. Neglect of this dimension has significant moral, legal and interpersonal consequences, which service providers are often unaware of but which are central to genuinely person-centred and holistic support. The paper offers some insights and pointers that will enable service providers to begin to understand and incorporate spirituality into the lives of people with learning disabilities.*

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## SPIRITUALITY: THE MISSING DIMENSION?

People with learning disabilities have been the focus of much quantitative, medical, educational and rehabilitation research and they have generally been the **objects** of the research process, which centres on the perceived problem (Rioux & Bach, 1994). Until relatively recently, very little research has examined the goals, meanings and life experiences of people with learning disabilities, and there remain areas where there is a shortage of descriptive, first-hand information that service providers can draw on as they seek to work out effective forms of care and support. One dimension of the experience of people

with learning disabilities that has been significantly under-researched is **spirituality** and the ways in which it affects lives and expectations. This is despite evidence that the spiritual dimension of people with learning disabilities is important and potentially health-bringing (McNair & Smith, 1998).

## SPIRITUALITY AND HEALTH

There is a body of literature from health and social care which suggests that spirituality is a basic human need and, some would argue, a human right (Foster, 2000; Curtis, 2001), and is a necessary component of both mental and physical health. This literature presents empirical evidence pointing towards a positive correlation between spirituality, health and well-being (Koenig, 1997; Larson *et al.*, 1997; Swinton, 2001). Increasingly, spirituality is being seen as a vital dimension of holistic practice and person-centred care. In parallel, the official

documents from a number of caring professions and governmental organisations indicate that recognising and effectively incorporating the spiritual needs of service users should be seen as a priority (the UKCC's *Code of Professional Conduct*, 1992; NAHAT, 1996; DoH, 1993). Clearly, therefore, spirituality is an important, if often overlooked, dimension of health and well-being and as such provides a potentially valuable resource.

## SPIRITUALITY AND PEOPLE WITH LEARNING DISABILITIES

While there appear to be potential benefits in including spirituality in caring and support strategies, there is also evidence to suggest that this dimension of people's lives is being ignored. Carers and support workers frequently fail to recognise spirituality, and when it is noticed they may feel unprepared to deal with it in constructive ways (Oldnall, 1996; Foster, 2000). Consequently, people with learning disabilities risk being starved of the opportunity to make informed spiritual choices which have the potential to benefit their quality of life. In the light of recent legislation (eg the *Human Rights Act, 1998* and the *Disability Discrimination Act, 1995*), this could have significant implications for service providers. If spirituality is indeed a basic human need, and if people have a right to express their spirituality in appropriate ways, then exclusion from necessary means of spiritual fulfilment has serious implications, making spiritual care a basic moral and legal obligation, rather than an option for service providers.

## A GAP IN OUR KNOWLEDGE

It might consequently be expected that there is a good deal of research evidence to draw on. Yet little research has been done which has sought to explore the ways in which people with learning disabilities experience their spiritual lives, express their spiritual needs and seek to nurture their own spirituality. This is not because a focus on spirituality is irrelevant to their lives, as what evidence there is suggests that it may be highly relevant (Balkizas &

O'Hare, 1994; McNair & Smith, 1998; McNair & Leguti, 2000; Bassett *et al*, 1994). Indeed, there is evidence that the spirituality of people with learning disabilities can be a powerful source of social and **psychological support** – particularly if the person is involved with a religious or spiritual community (McNair & Leguti, 2000; McNair & Smith, 1998); **meaning making** (Gaventa, 1993); **friendship** (Swinton, 1999; Gaventa, 1993); **acceptance** and **self-worth** (Vanier, 2000). As such it may well hold the potential to be highly beneficial in overcoming stigma, social isolation, low self-esteem, hopelessness and loneliness, all of which form a significant aspect of the lives of many people with learning disabilities (Stiemke, 1994).

## THE RESEARCH PROJECT

It was against this backdrop that in the summer of 2000 the Foundation for People with Learning Disabilities (with funding from the Shirley Foundation), commissioned John Swinton (University of Aberdeen) to carry out a feasibility study designed to take some initial soundings about the role of spirituality in the lives of people with learning disabilities. Rather than formal research, the study was meant as an information-gathering exercise that could provide pointers and insights, which might feed into wider, more substantial research.

The feasibility study comprised two aspects: a ten-year retrospective literature search of works exploring spirituality and learning disability (from 1990 to 2000) and a series of individual and focus group interviews with people with learning disabilities, support workers, service providers and representatives from religious, humanist and spiritual traditions at various locations (Scotland and England). The information was recorded via notes and audio and video recordings which were later transcribed and reflected on thematically. The findings of the study threw up some fascinating insights into the role of spirituality in the lives of people with learning disabilities (Swinton, 2002). Here we reflect on five central points which emerged from the study.

## Spirituality is not just religion

Evidence suggests that one of the reasons many professionals are wary of incorporating spirituality into their practice is that they assume spirituality and religion to be synonymous (Swinton, 2001). Some are wary of religion and the possibility that unhelpful morals and values might be imposed upon a group of people who may be particularly vulnerable to certain forms of psychological manipulation. Others feel that religion may be appropriate for 'religious people', but that it bears little relevance for the majority of service users, whom they perceive as having no religious beliefs. Thus spirituality may be rejected as a potential resource for caring for spiritual needs, the assumption being that this area of care and support is the domain of the 'religious specialist' (the chaplain, priest, imam and so forth).

However, both the literature and the life experiences of the people with learning disabilities who participated in this study suggest that the equation of spirituality with religion is neither necessary nor particularly helpful. Certainly some people will choose to work out their spirituality within a religious framework, but for others their spirituality is manifested in different ways which need not include a specifically religious dimension. In order to understand this, it is necessary to make a provisional definition of spirituality. At its most basic, human spirituality contains three primary components:

- the need to find **meaning, purpose** and fulfilment ... in life, suffering and death
- the need for **hope**/will to live
- the need for **belief** and **faith** in self, others and God (Renetzky, in Ross, 1994).

For some, the narratives, rituals, community and purpose of religions and religious communities provide an effective context within which they can work out their spirituality. However, for others, the quest for 'something beyond' will be worked out in other ways - through relationships, family, work and so forth. **Religion is thus an expression of human spirituality, but not the definition of it.**

This being so, spirituality is something that has relevance to the care of all people, and not only those with an overt religious commitment.

## Carers and support workers

Discussions with various service providers indicated that the importance of spirituality was not always recognised by carers and support workers. While some were obviously tuned into the issues, when asked about the relevance of spirituality some responded that it was something they had never really thought about or that it bore little or no relevance to their daily practice. It was not something that had been part of their training and, unless they happened to be particularly religiously or spiritually oriented themselves, it was not an issue that fell within their worldview. The main difficulties people seemed to encounter can be summarised under four main points (**Box 1**).

## People with learning disabilities

In contrast, the majority of people with learning disabilities who took part in the study expressed a deep spirituality. Some expressed this in specifically religious terms. For them, the belief in God or a higher power gave them security and a sense of acceptance.

*'God loves me and he looks after me, even when I am bad.'*

It also helped them to feel loved, guided and protected.

*'He's helped me get through life and what goes on in my flat. He helps me go out, get food, go to the market. He helps me in all of these things.'*

The idea that God cares for people and is an ever-present source of comfort, protection and hope was a primary theme that ran through many of the responses.

*'[God] helps you understand why things go wrong'; 'gives you something to look forward to'; 'gives you friends'; 'looks after my family when they are sick.'*

From listening to people's responses, it was clear that the idea of God provided a framework within

## Box 1

## DIFFICULTIES IN DEALING WITH SPIRITUALITY

- **The question was not on the agenda**

For many service providers, the relevance of spirituality was not clear and so it was simply not on their agenda, as they had developed in situations where it was never spoken about or considered relevant. Therefore, there was often no foundation of meaning to build on when the term 'spirituality' was introduced.

- **Implicit and explicit assumptions that spirituality is equated with religion and consequently only relevant to 'religious people'**

Referral appears to be the most common form of spiritual care.

- **Fear of religions imposing 'dangerous ideas' on vulnerable people**

Some expressed an understandable reservation about certain forms of religion which may be less than helpful to the lives of people with learning disabilities.

- **Lack of training or education in this area**

A number of support workers said they would like to look after this dimension of someone's experience, but felt ill-equipped to do so.

which they could make sense of the things that happened to them as well as their relationships with those who were close to them. Belief in God provided a significant source of comfort and a way of coping with and constructively understanding the complexities of life.

*'I don't need to worry too much when things go wrong. God watches over me... I suppose I trust him... He cares.'*

The danger of missing the significance of this aspect of people's lives is illustrated by Foster (2000), who tells the story of a colleague who failed to recognise this.

*A learning disabled friend of mine was recently unable to attend church one Sunday morning*

*because a newly appointed carer would not take him, the carer claiming that he 'did not believe in that sort of thing'.*

Such attitudes indicate a serious lack of understanding of the spiritual dimensions of human beings and the meaning of spirituality in the lives of people with learning disabilities. 'Professional carers have a clear responsibility to provide for clients' needs on a holistic basis, irrespective of the carer's own beliefs and value systems.' If this is forgotten, care can become reductionistic and potentially oppressive.

### Spirituality and personal relationships

While some participants worked out their spirituality in relationship to God, others worked theirs out through personal relationships, in particular **friendships**. The importance of friendship as a significant spiritual relationship became clear during many of the interviews. Even those who experienced a relationship with God or a higher power tended to express that relationship in the language of friendship. Friendship was found to be a close meaningful relationship which enabled people to develop vital aspects of their spirituality – hope, meaning, purpose, value, relatedness and self-transcendence. When asked what made his life worth living, one young man with Down's syndrome responded that:

*'It's me and Elaine [his fiancée]... that's all I want from my life... to get married... get a house... be happy!'*

Although he did not have a specific belief in God or a higher power, he did have a strong sense that life had purpose and meaning, as long as he was secure in his relationship with his girlfriend.

### God as friend

People's understanding of God was most often expressed in the language of friendship. People tended to refer to God in human-like terms as 'a friend', 'me mate', 'a good man', 'the gaffer'. In other words, God was drawn into their circle of friends and understood and treated in a similar way.

In this sense God became a natural extension of everyday social relationships and a vital form of social support. This is an important observation. It is clearly inappropriate to discard a person's beliefs as unimportant or something that stands apart from the central process of support and care. Indeed, the experience of the participants in this study suggests that their belief structures are a central part of their social support system and a vital resource in understanding and coping with the complexities of life. While service providers may not share a person's beliefs, it is vital that they are in a position where they can at least understand, acknowledge and respect them.

### **The significance of religious communities**

Religious communities can provide a vital context for the types of friendship and spiritual development previously highlighted as beneficial for the spiritual care and development of people with learning disabilities. Religious communities can bring together disparate groups of people and instigate forms of integration and community which may be missing from wider society. Over all there is evidence that:

*[t]he quality of life of people with developmental disabilities may be related to whether they are identified as members of networks and associations in the community. Individuals who are seen as members gain opportunities to participate in significant social roles and to form personal relationships through ongoing transactions (McNair, 1997).*

However, religious communities can be problematic, and there is evidence that religious communities can be as exclusive and excluding as wider society. As McNair and Smith (1998) observe, 'One barrier to the integration of individuals with disabilities in the local church may be the churches themselves'. For example, the assumption within certain religious traditions that spirituality is cognitively based and demands intellectual assent to certain verbal formulations can serve to exclude people with learning disabilities, not because they are less spiritual, but because spirituality is defined in such a

way as to exclude them. There is evidence that people with learning disabilities have been prevented from participating in vital dimensions of religious life such as the sacraments (Webb-Mitchell, 1996) and the Jewish Bar Mitzvah (Riordan & Vasa, 1991) on the grounds that a perceived lack of intellect somehow defiles the sanctity of such rituals. This is clearly unacceptable, and although religious communities may have great potential for fulfilling the spiritual needs of people with learning disabilities, in practice complex internal dynamics need to be recognised and reflected on if the spiritual needs of people with learning disabilities are to be met in meaningful and re-humanising ways.

### **Spirituality and social justice**

The connection between spirituality and social justice is potentially strong. Lisa Curtis (2001) argues that people with learning disabilities have been socially marginalised and that their opportunities for employment and income have been seriously compromised.

*As a result their quality of life is significantly poorer than many others in the community and striving to achieve full social citizenship for people with learning disabilities is therefore a question of equity and social justice.*

She highlights the ways in which people with learning disabilities are oppressed and marginalised within contemporary British society, deprived of employment opportunities, their status as adults, their sexuality, and spiritual deprivation and oppression. Such oppression may manifest itself in a number of ways (**Box 2**, below).

Curtis suggests that refusing to recognise people with learning disabilities as spiritual beings may be the latest frontier to be crossed in their emancipation, and calls for a radical programme of education for carers and religious communities which will facilitate the raising of people's consciousness to the significance of spirituality.

The critical, socio-political dimension to spiritual care is significant, and mirrors similar developments within the wider area of disability

**Box 2** MANIFESTATIONS OF OPPRESSION

- Communicational barriers prevent carers and others from exploring the emotional and spiritual aspects of the lives of people with learning disabilities
- Assumptions that spirituality and ideas about God require a high level of abstract thinking, leading to decisions on the cognitive 'threshold' for church membership
- A painful legacy within certain strands of theology which equate disability with sin, leading to blame, exclusion and alienation
- Suspicion of the value base of religion
- A general unwillingness to address spiritual issues, which is indicative of a wider failure to address emotional needs

studies (Oliver, 1990). It is an important dimension in that it highlights that, while interpersonal endeavours may be useful in offering spiritual care to people with learning disabilities, unless there are some fundamental changes in the structures of both society and religious communities, spiritual care will be at best lacking and at worst inappropriate and oppressive.

## CONCLUSION

The feasibility study highlighted some fascinating insights into the potential benefits of spirituality for the lives of people with learning disabilities. The findings are **indicative** rather than conclusive, and there remains a need for further research and reflection. To this end, the Foundation for People with Learning Disabilities has commissioned a two-year nation-wide study which is currently in progress, based in the School of Divinity and Religious Studies at the University of Aberdeen. It will use a participatory research methodology to explore the significance of spirituality for the lives of people with learning disabilities and develop educational strategies to meet the perceived gap in current provision.

Currently, we are standing at the edge of what may be a highly significant development in the care and support of people with learning disabilities. It will be both fascinating and challenging to see what happens when we begin to examine in detail this 'forgotten' dimension in the lives and experiences of people with learning disabilities. It is now vital that service providers begin to reflect sensitively and creatively on the implications of taking seriously the spiritual dimension of the lives of people with learning disabilities.

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