



Invited Commentary

Culture, Spirituality & Psychopathology: Personal reflections from clinical practice in intellectual disability psychiatry

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Abstract. *Approaching spiritual life or spiritual needs in people with intellectual disabilities has been usually deemed unnecessary, superfluous or inapplicable. The author expresses her point of view contradicting this position and highlighting how clinical practice with people with intellectual disability suggests a new and broader vision of the meaning of spirituality in human life.*

Keywords: Spirituality, Intellectual Disabilities, religiosity, well-being, normalization.

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What is spirituality? Narayanasamy (2006) considers it to be 'the essence of our being' giving 'meaning and purpose' to our existence. It is that aspect of human existence that gives it its 'humanness' (Swinton, 1999) and often it becomes more important at critical junctures in our lives when we face distress, emotional stress, physical illness, loss, bereavement or the approach of death (RCPsych, 2013). Spirituality is about validation; it shows that all human lives have purpose and are positively influencing other lives. Each human life matters – there are no exceptions and there is no hierarchy (Raji, 2009). Health, well-being and spirituality are interlinked in most people's lives.

What does it mean for people with intellectual disabilities (previously known as mental retardation or learning disabilities)? What does it mean to them when history and society as a whole have made considerable efforts to eradicate their existence?

I worked with a woman with moderate intellectual disabilities, Down Syndrome and an eating disorder. There were very complicated family dynamics and she required admission into hospital under the Mental Health Act. I worked with her as an inpatient and in the community and saw her through many life transitions. My most striking memory of her was when she came into my room one day wearing a t-shirt that read 'hug me'. She spoke then about her pain of knowing that there were antenatal tests available to prevent her birth, and that society routinely screened for this and offered terminations of pregnancy. She responded best to psychoanalytically informed music therapy (Heal & O'Hara, 1993).

The recent scandal of Winterbourne View Hospital in the UK (Department of Health, 2012), which saw the systematic abuse of people with intellectual disabilities and autism in an independent hospital

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that was meant to offer specialist assessment and treatment services, led to criminal proceedings and those involved prosecuted and found guilty of hate crimes. Yet this appalling abuse and neglect is not an isolated example (Cooper, 2012).

Some cultures hold that people with disability are of 'lesser value', considered 'undesirable' or even feared and different cultures deal with these attitudes in various ways. The lives of people with intellectual disabilities are more often filled with experiences of trauma, abuse, rejection and stigma, upon a societal, cultural and religious history that has perpetuated this.

The neglect and ill-treatment of people with intellectual disability probably exhibits one of the worst histories for any group in society (Sperlinger, 1997; O'Hara & Bouras, 2007). Western reactions have often been brutal. Those with intellectual disability have been killed, kept to entertain guests (a Roman practice that subsequently became common in the courts of European royalty), exhibited as freaks for profit, threatened with eradication and put at risk for the good of others (as in early trials of the measles vaccine). More compassionate views, tempered with pity, horror and contempt, prevailed through the 19th century, with Western attempts to provide institutional treatment and training.

'The feeble-minded are a parasitic, predatory class, never capable of self-support or of managing their own affairs. (...) We have only begun to understand the importance of feeble-mindedness as a factor in the causation of pauperism, crime and other social problems. (...) Every feeble-minded person, especially the high grade imbecile, is a potential criminal, needing only the proper environment and opportunity for the development and expression of his criminal tendencies. The unrecognised imbecile is a most dangerous element in the community.' (Sarason & Doris, 1969)

There is little in the literature on the views of non-Western societies of the past. Whilst some societies inflicted casual cruelties others, including many in Central Asia, India and the Middle East, offered such persons protected and favoured roles. Some cultures give spiritual explanations for disability that allow control to rest with a superior being, whereas others attempt to find a human understanding to the lives of people with a disability.

Beliefs about the relationship between disability and sin, adequacy of faith and miraculous healing can be challenging concepts with profound psychological consequences (Treloar, 2002). There is a large proportion of the Chinese culture that is still deeply entrenched in the teachings of Buddhism. The Buddhists believe that a handicap or deformity is an act of karma or fate. Thus, there is greater passivity and a fatalistic outlook of their disorder compared to the West (Cheng, 1990). This would have implications for their desire and motivation to seek treatment and even the satisfaction after any treatment received. There may be concerns about upsetting the spiritual dimensions of their life after receiving treatment for their deformities as these are perceived to be an act of fate (Loh & Ascoli, 2011).

Studies from Pakistan found that culturally shaped ideas about intellectual disability contributed to delays in seeking mental health service contact (Tareen *et al*, 2008; Mirza *et al*, 2009). They provide a powerful depiction of help-seeking behaviour and access to services in low-income countries, revealing glaring deficiencies in availability and provision of services that showed striking differences with Western countries. Durà-Vilà and Hodes (2011) postulate that mental health service uptake could have been influenced by the extent of family composition and support; beliefs and understanding of intellectual disability across cultures (O'Hara & Bouras, 2007), stigma especially if associated with mental health problems and the belief in the reversibility of intellectual disabilities, a view not shared by services. This important misconception, the notion of 'curability', is not unusual in Asian communities (O'Hara, 2010). In cultures where families invest heavily in the search for a 'cure', they invest not only emotionally and physically, but financially, often spending their life savings in the hope

of finding a cure for their family member with ID. These families are particularly vulnerable to financial exploitation and unscrupulous charlatans (RCPsych, 2011).

Many non-Western medical systems do not differentiate between physical and mental states, and the spiritual and supernatural elements are intertwined (O'Hara, 2010). In indigenous peoples of sub-Saharan Africa, there is a tendency to believe in metaphysical/spiritual explanations of disability and the role of traditional and spiritual healers is formally recognised (Mpofu & Harley, 2002). Culturally relevant communication is important. The stigma of disability can stimulate a greater faith in one's own spiritual beliefs or it can result in complete loss of faith (RCPsych, 2011). Hatton and colleagues (2004) found scriptural interpretations concerning disability are inconsistent.

People with intellectual disabilities are at higher risk of mental health and physical health problems. They have a higher prevalence of mental disorders, epilepsy, sensory impairments, neurological and mobility problems, communication difficulties and may have an intellectual disability related syndrome with obvious physical manifestations. Physical attractiveness is highly regarded in many societies (Loh & Ascoli, 2011). Research has shown that physically attractive people are often perceived as being more intelligent and are easily accepted by others. They are thought to have better social habits and this leads to more positive response from others, compared to their less attractive counterparts (Hunt *et al*, 2005). Swinton (1997) argues that spirituality is not dependent on intellectual functioning and neither is the measure of spirituality dependent on eloquence or how it is expressed. He writes that faith and spirituality are not intellectual concepts but relational realities and that a person's spiritual life should not be evaluated according to intellectual criteria. Faith traditions believe that the spirit extends beyond the physical and that spiritual consciousness transcends the finite reality of this world. To deny that people with intellectual disabilities are spiritual is devaluing their human dignity, for every human being has the need to find a sense of meaning of life, a purpose and to feel he or she belongs. The more profound the intellectual disability, the less the person may be hindered by considerations of the here and now. Sulmasy (1997) reported that faith workers found that spirituality was profoundly felt with people with intellectual disabilities who were unhindered by everyday awareness, allowing the 'beauty of the spirit to be felt in its (pure) form'.

In the last quarter of the 20th century, the concept of normalisation (Wolfensberger, 1972) has brought people with intellectual disability more into mainstream society, with the aim of achieving social inclusion and with opportunities to build meaningful bonds within the community. The reality however, is that for some exclusion continues to be a significant part of their lives. Although a person does not have to be religious to be spiritual, organised religion remains the most common way of understanding and expressing spirituality. Religion attends to spiritual need by providing shared rituals, narratives, symbols and guidance through scriptures, prayer and modes of social support, furthering a sense of belonging. Within some cultures, people with intellectual disabilities are not included in social occasions, ceremonies and celebrations (Raji & Hollins, 2000; Oswin 1991). Some are never given the choice to attend a place of worship or to seek spiritual support as they may not have the skills or confidence to ask for help. For others with no spoken language, the challenge to ascertain their wishes is even greater.

I recall a young man with mild intellectual disabilities due to brain damage from birth hypoxia. He had an associated physical disability and developed epilepsy and schizophrenia. He often expressed to me his wish that his mother had let him die as a neonate. He lived away from his family, but with the help of our clinical team was able to re-establish a relationship with his mother. However he was estranged from his step-family. His struggles to come to terms with his life circumstances lead to misuse of substances, in particular alcohol. He had numerous psychiatric admissions, informally and formally under the Mental Health Act. When his mother was terminally ill, his step-

father refused to allow him to visit. The patient phoned me in a state of despondency. I was able to intervene, and thankfully he was not only able to spend time with his mother in her final days in hospital, but was invited by the family to her funeral. I had worked with this young man for 12 years, seeing him at least monthly and was probably the most consistent person in his adult life. When I eventually left the service, his last words to me were ... 'I cannot come to see you anymore. I won't know how to find my way'.

Henri Nouwen (1989) describes an experience in the *L'Arche* community of trying to support a young man with severe intellectual disabilities whose father had just died: 'It requires special care and attention to offer consolation and support to people who express themselves with so much difficulty'. People with intellectual disabilities are more likely to be subject to changes and loss than their non-disabled peer groups. They are much more likely to experience the death of a friend at an early age, or to experience loss through being moved from one placement to another, or to be in residential care as children. It seems all the more vital that they are given support to find ways of coping with loss. In a relatively secular Western society like ours, many health and care workers may have had little experience of any faith community and may feel ill-equipped to offer help (Raji, 2009).

Yet spirituality is no longer viewed as a religious concept (Swinton 2003); it has a broader meaning, as a human need that can be met away from institutionalised religious formats, although it is often intertwined. In modern cultures, the concept of spirituality has widened to embrace what might be termed 'secular spirituality', relating to the aspect of a person that links the deeply personal to the universe, providing an understanding of one's interrelationship with nature as well as people. It includes an appreciation of beauty, music and the creative arts and engenders a sense of harmony. For many people in society, an appreciation of art and of the beauty of the world around them enables them to make contact with important aspects of their lives. For many people without speech, and those with profound disability, music can be a doorway to spiritual experiences.

It is not just what we say but what we do and how we go about doing it. Many people with intellectual disabilities experience themselves as 'a disappointment to their parents, a burden for their families, a nuisance to their friends. To believe that anyone really cares and really loves them is difficult. Their heart registers with extreme sensitivity what is real care and what is false ... thus they often reveal to us our own hypocrisies' (Nouwen, 1989). Sinason (1992) writes very eloquently about the personal stories and narratives of people with intellectual disability who have suffered the most appalling abuse. Research tells us that prevalence of abuse and adult safeguarding concerns is particularly high in this population. Abuse is often perpetrated by those in a trusted relationship and can go on for a long time because of the particular vulnerabilities and personal care needs of the individual, their ability to communicate verbally and to be believed.

Spiritual needs exist whether we attend to them or not. How do we assess and meet the spiritual needs of people with intellectual disability? There is no standard 'language' of spirituality which can be tick boxed in a care plan. It is about creating an understanding of the person's internal world and requires sensitive handling and true person centered planning. It involves caring and thoughtful relationships (Fontaine, 2003), responding to the whole person to enable individuals to achieve dignified and meaningful lives whilst living with their mental illness and/or intellectual disability. Alridge and Ferguson (2007) suggest that the spiritual self is: the core of the individual and encompasses how they see themselves, what they think about themselves and how they feel about themselves. They suggest that the spiritual self includes: the religious, cultural and ethnic self; locus of control, self-confidence and self-determination; self-concept and self-knowledge; self-esteem; self-expression and communication. People with intellectual disabilities, when asked what is important to them and gives meaning to their lives, have talked about: loneliness and friendships; losing those we love, when people we love die, celebrations, finding a quiet space, believing in God, faith communities, inclusive practices, using people's talents and skills (Morgan, 2004; Swinton & Powrie, 2004). Addressing

spiritual needs should not be purely procedural but personal (Narayanasamy *et al*, 2002). Qualitative research approaches to the holistic and multi-perspective nature of spirituality has led to the development of two models of care for nursing education and practice. The ASSET offers a framework for spiritual care education and the ACCESS a framework for transcultural care practice, both being promoted to develop spiritual care interventions and to highlight how individuals use spiritual coping strategies such as prayer and other resources to cope with their chronic illnesses and disability (Narayanasamy, 2006).

Jean Vanier who founded the worldwide faith-based *L'Arche* communities for people with intellectual disabilities, had some fundamental messages for us about how we should treat individuals regardless of their functional and cognitive abilities. Respect every human being; create space for people to grow and mature; always stay in dialogue; keep adapting mutual expectations; enjoy the differences amongst people; always direct your attention to those who suffer most.

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