

Spirituality Matters

Jim O'Farrell

Prof John Swinton, Professor in Practical Theology at King's College, Aberdeen University and Founder of the Centre for Spirituality, Health and Disability (www.abdn.ac.uk/cshad), made a brief visit to Melbourne recently. Whilst here he gave an address at the Australian Catholic University (ACU) entitled: *Exploring the Spiritual Lives of People with Intellectual Disabilities*.



According to the professor, research indicates that spirituality is often an overlooked dimension of the lives of people with intellectual disabilities. In his report *Meeting the Spiritual Needs of People with Learning Disabilities*, he says that carers and support workers often do not understand what spirituality is or recognise its importance. Often those who do see its importance feel they are not trained to deal with this area of people's lives or that there is simply no time to incorporate it effectively. Prof Swinton believes policy makers and management often have priorities and expectations of services that omit the significance of spirituality and the importance of providing workplaces where people can find space to listen to each others' innermost experiences.

The research was conducted in such a way as to maximise the participation of people with intellectual disabilities. It included 19 one-on-one interviews in a variety of settings: six individual interviews with people with intellectual disabilities, four with people with high support needs, nine interviews with people with intellectual disabilities and their carers. Ten focus groups were also conducted: two with professional caregivers, five with people with intellectual disabilities and three with family carers and relatives. These took place in a variety of settings, including self-advocacy groups, user groups with members from minority ethnic communities, day centres and residential units.

Although understandings of the meaning of spirituality were diverse, complicated and personal, the participants in the study were clear that relationships with self, God and others lay at the heart of their understandings of spirituality. The study demonstrates clearly that people with intellectual disabilities are people first and have similar experiences and understandings to the rest of the population. Spirituality is an important dimension of the lives of people with intellectual disabilities, according to the professor, and as such should be taken seriously by carers, support workers and those responsible for developing policy and strategy.

At the heart of the understanding of spirituality that emerged from the experiences of people with intellectual disabilities lay the idea that it is primarily to do with connections. These connections may be with God, with others, with the world or with the universe. Whatever the source, it seemed clear that people had a deep desire to be connected with something beyond themselves. For some, this spiritual connectedness related directly to their relationship with God. For others, spiritual connection was encountered through close relationships such as family, friends and within particular communities.

Friendship with God, others and indeed with oneself was a primary source of spiritual fulfilment for many of the participants. It was in and through people's friendships that they seemed to discover who they were, why they were here and what hope there may be for the future. Friendship functioned as a primary spiritual relationship.

The study found that whilst people with intellectual disabilities desired exploration and care of their spiritual lives, there are significant barriers to the implementation of spiritual care. These barriers are not caused by bad intentions or malpractice – quite the opposite according to the professor. The problem lies in a lack of education and training combined with institutional barriers that prevent people from focusing on this area. Some care workers felt they needed to be quite careful in talking about religion or spiritual matters, or they felt they lacked the training to enter into these aspects of life and personal experience with those for whom they were a carer. Sometimes it was simply that the spiritual needs of the persons under their care do not fall within the ambit of needs they are required to attend to in their daily work.

Associate Professor Ruth Webber, Director of Quality of Life and Social Justice Flagship at ACU, said she found Prof Swinton's address challenging. Ruth said that one aspect of Prof Swinton's address that particularly caught her attention was the notion of people with an intellectual disability having 'one-hour friends' within a church congregation.

"People with an intellectual disability are often welcomed into the congregation and all sorts of adjustments are made by priests and laity to cater for their special needs. Members often provide transport and sit next to them in church and so forth. However, at the end of the service other people, particular the young adults, go out together and invite each other to birthday parties or to just hang out. The person with the intellectual disability is often over-looked, maybe out of kindness because it is perceived that he or she would not fit in or would feel uncomfortable," explains Ruth.

"However, let us take a moment to look at it from the point of view of the person who has been excluded or over-looked. He or she is often the only regular attendee in that age group not invited. Professor Swinton reported that a young man in his study indicated that he had 'one-hour friends' among his church congregation. The young man recounted an incident in which everyone in the youth group except himself was invited to a birthday party. He was so hurt at being excluded that he went home and conducted a make-believe party with invitations to everyone in the youth club. This man went on to say that he had no contact with any of the people at his church other than at the weekly church service. "This made me cringe, because I know that sometimes I am a 'one-hour' friend," Ruth said. "It was a salutary lesson for me and one that Christians might take into consideration when looking at the pastoral needs of their congregation."

Disability Projects Officer for the Australian Catholic Bishops Conference, Patricia Mowbray, believes that "Professor Swinton's research into spirituality and people with intellectual disability is certainly ground breaking and graced with hope. John's research not only affirms what many of us who journey with people with intellectual disability believe, but his work also encourages us to listen to people with intellectual disability so that, together, we can develop, provide and experience more substantial and meaningful spiritual opportunities within our Church. It is in this spirit of listening that we can truly be 'one Body in Christ' as we encounter, engage and explore our spirituality together as one community of believers."