

# Why Are We Here?

## Spirituality and the Lives of People with Learning Disabilities

### SUMMARY

Current research makes it clear that spirituality is a significant dimension of human experience within which people seek to find such things as meaning, purpose, value and hope. For some people it embraces a search for God. Up to now, very little research has been done into the significance of spirituality for people with learning disabilities. This research project sought to explore in depth the nature, function and significance of spirituality for the lives of people with learning disabilities and the ways in which they feel such needs can be best met.

People with learning disabilities recognise the importance of the spiritual dimension. They describe it as relating to value, acceptance, love, care, and connectedness with God and others. Grief, loss and a sense of relational disconnection were a common phenomenon amongst the people we spoke with. Faith communities could be powerful sources of friendship and support. However, the forms of their worship and uncertainty about their level of commitment to relationships with people who have learning disabilities need to be addressed. People were seeking 'sacred spaces', where they could find time and space to get in touch with their own spirituality. Training is required to enable those supporting people with learning disabilities to recognise and respond creatively to this aspect of their experiences.

### BACKGROUND

- Spirituality has increasingly been recognised as a basic human need and a human right, which is a necessary component of both mental and physical health.
- There is very little research being done into the role of spirituality in the lives of people with learning disabilities.
- The *Space to Listen* Report (2001) indicated that spirituality might be a significant aspect of the lives of people with learning disabilities. It pointed towards the need for further research within this area.
- It also suggested that carers and support workers needed education and training to enable them to deal effectively with this element of the lives of people with learning disabilities.
- The current research is a response to the findings of the *Space to Listen* report and the suggestion that spirituality is an important but often overlooked, dimension of the lives of people with learning disabilities.

## THE PROJECT

The two year study was based on a participatory methodology that sought to explore spirituality beginning from the experience of people with learning disabilities and to develop strategies and suggestions for good practice that emerged directly from the voices of people with learning disabilities. Interviews and focus groups were held in a variety of settings across the UK. They were designed to offer people with learning disabilities the opportunity to discuss spiritual issues in depth and to define the significance (or otherwise) of this dimension for their lives.

## THE FINDINGS

- Spirituality includes but is not defined by religion.  
*Personally, I don't believe in a God - a divine being - of any description..... But I do have a great wonder at the workings of the world and the universe, humanity is really important.*
- People with learning disabilities expressed a desire to have this dimension of their experience recognised and supported. Friendship was a primary conduit through which people expressed their spirituality and had their spiritual needs met.  
*Friends are important because they love me.*
- Some people with learning disabilities have significant difficulties in developing friendships. This often leads to loneliness, isolation and disconnection.  
*..... been lonely all my life...never felt loved.*
- Faith communities could be powerful sources of friendship. However, in some instances, the forms of their worship and uncertainty about committed relationships with people who have learning disabilities need to be addressed.  
*A couple of years back one of the teenage girls was having her sixteenth birthday and after the church service all the young people were going back to her house..... But of course George wasn't invited.*
- Grief and loss, in particular unresolved grief is a deeply spiritual experience that is part of the lives of many people with learning disabilities. People require assistance in dealing with this.  
*My Dad is dead and he's gone. That was a fairly long time ago - a fair long time. I'm still missing him. I just wish he could come back but he's dead.*
- People desired space within their daytime situations and at home to allow them to think, reflect and pray, i.e. to get in touch with their own spirituality.  
*Sometimes, I feel as though I need space, but I find it difficult in like this environment because... it's very difficult.*
- Creativity was found to be an important conduit for spiritual expression. For example, art, music and stories were used by people with learning disabilities to express what was most important to them in their lives.  
*Art and beauty is an expression of peace and calm.... Pottery is making me..... think about spirituality.*

- There were some significant barriers in services to the implementation of spiritual care. These included: lack of time, uncertainty about what spirituality was, lack of education in the spiritual dimensions of people's experience, uncertainty as to how to incorporate spiritual care into the role of the professional and fears of imposing values on people.  
*There's not a box to tick to say I have helped Bruce think about mortality. There is a box to tick to say I've cooked the tea and that it was wonderful.*
- Staff needed training to recognise and support the spiritual needs of people with learning disabilities.  
*Historically we've always focused on functional ability at the expense of people's emotional life...we talk about wanting to give people a good service. But if we're missing that chunk out of their lives,[spirituality] maybe the service we do offer these people is anything but good.*
- Faith communities have the potential to offer support and provide a valuable source of value. However, they also need to be aware that certain exclusive forms of practice can serve to exclude and oppress people with learning disabilities.  
*How are people with learning disabilities going to learn more about God..... if there's no opportunity for them to access teaching that's really pitched at their spiritual level?*

## IMPLICATIONS

- *Research:* This research has shown that spirituality has significance for the lives of people with learning disabilities. However there remains work to be done within this area, particularly with people who have profound and complex needs. As far as possible their voices have been included in this study. However, there remains a need for a dedicated study to explore the rich inner lives of people with this type of life experience.
- *Training:* Since many carers and support workers recognise the importance of the spiritual dimension, but feel unprepared to deal with the issues involved, there is a need for education and training in this area both in terms of basic training for trainee professionals and continuing professional development.
- *Faith communities:* Faith communities hold much potential in terms of developing the religious and the non-religious dimensions of people's spirituality. However there is a need to enable them to reflect on issues of inclusion, inclusive language and how best to develop meaningful friendships with people who have learning disabilities.
- *Policy making:* Those responsible for policymaking and strategy development must take seriously the suggestion that time limitations on carers and support workers might be preventing them from caring for a vital dimension of the experience of people with learning disabilities.

## FURTHER READING

1. Swinton, J. (2001) *A Space to Listen: Meeting the spiritual needs of people with learning disabilities* London: Mental Health Foundation.
2. Crompton, M. and Jackson, R. (2003) *Spiritual Well-being of Adults with Down Syndrome* Southsea Down Syndrome Educational Trust.
3. Oswin, M. (1991) *Am I Allowed to Cry? Study of Bereavement amongst People who have Learning Difficulties* London: Souvenir Press.
4. Knox, Marie, Hickson, Fay. (2001) The Meanings of Close Friendship: the Views of Four People with Intellectual Disabilities *Journal of Applied Research in Intellectual Disabilities* 14:3 pp. 276.

**This Update was written by Professor John Swinton, The School of Divinity, Religious Studies and Philosophy, The University of Aberdeen.**

The report *Why Are We Here? Meeting the spiritual needs of people with learning disabilities* by Professor John Swinton with Elaine Powrie is published by the Mental Health Foundation.

It is accompanied by a booklet for people with learning disabilities, *What Is Important to You* and a booklet for support staff and carers, *No Box to Tick*.

The Foundation has also published *What About Faith?: A good practice guide for services on meeting the religious needs of people with learning disabilities*.

To obtain these publications please call 020 7802 0300.

For further information about the spirituality programme, contact Hazel Morgan at the Foundation or email [hmorgan@fpld.org.uk](mailto:hmorgan@fpld.org.uk)

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Another *Update* on learning disabilities and spirituality has been produced in this volume, see issue 12.

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