

*Why Are We Here*

Meeting the spiritual needs of people with learning disabilities

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## Preface

The Foundation for People with Learning Disabilities has taken the lead in working with people with learning disabilities to explore their spiritual needs, thanks to the vision and support of the Shirley Foundation.

In the preliminary study, *A Space to Listen*, the author Professor John Swinton gave the example of a young woman, Samantha, who asked at the coffee break, ‘Why do you think we are all here?’ She received a mundane reply from her support worker about the purpose of the day centre to help her acquire skills. She then persisted. ‘Me, Derek, Fran, Brian, you.....why do you think we are alive?’ But she was not taken seriously and did not get an answer or the opportunity for a discussion.

The findings of the subsequent two year research project with people with learning disabilities, described in this report, show that people with learning disabilities want to explore what gives their lives meaning and have clear ideas about what is important to them. Yet rarely do they have the support to fulfil their dreams and hopes, because this is not seen as within the remit of those who support them. Some people value belonging to a particular faith tradition and want to explore it for themselves, but opportunities are limited both because this is not seen as part of the role of services and because faith communities are not always welcoming or inclusive, despite the requirements of the Disability Discrimination Act (1995).

The Foundation believes that this is a negation of the human rights of people with learning disabilities and in particular the right to the freedom of thought, conscience and religion enshrined in the Human Rights Act (1998). This arguably includes spirituality in all its dimensions. There is also now greater awareness in education and health services, that to fail to address the population’s spiritual needs may put emotional well-being at risk.

The Foundation for People with Learning Disabilities is proud to be at the forefront of the call for attention to be given to religion and spirituality. This report is one of a series of documents being published this year, (see px).

As part of the Mental Health Foundation, it is part of a wider campaign to get spirituality recognised in services and to alert the faith communities to be truly inclusive.

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## **Acknowledgements**

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We would also like to thank the members of the advisory committee to this project and the spirituality advisory committee at the Foundation for People with Learning Disabilities for their suggestions and advice. (See Appendix 2)

We benefited from the support of staff from the Foundation, Julie Ballard, Cathy Goodwin, Hazel Morgan Celia Richardson, Amy Sutton and Patricia Umolu.

This report is part of a series of publications on meeting the spiritual and religious needs of people with learning disabilities.

It is accompanied by two information booklets by John Swinton to raise awareness about meeting spiritual needs, one for people with learning disabilities and one for carers and support staff.

*The Forgotten Dimension? A Good Practice Guide* for services to meet the religious needs of people with learning disabilities, by Professor Chris Hatton, Suzie Turner, ..... is also available from the Foundation. A report about this research..... can be downloaded from the Foundation's website, [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)

**The Foundation for People with Learning Disabilities would like to thank The Shirley Foundation for its support.**

# *Accessible Summary of the Report on the Spiritual Lives of People with Learning Disabilities.*

## *Introduction*

This report is about the way that people with learning disabilities understand spirituality. It tells their stories and helps us to understand what they think is most important in their lives.

### *What is spirituality*

The people with learning disabilities we spoke to talked about spirituality in different ways. Some people said it was about God. They felt that God loved them and cared for them and that this was the most important thing in their lives. Other people thought that spirituality was about having friends and this gave meaning to their lives. People felt that it was important they belonged to a group or a community. Some people liked to go into the countryside. Some liked music and art.

## *Spirituality and friendship*

People felt that friendship was the most important thing in their lives.

Sometimes their friendship was with God and sometimes it was with people they liked. Friends look after one another and care for one another. Friends help people when they are in trouble and make people feel special and loved. Friends accept you just the way you are. You can trust your friends. They can help you feel safe. They can help you plan your life. All the people we spoke to felt that having friends was an important part of their spirituality.

People valued the work of carers and support workers. But, they wanted friends who chose to be their friends rather than people who were paid to look after them. This was very important for people.

Some people found it difficult to meet people and make friends. They were very lonely.

Religious communities were good places to find friends. Many people had made friends by going along to services of worship and meeting people.

Some religious communities were very good at making people with learning disabilities feel welcome. But in others, people found the services difficult to understand because there were lots of words they did not understand. Some people found that religious people were friendly towards them but never invited them back to their houses. The people with learning disabilities we spoke with wanted people to become real friends who would stay their friends for a long time.

### **Sadness and grief**

Some people's family members or friends had died. People found different ways to cope with their sadness. Some people accepted that the person had gone and would not be coming back. They had happy memories and did not feel as sad as they had done in the past. Other people felt they were still in touch with the dead person. Some people still spoke to the person and felt close to them.

Some people with learning disability felt that when a person died they went to heaven – they were with God. They felt comforted that God was

looking after the dead person. This helped people to feel better about losing someone they loved.

Some people were still very sad even though the person had died a long time ago. They would have found it very helpful to talk to someone about their sadness. Many people never got the chance to speak to anyone about how they were feeling.

Some carers and support workers felt a bit awkward about speaking about these things. People with learning disabilities felt that carers and support workers should try and get to know how sad people were and help them talk about the person who had died. This would help people to feel less sad.

### *Having time and space for yourself*

Some people felt that their lives were so busy, they hardly ever got the opportunity to have any quiet time to themselves. They wanted a place to think or to pray. Some people used church buildings to do this. Others



found a quiet place at work or at home. It was not always easy to find a quiet place. Many people wanted the chance to find time and for these things.

Some people found music helpful. It made them feel happy and helped them remember good times. Some people used paintings and drawings to show others what was important for them, what made them happy and what made them sad.

Some people looked at pictures and beautiful things or listened to music. This helped them feel good. Being in the countryside or looking at the sky at night made them think about how lovely the world is. Some people began to think about God and how God made them feel good about themselves.

### *Some problems*

Some carers and support workers did not feel comfortable talking about God, friendships, sadness and other things that people with learning

disabilities thought were important. Carers and support workers also felt they didn't have time to speak with people about a lot of important things. They were too busy. People felt that managers should listen to what is important to people with learning disabilities and make sure that staff have time to talk to people about spiritual things.

Many people with learning disabilities feel that religion is very important. But some carers and support workers do not understand this. Even if staff don't believe what they believe it is still important to allow people to express their feelings about God in their own way.

### *How can we change things?*

Once we had listened to the opinions of people with learning disabilities we felt there were ways services could be changed. We suggest that these things should happen:

1. People must listen to the opinions of people with learning disabilities and take their views seriously.

2. People with learning disabilities should be allowed to speak up about how important spirituality is and what it means for their lives.
3. People with learning disabilities should get the opportunity to use things like music, art, drawing and painting to express what is most important to them.
4. People with learning disabilities should have the opportunity to make real friends who care for them just as they are.
5. People with learning disabilities who have lost someone close to them need to be listened to. People must take seriously how sad they are feeling.
6. Religious communities must learn to understand what people with learning disabilities want.
7. Religious communities need to listen to people with learning disabilities They need to make sure that what they teach and the way they teach things can be understood by people with learning disabilities.

8. Carers and support workers must be trained to understand how important the things in this report are for people with learning disabilities.
9. Carers and support workers need more time to help people with things that are important to them, like spirituality.
10. People in the government need to realise that carers and support workers must get more time to spend with people with learning disabilities. They should listen to what people with learning disabilities are saying.

# Introduction

Spirituality is an overlooked dimension of the lives of people with learning disabilities. Carers and support workers often do not understand what spirituality is or recognise its importance. Even those who do see its importance feel they are not trained to deal with this area of people's lives or that there simply is no time to incorporate it effectively. Policy makers and management 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. It can be overlooked by religious communities where people with learning may be given the hymn books to hand out on a Sunday but are rarely invited into the heart of the community and offered meaningful, friendships.

But, you may say, "surely this is nothing more than a caricature? We don't really behave in these ways do we? Where is the evidence?" The evidence lies in the life experiences of people with learning disabilities and the stories they tell about their spirituality. Spirituality is not overlooked by people with learning disabilities. When we begin to listen to their stories it becomes clear that they have rich spiritual lives and want people to take this seriously as a vital dimension of the care and support they receive <sup>1-6</sup>. People with profound and complex needs have expressed the importance of spirituality for their lives and their desire to have this acknowledged <sup>7</sup>. Those who have taken time to listen to the spiritual stories of people with learning disabilities find that spirituality is a valuable source of social and psychological support <sup>8,9</sup> a vital source of meaning making <sup>10,11</sup>, and a crucial aspect in the development of friendship, connection acceptance and self-worth <sup>12-14</sup>.

## **A care gap**

There seems to be a significant split between what care and support services are offering and what people with learning disabilities actually want and need. Despite the potential benefits of spirituality, there is evidence to suggest that carers and support workers are ill-equipped to deal effectively and positively with this dimension of people's experience<sup>15-18</sup>. This lack of attention to spirituality exists despite a growing body of scientific literature that suggests that spirituality is a basic human need, vital for mental and physical health<sup>19-21</sup>.

### *Spirituality as a human right*

Article 9 of the Human Rights Act 1998 says:

*Freedom to manifest one's religion or beliefs shall be subject only to such limitations as are prescribed by law and are necessary in a democratic society in the interests of public safety, for the protection of public order, health or morals, or for the protection of the rights and freedoms of others.*

This implies that the freedom to express one's spirituality is a basic human right and therefore has significant implications in terms of the human rights of people with learning disabilities. If the way in which services are delivered implicitly or explicitly militates against such expression, there is obviously a serious problem.

The omission of spirituality not only has legal and moral implications, it also challenges us to ask disturbing questions as to whether or not we are serious about developing models of care and support which are genuinely person-centred. To be person-centred a service needs to provide more than just basic functional needs. Genuinely person-centred services must be flexible, open and empathic enough to deal with the unique needs of individual service receivers and to reflect a deep

understanding of what it means to be human and to live humanly. If we take seriously the evidence that spirituality is a crucial dimension of the experience of many people with learning disabilities – and for a variety of reasons is being overlooked - then there seems to be a significant gap in our current strategies and practices.

### ***A Space to Listen: taking the voices of people with learning disabilities seriously***

In 2001 the Foundation for People with Learning Disabilities published its *Space to Listen* report. This report was based on a 10-year review of the literature on spirituality and people with learning disabilities, combined with a series of interviews with people with learning disabilities, carers and support workers. The report found that:

- Spirituality is a common human phenomenon that includes but is not defined by religion.
- There is evidence to suggest that spirituality plays a significant role in the lives of many people with learning disabilities.
- Carers and support workers are often unaware of the significance of this dimension and consequently fail to address it.
- Training is required to enable those supporting people with learning disabilities to recognise and deal effectively with this aspect of their experiences.
- People with learning disabilities need to be given accessible information and opportunities in order that they can make informed spiritual choices.
- Faith communities have the potential to offer support and friendship, but they need to be aware that certain exclusive forms of practice can serve to exclude and oppress people with learning disabilities.

The *Space to Listen* report indicated a need for a change in outlook and practice. The findings of this report also indicate a real need to understand more fully the significance of the spiritual dimension of the lives of people with learning disabilities and to re-examine current strategies of care and support. To this end the Foundation for People with Learning Disabilities set up a two-year UK-wide research programme, comprising two projects, designed to explore these issues. One was an action research project led by Professor Chris Hatton at the University of Lancaster piloting draft materials on meeting religious needs with five services, leading to a Good Practice Guide.

The findings of the second research project are presented in this report. The names of the participants in the research have been changed.



## Section 1:

### *Understanding Spirituality*

#### **Setting the context**

Before we can begin to understand the spiritual lives of people with learning disabilities it is helpful to reflect on how spirituality is understood within the present multi-ethnic culture of Britain. This will help us understand more clearly the rich meaning of the spiritual experiences of the people who participated in the study.

#### *Spirituality and religion*

Traditionally spirituality has been equated with religion. Understanding spiritual needs meant people finding fulfilment and acceptance within their own particular religious tradition. Spiritual care would include prayer, study of the religious scriptures, rituals of initiation such as baptism and bar mitzvah, and keeping religious festivals such as Ramadan. However, while religion remains a major spiritual force within the United Kingdom and indeed throughout Europe and the Western world, there has been a sharp decline in adherence to institutional religion throughout the post-war period. This decline has carried on into the new millennium. However, as the recent work of Hay and Hunt suggested<sup>22</sup>, although people may be less religious in the sense of formal adherence to specific forms of institutional religion, it would be a mistake to assume they are necessarily less spiritual, or that they are no longer searching for a sense of transcendence and spiritual fulfilment: quite the opposite. People are actually becoming more spiritual. The difference is that they are expressing that spirituality in ways that are different from traditional understandings. It is clear that

while many people wish to believe in the spiritual dimension, they are less inclined to want to belong to religious organisations<sup>23</sup>.

This migration from the strictly religious into much more diverse forms has led to a change in the meaning of spirituality. It has opened up traditional understandings to include dimensions that may appear functionally similar to the traditional religious quest but are in fact significantly different. These new forms do not necessarily have a formal religious framework. They are located within such things as individual belief systems and personal relational networks.

Spirituality is not viewed simply as a divine gift or a consequence of sustained interaction with God or a religious community. It is seen more as a general human need which reveals itself in a search for meaning, purpose, value, hope and, for some, God: it is that dimension of a person's experience that contains the beliefs, values, attitudes and world views within which individuals make sense of the world and understand who they are and why they are here.

This is not to suggest that religion is insignificant or that it is passing away. That is not the case. Religion remains a powerful spiritual force that plays an important role in the lives of many people we spent time with during this study.

All people have a spiritual dimension<sup>24</sup>, i.e. a need for meaning, purpose, hope, value, relationship and perhaps a sense of the transcendent. Some people work this out within religions through the signs, symbols, rituals and stories of that particular tradition. For others the search for spiritual fulfilment is worked out in different ways, through meaningful relationships, personal searches for meaning and individual belief structures. Such a suggestion would be in line with current research that argues that there may be a biological basis for spiritual experience<sup>25, 26</sup>. This research suggests that human beings are "hard wired" to experience spirituality and religion; that human beings have

a natural desire for spiritual experiences <sup>(Footnote 1)</sup>. If this desire is not met through traditional modes of expression, people will work out these feelings and experiences in other ways and through different means. This suggestion cannot be explored here. However, the idea that spirituality is a universal norm with particular individual and cultural manifestations is worth bearing in mind.

This broader understanding of spirituality was neatly summed up by one of the study's participants:

*For me spirituality is those feelings people get that make some people want to run out and start religions. Personally, I don't believe in a God - a divine being - of any description. That's just my personal beliefs. But I do have a great wonder at the workings of the world and the universe. I suppose you could call that a spiritual response. I don't necessarily think religion and spirituality go together.*

This openness to a variety of different understandings of spirituality came through in the experiences of many participants. The important point here is the suggestion that spirituality is a dimension of human experience, which is of significance to all people, and not simply to those who express a religious preference.

### **How do people with learning disabilities understand spirituality?**

It is useful to begin by exploring prominent themes and ideas that emerged in our conversations.

*An experience or relationship which offers value*

Spirituality, whether it was worked out in relationship to God, or through other forms of meaningful relationship, seemed to offer a form of relational connectedness that people deeply

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<sup>1</sup> This notion was first expressed fully in Hardy's Gifford Lectures in Aberdeen, that spiritual awareness is biologically inbuilt in all members of the species 'Homo sapiens' and thus is the precursor of all cultural manifestations of spirituality, normally but not exclusively the form of religious belief and practice. The idea of humans as biologically programmed for religious and spiritual experience has recently been developed in more depth and with a good deal of scientific rigour by Andrew Newberg (2002)

valued. The word 'special' was used many times. Being in relationship to God or to others made people feel special and valued, an experience that was often missing in other parts of their lives. Sylvia, a woman with Down's Syndrome, felt strongly that

*God is the only person who helps me: no-one else - nobody else.*

God was a refuge and a strength that enabled her to cope with difficult situations. In her world, God viewed her as special and was able to do things for her that no one else could. When asked what made her feel valued, she reflected for a while and then said:

*I was born with a hole in my heart. When I was little it needed a patch and I was very ill. It might be because of this but I have always felt special... God is my best friend. God made me special because I was special to him'.*

She then sang a song that contains the lyrics: "I'm special because of God's love." For this young woman spirituality related to being marked out by God as someone who is "special" and worthy of love, care and attention. This was central to her understanding of herself and her struggle to feel valued within a world where people with learning disabilities are often profoundly devalued.

The ability of spirituality to bring a sense of value to a person's life became particularly significant in times of stress and trauma.

Jean: *It didn't look like a person was going to live and he[God] has the power to bring that person back to life.*

Interviewer: *Are you talking about someone you know?*

Jean: *Yes.*

Interviewer: *So you've seen God working in other people's lives. In your own?*

Jean: *But I don't believe that I have to go to church to feel the power of God.*

Interviewer: *Are you saying that he has directly helped you or made you well from being ill?*

Jean: *Yes I suppose I am.*

Interviewer: *Are you saying that God's got you through something very difficult?*

Jean: *Yes. God and family and friends.*

Interviewer: *and can you say how that actually makes you feel about God or yourself?*

Jean: *I must be very special.*

For Jean as for others, spirituality was understood as a ‘specialness’ that emerged from connectedness to God and to others, a connectedness that took on particular poignancy in times of struggle.

Other people emphasised the importance of spirituality for helping them cope with difficulties. The following conversation between Hilary, a young woman with a learning disability and her carer addresses this point.

- Hilary:     *He’s[her father] been very ill and I believe it was God that pulled him through it all. If you’ve seen him now, a picture of health.*
- Carer:     *Was that a bad time for you?*
- Hilary:     *It was, but I had to keep strong for my mum.*
- Carer:     *Where did you get your strength from?*
- Hilary:     *I reckon...I don’t know where I got it from...but I reckon it was from God.*

Hilary’s awareness of the presence and care of God enabled her to draw strength to support not only herself but also her mother in a time of crisis.

A number of participants emphasised the importance of spirituality in the process of coping with suffering and loss. It introduced value and hope to difficult situations. When other sources of value in their lives began to break down, a focus on spirituality enabled them to recover, reaffirm their value, and move on. The idea that spirituality makes a person feel special is particularly significant bearing in mind the level of exclusion, loneliness and depersonalisation that people with learning difficulties often encounter in their daily lives.

### **A sense of belonging**

The specialness, connectedness and sense of value that people highlighted often came from God, but it also emerged from and was reinforced by their relationships with others within some form of community. These communities could be religious or secular - clubs, People First

groups for example. The important thing was that they provided a context within which people could feel valued, affirmed and meaningfully attached. The focus groups themselves frequently became a place for the mutual reinforcement of value, worth, belonging and spiritual development. The following extract is from a discussion held at a People First group on what spirituality is and how it related to their community:

Brian: [in this community] *No-one's famous - we're all special.*

Interviewer: *No-one is famous?*

Brian: *Yes - but we're all special people.*

Interviewer: *How come we're all special?*

Brian: *Because we all need one another. By caring for one another. By giving to one another. You buy a box of chocolates for a friend.*

Here people were identifying spirituality with a sense of belonging, security, trust and community. People felt this sense of belonging particularly through friendship – being in a community where they could be with their friends.

Interviewer: *What is the most important thing we've talked about tonight?*

Laurence: *Friends*

Tina: *Relationships*

Ronald: *So life centred relationship... people think is the most important thing in life?*

All: *Yes.*

Developing this sense of belonging in meaningful ways was central to the ethos of all the groups we worked with. The specialness of the individual and a sense of belonging no matter what challenges a person may be facing was seen as paramount. Although not all the groups were spiritual in a religious sense, what emerged from all of them was that spirituality, in its widest sense, is closely related to a sense of belonging and is something they wanted to promote within their communities.

Interviewer: *What are the key elements of your group?*

Susan: *The feeling of belonging*

Michael: *It is actually putting the person with the difficulty at the centre of things, rather than pushing them out into the margins. I think that is the plus of the group and the*

*organisation which is for the benefit of people with learning difficulties. But we all benefit from it in so many ways.*

Fiona: *The spin offs*

Michael: *The spin offs, yes.*

Interviewer: *What did you mean by belonging?*

Fiona: *I enjoy seeing all my friends. Well, it's a family feeling isn't it.*

Michael: *The word that very often comes to mind is one of joy. Really you feel uplifted after meeting together.*

Fiona: *Things happen.*

Michael: *Things happen and you sort of have a smile on your face and it seems to come naturally.*

Michael: *Well it's being - like in communion - one with another isn't it?*

Fiona: *Being with your family.*

For all participants in various different ways, this quest to find a sense of belonging, a quest which participants clearly identified with their understanding of spirituality, provided a primary life-goal.

### **A hidden personal value**

Spirituality had a variety of meanings in people's lives. Though there were shared features, for example the need for relationships with God and others, the need to be valued and to belong, it was only as spirituality was worked out in unique ways within individuals that its true meaning became clear. Spirituality was described as a 'hidden personal value.'

It is hidden insofar as many people have never had the opportunity to reflect on it publicly. They know in themselves what their spiritual desires are, but rarely (if ever) get the opportunity to share this with others. This was certainly the case for non-religious spirituality, but also for religious spirituality. It was clear that carers and support workers had not reflected deeply on what religion might mean to unique individuals who use it in very particular ways.

It is personal for similar reasons. People experience their spirituality in many different ways. In order to understand a person's spirituality it is not enough simply to look at their spiritual label and

assume that they should act in a particular way. It is necessary to explore what it means to the person-as-person, rather than simply the person-as-Christian/Muslim/Jew/Buddhist/humanist.

The idea of spirituality as a hidden personal value was not necessarily connected with institutional religion. It was understood in terms of a code or a set of values which people felt they should live by in order to be 'good people'. Jonathan, who is Jewish, put it like this:

*I think for me, it [spirituality] fundamentally has to do with...with praise...as it were, for the rest of life. That means a kind of respect for other people and a kind of respect for humanity and for other people.*

The idea that spirituality relates to being a better, kinder, more compassionate way of being human emerged during a number of interviews. A young Muslim woman described it this way:

Rafina: *I think the biggest relationship or the biggest religion is humanity, looking at a human being despite their religion, race, background, age. It's treating everybody equal, that's really important to me.*

Interviewer: *Humanity is religion?*

Rafina: *The biggest. Yes, humanity is really important. It's not your race, religion, age, background: it's seeing another human being. It doesn't matter what your religion is.*

For Rafina, spirituality had to do with the experience of valuing human beings and feeling connected to the wider human race, a form of connection which transcended religious boundaries and drew her into communion with the whole human race.

## **Enabling altruism**

Spirituality was viewed as a set of values that helped participants to be better, kinder and more humane people. For some this kindness came from outside of themselves through a relationship with God which offered them guidance and support. For others spirituality was manifested in the kindness revealed in their relationships with others. One man put it this way:



*I am convinced that people who are kind to me help me to believe in God, even when they are not Christians, because the kindness seems to me to come from God even if they don't know it. Valerie is not a believer but she is hoping that I will succeed with my quest for inclusion and I feel that her sensitivity to me is God-given.*

Even for those who felt that spirituality was deeply connected with God, the way in which it was understood and affirmed depended on their relationships with other human beings. As Rowan put it:

*I think the most important thing I have said is that the purpose of life is the acquisition of the Holy Spirit and this is my purpose. But I cannot do it without the help of kind people who will support me and help me.*

There was an intimate tie between the transcendence of a God figure and the spirituality revealed in human relationships; the experience of love at a temporal level enabled the experience of being loved by God at a transcendent level. Even if a person believes in God, what goes on at the mundane level of human relationships is deeply spiritually significant.

### **Awe and Wonder**

Participants related spirituality to the inexpressible experiences which reflecting on the world can bring about. For some the experience of awe was induced by the general awe, wonder and mystery of life. The mystery of the world moved a number of participants to reflect on the meaning of life and their reasons for being alive.

*Spirituality has to do with where did it [the world] come from - how did it get there - that kind of thing.*

*Well I think there's more to life than this planet. Life is important because you can do so much, it's a mystery to think about why we are here. Life is about taking every opportunity to do things and learn things.*

A mother described the experiences of her son who has profound and complex needs:

*When he comes to tell us to look at something out of the window it's really special because he doesn't say very much to us. The moon is something he seems to really appreciate. If it's a really bright night and a dark sky and the moon is shining he just has an immense*

*appreciation of that. He wants to stand and look at it for ages and to share that moment of looking at the moon.*

From this mother's perspective, her son's experience of awe and wonder is spiritual. Whilst not always expressed directly, this awareness of mystery in life formed a significant dimension of many participants' experiences.

### **Being connected**

A sense of connectedness was a key theme and underpins all that has been said thus far about people's understanding of spirituality. It was expressed implicitly and explicitly in all the interviews. Participants frequently emphasised the importance of relationships, community and belonging: all concepts that indicated the way in which people's spirituality seemed to hold together various connections in their lives. These connections were in the present, for example through friendship, but they also stretched back into the past and forward into the future. For example, some participants understood spirituality as a bond between themselves and those who had passed away. An elderly man, Nigel, expressed it this way:

*Your family, your mum, your dad, your brother are always around you, but you can't see them because they're in heaven. They're looking down on you to make sure you don't go off the pathway.*

It was important for Nigel that he remained connected with his family and that the possibility and hope of being with them again was kept alive.

People used various ways of sustaining their connections, for example through personal possessions. People treasured particular objects that were symbolic of friendship or relationships. Some people always carried these with them. They formed a tangible connection with the past, the present or a hope for the future. Sometimes they related to a specific relationship. Sometimes they reminded people of their spiritual tradition and the way it held together the various connections in

their lives. The following replies came in answer to the question *Can you say what the message of the cross you carry is?*

Mark: *Believe in yourself. Have hope.*

Simon: *For the future.*

Francis: *As well, going forward.*

Mark: *Believe in life.*

Within Mark's tradition, for example, the cross stands for hope; hope that there is life after death, that God is with him and that his life makes sense in the light of this. The symbol of the cross connects Mark to a wider story that relates past, present and future in very specific ways. He draws on this symbol to help him make sense of past present and future and to retain a sense of connectedness with God, self and others.

### **A sense of responsibility for the wider world**

For a number of participants spirituality was associated with concern for the world and with doing what is best for others on a personal and a political level. There was an awareness of being a member of the wider human race with responsibilities beyond their particular communities. Concern about conflict and world peace was raised in all the focus groups with people with learning disabilities. The following examples indicate the depth of people's concerns over social issues.

Interviewer *What do you think is the meaning of life - why are we here?*

Rhonda: *To have peace, peace on earth, more peaceful. To aim for peace.*

David *I just wish they'd stop fighting and shooting people so the religions can get on like, Protestants and Catholics can get on without all the fighting.*

Interviewer: *Do you know what would help that?*

Rhonda: *I don't know what would help it but they should get on and try to sort things out.*

Michael *My advice is to tell people that suffering, conflict, their suffering, war, riots.....help people to try and solve what they have started and why they have started it.*

*Try and sort the circumstances out as well and make sure the peace is spread, all the other people that started the conflict. I think the ideal world should be not countries at war but countries at peace and the world at peace.*

World conflicts also influenced the way in which people developed their personal beliefs and sometimes challenged them at a deep spiritual level:

Interviewer: *Has anybody got any views about God or if there is a God?*

Jane: *Is there a God? When this world gets desperate because of all the shooting and things like that.*

Interviewer: *Because the world's desperate, it doesn't look like there's a God. Is that what you're saying?*

Jane: *Yes. It's difficult.*

In a world so filled with suffering, some people felt that it was very difficult to believe in the reality of a God. For others the presence of suffering in the world raised important theological questions that were of continuing concern.

It was clear that spirituality related to a sense of belonging to and responsibility for the wider human race and a genuine concern for the plight of human beings at home and abroad. The depth of the questions raised showed that people understood and were concerned about many difficult world issues and that, given support, were able to express their views and begin to work through some deep and complex existential issues.

## **Conclusion**

Spirituality is very diverse. It is complicated and personal. Nevertheless, the participants in this study were clear that relationships with self, God and others lay at the heart of their understanding of spirituality. It would appear that spirituality is fundamentally a relational concept that may be expressed vertically towards God or horizontally towards other human beings. Both are authentic

forms of spirituality that need to be respected and understood not as general phenomena, but as unique human experiences.

The experience of the participants in our study relates closely to observations on spirituality expressed in research literature. Carson, for example, observes the need for a continuous interrelationship between the inner being of the person (the person's vertical relationship with the transcendent/God or whatever supreme values guide the person's life) and the person's horizontal relationships with self, others and the environment <sup>27</sup>. As Spaniol puts it <sup>28</sup>;

*Spirituality involves relationship - a relationship with someone or something beyond ourselves; someone or something that sustains and comforts us, guiding our decision making, forgiving our imperfections, and celebrating our journey through life. This someone or something can be another person, a spiritual guide, a belief in the goodness of human nature, and/or a belief in God. Our deepest spiritual encounters are experienced in and through our relationships - relationships that are intimate, mutual, and have the capacity to move us deeply.*

People with learning disabilities are people first and have similar experiences and understandings to the rest of the population. Nevertheless, the ways in which people described it and the nuances of their experiences presented us with a specific and valuable perspective.

We might draw together the threads of discussion thus far in this way: Spirituality is a relational concept that concerns a person, experience or relationship and which provides people with a sense of value, hope, meaning, direction and belonging. Spirituality can manifest itself in meaningful relationships with God or others, in a sense of awe and wonder, as a hidden personal value, as a sense of responsibility that extends beyond oneself and in a sense of compassion for the world. Spirituality provides a sense of connectedness with the past, the present and the future, a form of connectedness that is closely related to a person's relationships with God, self and others. Spirituality is an important dimension of the lives of people with

learning disabilities and as such should be taken seriously by carers, support workers and those responsible for developing policy and strategy.

In the following sections of the report we examine the practical implications of an increased understanding of spirituality within the lives of people with learning disabilities and begin to explore the care and support that people want, and the strategies that need to be adopted by individuals and services if spiritual care is to be implemented in a way which is meaningful and authentic.

## Section Two:

### *Spirituality and Friendship*

At the heart of the understanding of spirituality that emerged from the experiences of people with learning 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.

*I am very lucky in this way as I have no doubts about the existence of God. I experience his presence as a tangible reality. I am so sorry if this is madness to you but to me it is the very essence of life and there is nothing more important.*

We have seen that connection with God promotes a sense of value and feelings of being special. Experiencing a relationship with God seemed to affirm what was positive in people's lives and made them feel equal with the rest of society. As one young woman put it:

*We are all equal at the end of the day. All one in God. God loves you if you're bad or good.  
The promise is all the time.*

Such a connection with God, particularly when it is experienced through good relationships within a religious community can be a powerful and positive shaper of personal and corporate identity and self-worth.

For others this sense of spiritual connection was encountered within close relationships such as family, friends and within particular communities - social groups, People First groups, day centres. Some people developed their sense of connection in relation to nature or the significance of particular places.

Interviewer: *Within your life, what do you think has given you meaning?*

Mary: *Seeing blossom on the trees and seeing new buds. Yes, like flower buds or leaves on the trees.*

Here spiritual connectedness is discovered within the simple but profound experience of noticing the beauty of nature and responding with a sense of mystery and wonder.

### **Connected through friendship**

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 a person's friendships that people 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.

Friendships were a vital source of connection, social inclusion and a sense of belonging: an experience of trust and hopeful possibilities. As one woman, Julie, put it:

*If you don't have friends you wouldn't go out and you'd be left all on your own. You wouldn't have any contact with anyone and you wouldn't believe in what they would say and you wouldn't believe what they think.*

Friendships affirmed people's identities and provided a safe space within which they could find acceptance and love. Friendship provided a sense of connection both personally and socially within the wider community.

Interviewer: *You are now training for different jobs aren't you, so you must have learnt an awful lot over the last ten years. Is that through Kay?[Heather's carer]*

Heather: *Yes and Pauline.*

Interviewer: *Pauline?*

Heather: *Yes, my friend, she was my rock. I can go to Pauline and say this and she'll just listen. And not many people would do this.*

Interviewer: *They wouldn't have the time or they wouldn't listen properly?*

Heather: *Yes.*

Interviewer: *What would happen after that, after she listened?*

Heather: *The weight would lift off my shoulders.*



Heather's friendship with Pauline made her feel valued, accepted and secure. Pauline was there for her in the midst of life's complexities.

People talked about how their friends cared, took time to listen and were prepared to share the burdens of their lives. For some, the quest for friendship was a primary life goal:

Interviewer: *You said that friends are important - people spending time with you?*

Lorraine: *Well that's my opinion.*

Interviewer: *Is there anything else you need to get through life?*

Lorraine: *I can't think of anything.*

Lorraine's main goal in life was to gain and maintain friendships: there was nothing more important.

Friends provided stability and a context for openness and sharing at an intimate level.

Interviewer: *You've said that you get bored.*

Harold: *I do sometimes.*

Interviewer: *What would make you feel useful?*

Harold: *Sitting by a person and chatting to them. Now Peter is in the lounge but he don't sort of sit next to me.*

Interviewer: *Someone to sit down and talk?*

Harold: *That's what I would like. Now Simon - he'll have a shower after tea, then he'll go and listen to his CDs, but he's no company for me. No company.*

Interviewer: *So it's someone who's going to spend time talking?*

Harold: *That's what I'd like more than anything.*

This elderly gentleman lived in a shared home with a number of other men but in spite of the constant contact, he did not think of them as his friends. This shows that the process of enabling friendships is much more complicated than simply putting people together. It overlooks the important fact that, like all relationships, friendship has to be learned, facilitated and nurtured.

### *Friendship and belonging*

It was clear that to choose and be chosen as a friend was an experience that could be life changing for some participants. To be chosen as someone's friend was to be recognised for what one is: to have that something within us which is special and unique, affirmed as worthy of a relationship. Befriending and being befriended was a profoundly spiritual and affirming experience. Friendships, in a very real sense, determined the type of person people became, the opportunities they had for socialisation and self-development, the ways in which they viewed themselves and their expectations for their lives.

**Friends provided such things as:**

- Love: *Friends are important because they love me;*
- Guidance and support: *Derek is a guide...he is a friend;*
- Non-judgemental acceptance: *Friendship means not being judged and being pushed away.*
- Self-transcendence: *A friend is someone who can rise above and beyond one's own life context.*
- Dependable presence: *Knowing someone is there for you.*
- Foundational support: *She was my rock...'cos I can go and say this and she'll just listen...the weight would lift off my shoulders.*

Friends provide a powerful source of meaning, hope, value, acceptance and love, all attributes which are basic components of the wider definition of spirituality. Close relationships such as friendship seem to fulfil roles similar to contemporary understandings of spirituality, but without necessarily being carried out within the context of formal religious systems.

## **Modes of friendship**

It is important to note that in order for it to be spiritually fulfilling, friendship has to be authentic and the product of a meaningful choice. The people with learning disabilities that we spoke to said that the type of friendship they wanted was voluntary friendship. This does not necessarily exclude friendships with paid carers and support workers. However it does suggest a need to be needed which goes beyond professional responsibility and duty.

### *Professional friendships*

Some participants did comment on the importance of friendship with the professionals who offered them care and support. They wanted more quality time with carers although they were aware that staff were busy and often had no time for meaningful friendships.

*What is important to me? I would say me having friends: people staying with you and... listening to the telly with me, and company...But I know the staff here are busy all the time. The staff come round at four o'clock, and I like to have a chat with them but they don't seem to have the time.*

The issue of staff time has significant implications for the spiritual care of people with learning disabilities. Sometimes lack of time is the reason due to the pressures of the system. Professional carers and support workers simply do not have time, or are not prepared to make time, to develop meaningful friendships. Sometimes the problem is a lack of clarity as to what professional might mean in terms of levels of relationship.

### **Robert's Story**

Robert has lived at home with his mother and sister for most of his life. He is 73 years old, with a mild learning disability. Recently he moved from home to sheltered accommodation and is struggling with the changes this brings to his identity and the meaning and purpose of his life. He spoke about his upbringing and how he was left sitting in a room on his own most of the time whilst his mother and sister washed his clothes, did his ironing and cooked his meals. It was clear that he had never learned to relate to others and had no sense of responsibility for himself or his future.

Since moving into a hostel, he has begun doing things for himself but still has no real companionship. He gave a mixed picture of his life. He is a member of many community groups

and is involved in education classes, but he has never been able to make any real friends. He still finds it upsetting to socialise on his own. Although he has community contacts he is very lonely. He appears to identify with staff more than other people with learning disabilities which increases his loneliness because staff do not have time to be with him. Robert views this partly as a result of him becoming more independent and self-sufficient: other people with greater needs have priority on staff time.

Robert's loneliness and sense of isolation contrast sharply with the perceptions of staff and care workers. They hold him in high esteem - a success in community rehabilitation. But for Robert, life is marked by loneliness, disconnection and a longing for friendship. He feels a strong affinity towards staff but they don't have the time to explore basic relational issues with him, so a crucial dimension of his life goes unnoticed. Robert is experiencing spiritual distress.

The point here is not that staff are uncaring or disinterested. They simply haven't noticed what is going on in a highly significant dimension of Robert's life. Ironically his success according to professional criteria for community integration and self-sufficiency has actually separated him from the type of spiritual support that he desperately needs. This would indicate that spiritual care may well have systemic and institutional dimensions which need to be addressed. If spirituality is as important as the people in this study suggest it is, and if the system militates against the individual receiving the support they require for good spiritual living, then the system needs to change.

### *Voluntary friendships*

However, most participants felt that professional friendship alone was not what they wanted. What people wanted more than anything else was voluntary friendship - that is, friendship that is given freely and not simply the product of professional roles. A good example of such a friendship was given by a mother about her son Steven, who has profound and complex needs. She described Steven's friendship with Michael, a member of her local church, as crucial for the development of Steven's spirituality.

*Stephen regularly looks out for Michael when we drive up in the car park. If Michael is hanging around the front door he's out of the car like a shot and runs to greet Michael, usually with his sort of hi-five thing and big smile and Michael will say, "Well how are you today buddy" - that's his sort of language. Steven may not even respond verbally, he might just smile and just stand there beside Michael. Or he will go into the church and find out where Michael is sitting and invariably sit beside him if he's there. He's not always there because he works shifts. But if he's there he'll sit beside him and as soon as the band in the church strikes up Michael will be up there in the aisles to give it laldy and Steven will be right by his side. He joins in on everything that is going on in terms of the sort of songs. If it is a clappy, happy, dancy type song Michael will be right there joining in. So there's the sense of real connection there with Michael.*

Michael's freely given friendship enables Steven to be integrated into that community in a way that is meaningful and significant. Again in their relationship we see the importance of 'specialness', and its implications for relational connectedness and spiritual development.

Michael and Steven's friendship illustrates well the significance of voluntary relationships. Listing the differences side by side, the distinctions become clear.

<b>Professional Friendship</b>	<b>Voluntary Friendship</b>
People become friends as part of their role as paid professionals.	Both enter into the relationship for reasons that are not related to profession or vocation.
People are paid to be friends with people with learning disabilities.	Neither receive any form of remuneration for their relationship.
People begin their relationships with people primarily because they have a learning disability. If the person did not have a learning disability the relationship would not have come into existence.	The relationship may involve, but is not dependent on one person having a learning disability. They are there for one another.
People become friends with people within the context of a professional relationship that is bounded by the number of hours that a person is paid to be there.	The amount of time that they spend together is determined by themselves according to criteria which both are open to negotiate.
Professional friendships have fixed boundaries and codes of ethics and professional conduct to prevent these boundaries being abused.	Friendship has no official boundaries. They must negotiate the parameters of their relationships between them.

The importance of the voluntary nature of friendship was not lost on professional carers. One focus group of carers placed a strong emphasis on the need for volunteer rather than paid workers to offer friendship. They felt that friendships with people who have learning disabilities are most effective when they involve non-service people.

*I think that we do have service users who are genuinely very happy: they don't have any great protests. We often have social services coming round and saying: "Could you take John because he won't fit in anywhere else? He does this and he does that." Within a very short time he settles down and becomes very much part of the surroundings without any problems. I think a lot of that stems from the fact that we have many volunteers. People who genuinely want to be there. They're not there for the money and they're not watching the time to see it's three o'clock I shouldn't be there. You see that from the support staff that come in from houses. Right in the middle of an assignment, they'll take their 'client', as they call him, away because "My shift is finishing at ten. It doesn't matter what he's doing, my shift is finishing at ten". Doing that to someone who has got challenging behaviour.... and you're just managing to get them calm, causes all sorts of problems. But we don't get that because we've got people who want to be here. I think in that respect we're very lucky.'*

This is not to suggest that professional friendships are meaningless or necessarily inferior. But there is a significant difference between these two types of friendship and that difference was important for the people with learning disabilities who took part in this study.

Some professionals make a concerted effort to develop friendships and some of the carers and support workers we met gave up their own time in order to develop meaningful friendships with people with learning disabilities. However, when people do this, they move from being professional friends to voluntary friends. This is good insofar as voluntary friendships are precisely what people with learning disabilities want. However, it brings with it certain expectations. The questions which all potential befrienders, (lay or professional) must ask themselves is whether or not these expectations can be met or whether they are creating a situation where the person with a learning disability may end up deeply disappointed. One support worker made this point poignantly:

*I think that in today's services where there's constant change of staff, people are constantly losing their history...it is being lost all the time. It's the most devastating lack of belonging, to be faced with yet another team of people. Everything of your history, maybe in the house you're living in, is wiped out. You can also lose what is a spiritual experience - that of being asked or involved or having a role in your community - because the new people don't know that last year you were responsible for this, or did that, or had that job..*

In other words, when significant individuals – professional or non-professional - move out of a person's life they leave gaps that can be devastating for the person concerned. Unless the staff member is prepared to carry on a friendship over an extended period of time, with all the implications that involves, it might be better not to offer the relationship at all. 'Voluntary' friendships that end when the staff member moves on can be highly problematic.

### **Lack of friendship**

Sadly, despite the importance of friendship for participants, it was clear that some people found it extremely difficult to develop meaningful friendships. Loneliness, isolation and disconnection was evident in many people's lives. Roland's experience was typical.

Roland: *I'm still lonely now in a way, but with help and support I do lots for myself now.*

Interviewer: *In what way are you still lonely?*

Roland: *A whole lot of things. I have my own life now, travelling alone.*

Interviewer: *You'd prefer to go with someone.*

Roland: *Yes with someone, with a friend - not the staff, it's hard isn't it, it's hard you know. I went to the pictures on my own the other night, by myself because there was no support and shortage of staff...I cried.*

Interviewer: *Did you think it was worth going on your own?*

Roland: *No I don't think so, no not nice on your own is it?*

Interviewer: *Where could you find a friend to go with you?*

Roland: *I've tried. I've tried and I can't. I can't get...I've tried, I've tried, I can't.*

Interviewer: *So even though you've got the support staff you don't have other friendships?*

Roland: *Yeah.*

Interviewer: *Have you ever felt love in your life?*

Roland: *No, not really, been lonely all my life.*

Roland's distress highlights the difficulties people have in finding friends and their desire for meaningful, non-professional friendships. The idea that someone can feel they have been lonely all their life is both profound and deeply troubling. Loneliness is an intensely spiritual experience. If spirituality relates to connections with self, God, others and the world, then to be dislocated from a primary source of connection has implications for the spiritual well-being of those who are lonely. Significantly, Roland was not looking for professional friendship. He wanted a voluntary friend and companion. This raises the important question of where people with learning disabilities could find such friendships. Two community workers expressed their concerns about access to relationships within the community:

Heather: *A volunteer went into one of the houses. She said: "It reeks of loneliness, reeks!" I thought that was such an apt description really.*

Theresa: *I would describe that as... is there such a thing as... negative spirituality? To be so lonely means that your whole spirit is in distress, isn't it? I suppose that's why we have such an emphasis on volunteers - who may be friends, who may be what we call members of the safe community, people who have actually been chosen or choose themselves to be around an individual during their spiritual journey. [We hope that] gradually trust and friendship will grow. It's very hard to achieve. I'd love to say that there were lots and lots of safe communities around but it takes a lot of skill, a lot of hard work, doesn't it?*

Participants saw friendship as a spiritual priority that is one of the foundations of effective spiritual care and development.

## **Building friendships**

### *Religious communities and friendship*

Religious communities are one obvious potential source of voluntary friendships. they bring together disparate groups of people and instigate forms of integration and community that may be missing from wider society. They can provide a space within which people with learning disabilities can be given the opportunity to develop positive relationships with God, self and



others; positive spiritual relationships that can counter the disconnection and alienation that is so prevalent within many people's lives and indeed within society as a whole<sup>29</sup>. There is evidence that:

*The 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 on-going transactions.*<sup>30</sup>

Religious communities can provide a vital context for the types of friendship that have been highlighted as deeply beneficial for the spiritual care and development of people with learning disabilities.

This was the case for many participants. Religious communities provided support, welcome and in some cases participated effectively in developing people's sense of acceptance, belonging and well-being. We discovered some places where people with learning disabilities were well integrated and their spiritual needs appropriately catered for. Diane's experience is an example of this:

Interviewer: *You were saying before that you thought what was important in life was going to church?*

Diane: *Yes.*

Interviewer: *Can you say what's good about those [church] organisations?*

Diane: *They're good you know, good to make friends and then chat to them.....*

Interviewer: *Is that because of the people that go? What makes it really good?*

Diane: *Good fun...friends.*

A Moslem woman who has two children with learning disabilities, described how her 19-year-old son, Ahmed, who has profound and complex needs, is active in her mosque and takes great pleasure in learning about and participating in their religion. Ahmed is more enthusiastic about Islam than her other children. Although he is English speaking, he has spent a lot of time learning

the Qu'ran in Arabic, primarily by copying other children within their religious community.

Ahmed's mother emphasised that he was never forced to learn it.

*Allah gave him the ability to read Arabic, no one taught him- he just copied others- he was never forced to learn at all.*

He simply learned it through his participation in the community and his relationships with those around him.

Ahmed regularly goes to the mosque with his father and is fully integrated in the religious community where he has a solid and recognisable role. People have gone out of their way to facilitate his spiritual development although Ahmed's mother emphasised that there is a great need for information on Islam in symbolic and pictorial form for people with learning disabilities. She was unclear as to precisely why this particular community was accepting of her son, but she put it down to taking the issue of compassion seriously. Ahmed's story demonstrates the potential of religious communities to be places of friendship and spiritual connection. Although there remains a great need for education and consciousness raising, it would appear that particular communities have an innate tendency to react positively to the experience of people with learning disabilities in their midst.

Another example of good practice was narrated by Harry with the aid of his parish worker. Harry has profound and complex needs. He spoke with affection about his encounters with a priest and the ways in which he had managed to include people with learning disabilities within his religious community. Harry valued the ways in which the priest valued him and showed this by simple gestures such as buying him cakes and tea and praying for Harry's dad when he was ill. Harry told us that the priest used to hold monthly masses specifically for people with learning disabilities and their carers. He developed a form of liturgy that aimed to balance the needs of the people with learning disabilities and their carers. For example, he moved the front table forward during mass and walked closer to the congregation. He asked for prayer requests from people with learning

disabilities during the mass and did all he could to take people seriously and include them in every part of the service. This priest died recently and unfortunately, since his death, many of the people with learning disabilities who regularly attended his church no longer go there.

It could be argued that such services are exclusive and reflect an old-fashioned view of spiritual integration. At one level this may be the case. Harry's parish worker, Hannah, has realised this danger and currently holds integrated masses in many different churches. They take over the usual mass, sing choruses, have shortened homilies, and include people with and without learning disabilities in the offertory, everyone either holding a flower or a candle. They shorten and simplify the whole mass. This is probably a better model than the more exclusive service.

Nevertheless, the enthusiasm with which Harry spoke about these services indicates that we must take seriously their significance for him and for the many others who have benefited spiritually from this priest's efforts.

### **Problems with religious communities**

It is clear that religious communities are often appreciated by people with learning disabilities and that they are capable of providing an important dimension to people's spiritual development, in terms of friendship development and in enabling people to develop a deep and meaningful faith. Nevertheless, faith communities can also be difficult places for people with learning disabilities. Two areas that need further consideration emerged from the discussions.

1. Faith communities could be exclusive and excluding
2. The form of friendship provided by some faith communities can be superficial, uncommitted and in a real sense unspiritual.

## *Exclusion*

The exclusion of people with learning disabilities within religious communities can happen on two levels – the intellectual level and the social level. This exclusion can happen without anyone even realising it. People can be excluded by the ways in which the messages of the community are presented. Forms of teaching, liturgy, prayer and worship used by the community are often intellectually inaccessible for people who communicate and learn in different ways. Reflecting on the spirituality of her son, George, who has profound and complex needs, one mother summed up this difficulty:

*I do think there's an issue of social access and intellectual access. Intellectual access mainly in the fact that now he's virtually 18 and he's an adult, but when we come to the sermon it usually lasts at least three quarters of an hour and it's meaningless to him. So he'll sit and doodle on a wee notepad for all of that time. Actually I think it's commendable that he's willing to sit for that length of time and doodle and beside us, his mum and dad. I think there's a lack of intellectual access in general, not just in our own church. How are people with learning disabilities going to learn more about God and the Bible and Christian life if there's no opportunity for them to access teaching that's really pitched at their spiritual level?*

This intellectual exclusion is compounded by various forms of social exclusion. George's mother went on to tell us a story that illustrates well the social exclusion that people can experience within religious communities.

*We have a lot of young people in our church, a very lively church, very contemporary church, but I never see any of the young people getting alongside George. None of them ever sit beside him in church. None of them have ever sat beside him in church. None of them have invited George round to their homes at any time and as a parent carer I sometimes find it difficult. I see them all going off for lunch or whatever and George is going home with his mum and dad. I just think how he has missed out on social interaction in his teenage years. In fact maybe I could tell a little story. 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 for a birthday dinner and afternoon. We had sung happy birthday to her in the church and word was around obviously that the party was on. But of course George wasn't invited. As we drove off from the church we felt saddened that once again it was another example of exclusion and just how painful that was to us: not knowing how George felt about that. We came home and had our usual Sunday lunch. I went through to his*

*bedroom later on in the afternoon. He was cutting up bits of paper and I said to him:  
“What’s this you’re doing George”? And he said: “I’m making up tickets for the party”.*

George was not the victim of a deliberately unpleasant act. Had the young people known how George felt, they might have included him. The problem is that no one outside of the family did know and no one took the time to get to know George, so the question was never asked. This kind of subtle exclusion often goes unnoticed.

One group of carers spoke about their experiences with Kieran, a young man who has profound learning disabilities. After much debate the staff group decided to take Kieran to a local faith community. They viewed this purely as a social opportunity as they did not feel justified taking him on religious grounds. Nevertheless, they recognised this as an important dimension of Kieran’s life and were keen to help him explore it. During the three months he attended, not one person spoke to him. One person patted him on the head in passing but that was it! The staff wondered if people were scared of Kieran, or embarrassed, or uncertain how to approach him. Either way the experience was not a good one and they decided there was little point in Kieran continuing to attend. One member of staff said:

*Kieran gets a more positive response in the local coffee shop.*

Kieran has not been involved in any faith community since.

If faith communities are going to become places where spiritual friendship can be developed and nurtured, the important issues of education and consciousness-raising will have to be addressed effectively.

*The dangers of superficial friendship*

The friendship that people encounter within some religious communities can be superficial, uncommitted and in a real sense unspiritual. This perhaps presents the most serious challenge. It was clear that many people with learning disabilities benefited significantly from their encounters within religious communities and that spiritual friendships did develop. Often, however, these friendships tended to remain at a superficial level. Ina's experience illustrates this point well.

Interviewer: *Where do you feel you belong?*

Ina: *Well I sort of feel I'm trying to help in the community. I'm participating.*

Interviewer: *You're trying to help within this community.*

Ina: *Well this area here: I'm trying to build up a friendship.*

Interviewer: *You're trying to build up friendship. Where is that?*

Ina: *At the church.*

Interviewer: *At the church, and how are you getting on there?*

Ina: *OK.*

Interviewer: *Is that by meeting people or by them inviting you into their homes, ... or?*

Ina: *By meeting people at the church and in the home.*

Interviewer: *And how do you find that? Do you find it easy or difficult?*

Ina: *Easy.*

Interviewer: *Quite easy. So do you go to meetings during the week or do you go to people's houses or do you just see them at mass?*

Ina: *Just see them at mass.*

At one level Ina's quest for friendship has been fruitful. Within the boundaries of the religious service of worship she seems to have found acceptance and, at a certain level, friendship. However, that acceptance and friendship appears to stop at the door of the chapel. She has never been invited into the homes of her religious friends, although clearly she desires this. Her friendships are limited to the spiritual boundaries of the religious service and the physical boundaries of the church building. This is not an uncommon pattern and was acknowledged as significant by other people with learning disabilities, parents and other carers and support workers from various religious traditions. One carer commented:

*I think that if you are someone living in a service it's so rare to be invited into anybody's home. When we sat round at staff training and looked at when last someone was invited into another person's house it is quite, quite rare.*

The challenge for religious communities then is not simply to integrate people with learning disabilities into their various services of worship. The real challenge is to create forms of community where meaningful friendships can be developed, where people with learning disabilities participate in the whole lives of people within religious communities. Meeting-oriented friendship has a role and a function, but if that is as deep as the relationship goes, something fundamental is missing in terms of spiritual care.

### **Non-religious reasons for attending religious communities**

People were involved with faith communities for a variety of reasons, not all of them religious. For example, one man with communication needs commented on his past social isolation and the way in which he used the church as a stopgap. He felt it gave him company when he needed it, until his life “filled up.” He stopped going to church when he developed other interests. Now he attends a drama group, does voluntary work and also has a girlfriend. He feels that these new interests give him similar fulfilment to that which the church had offered him.

When asked what he thought people with learning disabilities got out of being involved with a religious community, one carer commented:

*To be honest I don't really know. I think it could be a reason just to get out as well. They're not really socialising they're getting out into the community, to be part of it instead of just being bound in one place.*

These comments indicate that some people with learning disabilities attend faith communities to meet needs that may be spiritual in the more general sense but are not necessarily specifically religious. They go there because it is a place where they can find some degree of acceptance, value, purpose and a place to belong. This of course is not something confined to people with

learning disabilities: many people use faith communities in this way. Faith communities need to recognise the various meanings that attendance might have, and learn to incorporate this knowledge into the ways they develop their caring and support practices. As with all people, we cannot assume anything about a person's spirituality until we get to know them and begin to understand what it means and how it functions in their lives.

Religious communities need to acknowledge the uniqueness of each individual as opposed to making general assumptions about people with learning disabilities. For example, within some strands of religion there is a perception that people with learning disabilities are 'holy innocents' whose faith is pure, unadulterated and somehow exemplary. But given that many people with learning disabilities have similar mixed motives for attending religious communities as the rest of society, religious communities may have to consider developing strategies to meet their spiritual needs as well as their religious needs. Of course, as we have already said, many people with learning disabilities are devoutly committed to their religious faith and are capable of deeply meaningful commitment to God and religion. The point is that the nature of a person's commitment to a particular faith community should be worked out in relationship with the individual and not via cultural stereotypes and naive assumptions.

## **Conclusion**

Friendship, understood as a form of spiritual connection, is fundamentally important for the quality of life and life expectations of people with learning disabilities. Friendship is a basic unit of spiritual care. It begins with recognising the importance of connectedness for spiritual development and human well-being. Reflection on people's experiences expressed within this study shows that this dimension of their lives is undeveloped and that appropriate and effective



facilitation of friendships is a priority in people's lives. Religious communities hold much potential in this area, but can also be exclusive, excluding and ineffective in this primary spiritual task. We need to think seriously and creatively about how people with learning disabilities can be enabled to develop meaningful voluntary friendships that will nurture and enable their spiritual development in its religious and non-religious dimensions.

## Section Three:

### *Grief, Loss and Disconnection*

While connection sits at the heart of people's perceptions of spirituality, it is disconnection that often marks the actual life experiences of people with learning disabilities. One important area of disconnection and consequent spiritual distress that emerged strongly from the research findings was within people's experiences of grief and loss, particularly grief and loss associated with bereavement. The profound sense of disconnection resulting from grief was one of the major spiritual struggles within their experience and one that, unfortunately, people are often left to wrestle with alone. Their responses suggest that death is something they find complex and perplexing and yet it remains a taboo subject for many carers and support workers.

#### **Bereavement**

For many participants the wounds caused by the death of a loved one had never healed. They used various strategies and approaches to make sense of the gap, regain a feeling of connectedness and cope with the continuing pain of the loss. It became clear that there were large pools of unresolved grief that had never been explored and which continued to edge into people's consciousness causing significant spiritual and emotional pain. For these people grief was a wound that had never had a chance to heal; a painful dimension of their experience that caused ongoing pain even after many decades.

We can explore people's experience of grief under four headings:

1. Acceptance and moving on.
2. Reconnecting with the dead person.
3. Reconstructing a hopeful future
4. Continuing pain and lack of resolution.

## Acceptance and moving on

The experiences of the participants would suggest that there is no single way in which people with learning disabilities cope with the pain of grief and loss. This is as one would expect. Grief is always personal and unique to individuals. Some simply accepted the loss and tried to rebuild their lives without the physical presence of the loved one. Sarah, who has a mild learning disability, expressed how she coped with the death of her father in this way:

*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.*

While her dad remained deeply missed, Sarah simply accepted this and moved on. One support worker reflected on her experience of this type of acceptance in the life of Lorraine who has Down's syndrome and profound and complex needs:

Carer: *I think when she was about twenty-five her father died. She accepted it immediately. They moved house fairly shortly afterwards to a flat because her mother knew she couldn't cope in a house with a garden. A few weeks later they went past the old house and Lorraine said: "We used to live in that house but now Dad's died and we live in a flat." End of story. Total acceptance. There didn't appear to be any grieving and her behaviour since hasn't suggested any sort of grief really: just that it had happened and she had to cope with it... She's a very adaptable young lady which is good.*

Interviewer: *Did she have a good relationship with her father?*

Carer: *Oh she did yes - a really good relationship - a lively one and a close relationship as she had with her mother. So it wasn't as though he was a distant figure. A very united family.*

A mother and father expressed a similar experience, reflecting on their profoundly challenged daughter's experience of the death her grandfather:

*Kate's father died and nobody was speaking about it. We weren't saying anything and June just said, as she does in a matter of fact way: "I don't know what you are all worried about. Grandpa's in heaven now." People were embarrassed then, they were embarrassed for themselves and she didn't know a lot of these people. She says things in a matter of fact way as if she's just saying it but it's not - that's just her way.*

This young woman's straight talking embarrassed those around her. The idea that carers, friends and support workers might be embarrassed or awkward about talking about death is significant and worthy of further reflection. For now the important thing to note is that some people simply accepted the loss and moved on, even though the relational bonds between the person and the deceased were strong. It seemed that some people had a capacity to cope with loss that others did not have

### **Reconnecting with the dead person**

The boundary lines between the living and the dead appeared at times to be very thin. A number of participants seemed somehow to continue their relationships with people after their loved ones had died.

Tommy, explained the way in which he received his identity through interacting with and being inspired by the spirit of his late grandfather:

*The spirit inside me comes from my late granddad, my dad's dad...I think to myself my granddad would be proud if he sees me taking on his role in life.*

Tommy's grandfather still provided an important source of identity, value and moral aspiration.

This extract from one of our focus groups also illustrates the point well:

Interviewer: *What are people's ideas about prayer?*

Harold: *I do a lot of praying...Especially, if sometimes I just pray for my family ...a person.*

David: *Pray for some person*

Danielle: *Not me*

Harold: *No but somebody*

David: *Who?*

Harold: *Just somebody – she passed away a while ago*

David: *Oh Yes*

Interviewer: *So when you are praying what do you mean by praying?*

Harold: *Go down on my knees*

Interviewer: *Are you praying to God or...?*

Harold: *No, I'm praying to the person.*

In this exchange, it is unclear whether Harold was praying to the memory of the deceased person or whether he actually believed that their spirit was somehow a real, continuing presence. The important point is that for him and for others the dead person, although not physically present, still maintained a psychological and moral influence on the living.

## **Finding strength, security and hope for the future**

### *Heaven and the afterlife*

People's understanding of what happens after a person dies suggests that for some there is an active and continuing role for the dead amongst the living. Although the person is no longer there physically, psychologically their presence is still felt as part of a person's social network, interacting in a meaningful way with the day-to-day living of those who are left behind.

It is worthwhile noting here, the similarities between the participants' experiences and the revised model of grief put forward by Tony Walters. Walters offers a revision of the ways in which we in the West have understood the process of grief<sup>31</sup>. He defines the dominant model of grieving as working through emotions, moving on and learning to live without the deceased. Instead of this model, Walters proposes what he describes as a sociological model. He points out that those who are left behind want to talk about the deceased and to construct a story relating to the meaning of the person and the loss for their lives. In the West, psychological models of grief tend to assume that the sense that the deceased is still alive is nothing but a temporary if perhaps necessary illusion that people experience before they begin to reconstruct life without the deceased. Walters offers an alternative perspective. He suggests that the purpose of grief is not to detach oneself from the dead, but to learn how to live with them. How a person achieves this varies. In other words there is no universal grieving process, but several kinds of grief process. This raises important questions as to

how we talk about the dead. Must we see people as stuck in grief if they will not entirely let go? Walters suggests not. Within his model of grief it is possible to integrate the dead with the living, an integration that people commonly embark upon and a way of dealing with grief and loss that was very evident in our study. Walters proposes a model of letting go and holding on. In opposition to our medicalised culture which states that holding on is pathological, the reality of the participants in this study, as in Walters' own research, is that holding on is inevitable and sometimes quite healthy. This being so, the types of reactions to grief and loss which we observed in this study may well be healthy responses to the pain of loss.

### *Prayer*

Prayer was significant for some people in coping with loss, although the way people used it varied. For some, it was a way of reconnecting with God, Self and others in the midst of the 'fragmentation' caused by grief and loss. Prayers were sometimes spoken and sometimes written. The aim was to express a person's inner pain and seek ways of exploring the possibility that there could be hope beyond the loss they were experiencing. Sometimes prayers were done within a religious framework and directed at God. One carer described the way in which one of her bereaved clients who has high communication needs used written prayer:

*She would write something like, "Dear Lord Jesus, please help Karen...who died last week. I think that would have been hard because Karen was a perfectly fit lady who'd just come back from holiday and died very suddenly. So she was quite upset.*

This type of prayer appears to be a simple expression of grief with no expectation of an answer or of reconnecting with the dead. Others directed their prayers towards the dead person. One young man of Afro-Caribbean descent described how he enjoyed participating in a local church. He did not go to church to meet God but to play music and sing. When asked if he prayed he said that he prayed to his dad, who is dead.

## *Imagining a hopeful future*

Religion, religious artefacts and imagery were all used by participants in their quest for a way to deal with grief. The possibility of an afterlife was used by some specifically as a way of discovering hope in the midst of grief and loss. The following extract from a focus group illustrates this point well:

- Interviewer: *What do you think is the message of the Bible? What do you think is the main thing the bible says to us?*
- Hugh: *Heaven.*
- Ursula: *Heaven.*
- Interviewer: *It's telling you what the future might be like?*
- Peter: *Mhmm. It helped me a lot. It helped me a lot since my grandad died. It helped me a lot.*
- Raymond: *My brother is dead and I'd like to go to Heaven to see him.*
- Interviewer: *So your brother's in Heaven?*
- Raymond: *My Dad and my wee brother died too and so I'll see him and my grandpa and my grandma. I'll see my whole family again.*

It is important to stress that nothing emerged from the interviews to suggest that this was a derivative of spiritualism, or any kind of formal ritualised attempt to contact the dead. Rather it seemed to be a refusal to let go of the memory of the dead person and a desire to maintain their presence within the individual's social and spiritual experiences.

At first such a way of coping with death may appear unhealthy, perhaps even to be a form of pathological denial. However, a similar pattern of interaction with the dead is not uncommon (if not generally expressed) in the experiences of many people within society<sup>32,33</sup>. There is evidence to suggest that such a grafting of 'unreal' people into one's social support network may in fact be psychologically and spiritually healing. Melvin Pollner points to the fact that alongside most people's real social network, there exists a network of imagined others that overlaps and interacts with the person's actual social network and significantly affects their relational encounters<sup>34</sup>.

These imaginary others may include contemporary figures such as film stars, pop stars and media

personalities. Individuals construct elaborate forms of imaginary interaction with these people, and often use them as imaginary dialogue partners when deciding on particular courses of action. Again, a Christian might ask how Jesus would act in a particular situation; a Muslim what Mohammed would do, a Buddhist, what Buddha would do. These figures can become central to the cognitive and interpretative mindset of individuals, who draw upon their identification with them, and ascribe meaning to situations according to the nature of their imaginary dialogue with them. In this way, they can have a major impact on a person's self-esteem and coping abilities, and are often an important source of advice and support.

If this is so, then an approach to death that seeks actively to reincorporate the dead within one's social network may not be unhealthy denial or avoidance. It may in fact be a healthy and perhaps even healing coping mechanism. The important point here is that before we pathologise the reactions of some people with learning disabilities to the experience of death, we need to be open to the possibility that dimensions of their experience which may appear unusual, may in fact be vital to the grieving/coping process.

### **Unresolved grief**

Time and again participants spoke of their continuing struggles with grief and the fact that they had never had the opportunity to speak about it or to work it through. Some people stated that the focus groups and interviews were the only opportunity they had had to talk about grief and pain that sometimes reached back 20-30 years. Within the focus groups in particular, participants shared different stages of the grief process with each other. It was clear that this group context acted as a safe space to express emotions and share hidden hurts and provided a real source of strength for the members of the group.



### *Fear of doing damage*

The main barrier preventing people getting the opportunity to speak about grief seemed to be carers' and support workers' reluctance to broach the subject, for two reasons. The first was a fear of doing damage. There seemed to be an underlying assumption that the grieving needs of people with learning disabilities are somehow different from the rest of the population. Graham's story illustrates this point.

Graham is 44 years old and has a learning disability with profound and complex needs. His verbal skills are limited but he is a friendly and open man who is able to communicate his needs to those who know him. Graham was 42 years old when his mother died. He had lived with her all his life and had become particularly close to her since his father died four years ago. Graham's mother was 62 when she passed away and her death was a tremendous shock to him and his family. Shortly afterwards Graham was taken into the care of the social services. He became extremely agitated and at times quite violent, an attribute which was very much out of character. His support worker was deeply troubled by the change in his behaviour and began to investigate its possible causes. He discovered that Graham's mother's death had never been addressed directly with him. Indeed on the day of his mother's funeral Graham's family had decided that he shouldn't be allowed to attend as it would be "too upsetting". He stayed at home with a babysitter, who turned out to be a friend of the family he had never met. Graham's last memory of his mother was peeking through the closed curtains and seeing the family and the hearse move away from the front of the house.

Graham's support worker spent a lot of time with Graham explaining what had happened and allowing him to spend time at his mother's grave. Thus the process of mourning was properly initiated and Graham's disturbed behaviour ceased.

For Graham, the consequences of his family's actions, albeit with his best interests at heart, were devastating. While Graham's situation may be extreme, the underlying principle of assuming different needs or protecting people from perceived harm is present in many of the implicit assumptions made by professionals and families about the grieving needs of people with learning disabilities. Whilst it is right that services should strive to protect people from harm, careful consideration needs to be given about what is appropriate for each individual to ensure that their protective actions do not at times actually cause harm rather than alleviate it.

### *Avoidance*

Some carers expressed caution and fear about raising the subject of death due to the perceived emotional vulnerability of people with learning disabilities. Sometimes this was for good reasons. One group of healthcare professionals highlighted the dangers of opening up wounds without facilitating a healing response.

*Inadvertently you can tap into very deep emotion and maybe that's something you have to be mindful of - not to leave people hung and dry.*

*It may take years to build up trust...I can't let them go all the way down there and then just go home!*

To attempt to explore issues of unresolved grief without having a strategic pastoral plan is obviously inappropriate.

Other carers were apprehensive about people's responses and whether they themselves would be able to cope with the expressed emotion.

*What I find by and large here is that if that subject comes up whether its related to them or not...a good portion of them will burst into tears.*

This comment indicates that at least part of the reason why some carers and support workers do not cope well with issues of death and grief may be due to their own avoidance of the issues. Whilst issues of protection are clearly important, it is necessary to balance the need to protect with the freedom to express what is important to the individual.

However, it was clear from the interviews and focus groups that people with learning disabilities very much wanted to speak about issues of bereavement, grief and loss and that they were well able to cope with the public expression of emotion. Rather than producing anxiety, talking about these issues within a focus group situation appeared to be a source of strength and encouragement for all members of the group. The following conversation between Fred and his carer illustrates this:

Carer *I feel quite privileged because it gave me an insight into things that I haven't been aware of. Maybe it's just that I was never in the right frame of mind to recognise. But did you feel better for speaking about it?*

Fred *Yes.*

Carer *You never felt upset when you left?*

Fred *No.*

Carer *Right. So you were glad you had shared that [his experience of grief after the loss of his father] with other people?*

Fred *Yes.*

Carer *Do you think that there isn't enough opportunity to discuss things like that?*

Fred *I sometimes speak to Mum and Dad.*

Carer *Right. Would you like more, maybe like a group at the centre where you could discuss these sorts of things?*

Fred *Yes...group for help.*

It seems that if carers can find the confidence to ask questions around difficult issues, it can be a healing and growing process for all concerned.

### **A perspective on death**

The experience of grief as it relates to death and dying is profoundly spiritual. Death whether real or anticipated involves the irreparable tearing apart of something that was once joined together. Such loss necessarily initiates an existential crisis within which not only meaning and purpose disappear, but the way the world was ceases to be. Our previous discussion on the spiritual significance of friendship and connectedness suggests that we make sense of the world around us in and through our relationships with others. Indeed we gain our sense of identity through our relationships with others. One can only identify oneself as a good and valued person if there is someone to be good to and if they affirm your goodness and value. Within close relationships such as marriages and close friendships, people even develop unique forms of language that only they share.

Death is so devastating because it is not only a loss of others, it is also a loss of part of oneself.

When we lose someone we are not the same as we were before. That part of ourselves which was created and shared in the relationship is no longer a part of us.

Thus death poses a serious challenge to our matrix of relationships and connections. Recovery from loss requires a reconstruction of the self and the creation of new forms of relationship which will enable us to recover from the loss, integrate the lost one as a meaningful part of our memory and try to begin to understand and accept what life is like without the missing person. In terms of spirituality and spiritual care, initiating and following through this process of self-reconstruction is of fundamental importance to all human beings. The ways in which we deal with this will determine not only our spiritual health, but also our mental and physical health.

The experiences of the people in this study showed that coping with death and the consequences of loss was a highly significant dimension of their life experience. While many had developed ways to enable the process of coping, many had not. There is clearly a need for this dimension of people's spiritual lives to be recognised and worked with in order that the process of reconstruction can be initiated and carried through in ways that are creative and healing.

## **Section Four:**

### ***Space, Time and Creativity***

Intimately connected with the ideas of connection and disconnection are the themes of time, space and creativity. These three concepts appeared to be central to certain ways in which people with learning disabilities developed their sense of spirituality and connectedness.

#### *The significance of space*

An unexpected theme that emerged during our conversations with people who have learning disabilities was the importance of space. Space is a dimension of our experience that we tend to take for granted. Yet we all need space in different forms if we are to remain at peace with ourselves and others: space to think, space to reflect, space within which to relate, space to stretch out after a hard day and so forth. Space is a dimension of our lives that is vital for the development and maintenance of mental and physical health. For the participants in this study, space was an important dimension of their spiritual experiences and longings.

The development and nurturing of meaningful personal relationships requires space, time and sometimes distance, if they are to function in a way that is spiritually fulfilling. Physical space enables people to meet others and develop friendships. Emotional space is needed in order that people can work through the complex but vital process of coming to terms with grief and loss and moving on in ways that are healthy and constructive. Spiritual space is required to discover the deeper dimensions of people's lives and to participate in rituals, prayer and other means that people used to explore the inner and outer dimensions of spirituality.

The need to create space to find oneself - and that which is not oneself - came through strongly in a number of interviews. Finding a space to listen to one's inner sense and one's experience of that which transcends the self was very difficult for many people. This was partly because of the physical environment – living very closely with others for extended periods of the day - and partly because of the pressures of contemporary life. The notion of people longing for space and peace but never quite finding either, came through strongly throughout the study. David, a man in his late twenties, neatly sums up the experience and feelings of many:

*I feel as though I need space, but I find it difficult in this environment because it's very difficult...I don't know...everything seems to be pressurised nowadays...to a certain time scale and if you can't keep up - I find it hard to adjust to the pace of life...I'd like to change myself but the pace of life makes it difficult to happen.*

David is experiencing the stresses and pressures that typify the current age: the need to be busy, the need to achieve, to compete, to keep up, to move on. In the midst of busy and often highly pressurised lives, people had a great desire to find space where they could find peace and inner stillness. As Laura put it:

*I think tranquillity is something you rarely get. There are very few places in the world where there is tranquillity. Sometimes, I feel as though I need space, but I find it difficult in like this environment because...it's very difficult.*

It was clear that many people were unhappy living this way and longed for a space where they could, in David's words, 'change themselves': a place where they could find the stillness to encounter themselves and perhaps something beyond themselves. Maria, a pastoral worker puts it thus:

*I think it's good to have a space in your living accommodation to be able to pray - somewhere you may have a focal point. If you're a Christian you can have a Bible, an illustrative Bible or something, or if you're not you could have a candle or a nice piece of artwork or a vase or some flowers. Just have a quiet space in your living room. I'm a firm believer in that because anything that presents a quiet aura or a quiet atmosphere will calm you down... or will calm somebody down.*

Maria highlights the ways that simple rituals in which spiritual awareness is raised and reflected upon can begin to carve out a space in the midst of a busy world; a space where people can listen to their inner selves and that which is beyond themselves. In terms of spiritual care this is of great significance. If people do not have the space in their lives to develop their spirituality (and it would appear that many do not), the types of inner longing they expressed will remain unfulfilled.

The type of space people sought was sometimes physical/geographical, sometimes psychological, but always in some sense, spiritual. For some, the space was finding refuge in a particularly favoured place that was not their home and not connected with their work. In one of the focus groups, Doris told us how a church building had become a place that provided space where she could pray and meditate.

Interviewer: *Is it the service or the minister who helps you to pray?*  
Doris: *No, just quiet and peaceful.*  
Maureen: *Oh it [the church building] helps you to pray?*  
Interviewer: *So it helps to go into the church when it's quiet and peaceful?*  
Doris: *Yes.*  
Interviewer: *On your own?*  
Doris: *Yes, on my own and not with anybody from the home... on my own.*

Doris' use of the church building as a quiet space was not linked to any religious ritual or ceremony, nor was it directly associated with a religious community. It was a kind of sanctuary where she could escape from the pressures of her life and carry out her personal spiritual practices. This 'sacred space' provided her with an opportunity to find space, peace and a sense of the transcendent.

A mother whose son has severe autism and high communication needs, related a similar experience:

Carer: *If we want to calm him down, you know? He responds terrifically well to being in a church building. He becomes very... awed in a way... you really feel a sense of awe in him... it uplifts him. He seems to respond to just being there by... a sense of wonder, really. A sense of wonder. In his own way.*

*He loves buildings which have interesting shapes and most churches are interesting shapes. He loves looking at lights and most churches have interesting lights. And he loves music. So all these things together mean that actually, he can be quite worshipful in a building.*

Interviewer: *But it's not tied to any kind of denomination beyond structure?*

Carer: *No.! Absolutely not! No.!*

Interviewer: *It's an openness?*

Carer: *It's an openness, yes. Definitely!*

For this young man the physical space and atmosphere of the church building, quite apart from the specific ordinances of religion enabled him to find a sense of spirituality and worship which was not present within his other life-spaces.

Other people found the space provided for them in their workplaces vital for their spiritual development. Davina expressed this need for space in her day-care facility in this way:

*Well she [her support worker] is helping me not only with the art and the pottery, she is also helping me to go to the quiet room; go to the multi-sensory room and it also helps me to sit down and pray for a few minutes and then come back. You feel better. It is a very calm and relaxing centre. It helps me to calm down so that I can talk to the tutors next door, or I can go away from the centre and go somewhere and then go downstairs and go to the quiet room or stay here and think of things which do not bother me.*

For others the space they sought or created had specific religious connotations. It was important that they had *sacred space*.

### **David's Story**

David is 22 and has a severe learning disability. He attends a day centre. David finds it difficult to relax and concentrate for any length of time. He spends most of his day playing with two spoons or forks whilst he is walking around and talking to his friends,. The only time that David sits quietly is when he and his work mates meet in the prayer room. David finds the prayer room a fascinating environment. He likes the coloured material that is draped around the altar on which is laid a copy of the Bible and an icon of Jesus. He enjoys watching the burning candle and listening to the quiet music. David is drawn to sit down, and put down his spoons for five minutes. He can concentrate on everybody passing round objects that represent God's love for them, for example, a stone with your name written on it. During this time, he feels more relaxed and senses that something



important is happening. Even though he gets up after five minutes, being in the prayer room has helped him relax and to feel supported by his friends

Physical and emotional space was obviously important to people. The nature of this space was personal, and the meaning and significance of the space was unique to each individual. The meanings attached to such spaces cannot be determined by others but the opportunity to create and enjoy such spaces can be facilitated and enabled. The experiences of the participants in this study should alert carers and support workers to the potential significance of space and the importance of watching out for indications that space might be significant for a person's well-being.

### *Creating space and time through ritual*

For some people the spiritual significance of space was firmly located in a particular place. Other people had to create such space in the midst of the hustle and bustle of their everyday lives. Here, ritual and symbol were highly significant. One young Jewish man highlighted the value of the rituals that take place within his place of worship.

Interviewer: *Have you always done that, have you always followed those procedures?*

Matt: *Yes, I have always followed them. My father followed them.*

Interviewer: *You followed them and your father followed them?*

Matt: *Yes.*

For Matt, participating in rituals enabled him to find a sense of place and belonging within the boundaries of his religious community. The space that the rituals created enabled him to share in the history of the tradition and to take his place beside his father and within his family.

People used a variety of rituals and symbolic actions to express their spirituality and work through issues that were profoundly important but often inexpressible in words. One person described her

friend Shona's first communion, highlighting the way it confirmed her place within the community and gave her a space which was unique for her:

Fiona

*The moment that really sticks in my mind is when she actually received the Eucharist for the first time. There's always this debate about do people really know what it is? If they've got learning difficulty then how can they reach that belief. She was sitting on the bench in front of me at the Easter Vigil. She came back after receiving the Eucharist, turned round to me and she went, "Mmmmm", I've done it. In other words, I've got it, I'm there now. I'll never ever forget that.*

Interviewer: *She felt that she'd got in the door?*

Fiona: *Yes, she'd crossed the threshold. That was a spiritual moment between Shona and I; Shona and God and that spread to Shona and I.*

In this case the ritual both symbolised and embodied the possibility of acceptance, love and a meaningful place within the community.

*Creating sacred space*

Ritual was also used in the creation of space that people perceived as spiritual. Susan's experience is a good example of how this was done. Susan is a middle-aged woman with a moderate learning disability. She considers herself to be a deeply spiritual person and is committed to her religion. She frequently prays, says the Rosary and lights candles. These spiritual practices are deeply meaningful for her. As she lights a candle she prays. When she does not feel like speaking prayers, she will write them in a petition book in the alcove of the home in which she lives. In this way she creates sacred spaces within which she can reflect on her spirituality and develop her relationship with God. When asked why she constructed this space, it emerged that she wanted to create *an atmosphere, a special time distinctive from trivial general aspects of life..*

Susan used ritual and symbols to create what might be described as ritualistic space. Here she could move beyond the trivial and mundane into a spiritual realm that was qualitatively different from her day-to-day life. Her simple ritualistic practices helped create sacred spaces within her

ordinary daily surroundings where another dimension of experience was made possible and tangible.

Prayer formed an important part of this process of space creation. It enabled people to find a space apart and to discover the possibility of peace and stillness. As one mother whose son has profound and complex needs said:

*I think for Daniel it has really brought him peace. I think more than anything it's brought peace and tranquillity into his life. Obviously there would be very high levels of frustration and bouts of anger and so on. I believe that prayer has really diminished that to an enormous extent. I'm not saying that it's perfect, he has occasional outbursts like any other person would and because of difficulties in communicating sometimes that's not always easy to handle. But generally speaking, I really feel that prayer has brought that peace and tranquillity about in his life.*

Regardless of the person's religion or the existence of specific beliefs, prayer often provided a conduit through which people could move beyond the mundane of the present to something beyond.

Gordon: *Prayer is like when you've got a hard day's burden and you get through it and then you do it after the day.*  
Interviewer: *So praying is a way of talking through the day?*  
Gordon: *Saying to the man you've had a nice day and you can look forward to another day.*

## **Time and space**

Within the business-oriented mindset of Western societies, time is conceived as always coming towards us and disappearing behind us. Time marches on. We may catch a glimpse of it as we look back and we may plan for it as we look forward, but rarely do we take the time to stop and recognise the significance of the present moment. This inability to recognise its significance may

well lie behind the increase in anxiety and certain forms of mental health problems within our society.

For those people with learning disabilities who sought to create sacred spaces, the time that was created was of a different shape and quality. Through prayer and various rituals people seemed to be trying to create an atmosphere, a special time within which they could remove themselves from the driving pressures of the day. Within these sacred spaces, time was contemplative and still; the significance of the present moment became the focus of attention with other more trivial movements of time shifted to the margins of significance. Within this ritual space people could find peace and connect with that which was not Self: for some it was God, for others, nature, beauty and so forth.

Once again, the difficulties people had in finding any space or time for themselves came through strongly. Lack of space in relatively confined home environments shared with others caused stress and sometimes aggression. If we believe in the importance of people's spirituality and in their quest for peace and the creation of sacred spaces, then we need to think seriously about the ways in which the lives of many people with learning disabilities are currently organised.

### **Spirituality and creativity**

Put simply, creativity is the ability to create; when one expresses one's creativity one brings into being something that did not exist before. This was well illustrated by the ways in which the people in our study used rituals to create space that was both sacred and previously unavailable. Creativity is a dimension of human experience that is not dictated by the intellect. Similar to spiritual experiences, creativity embraces physical and cognitive abilities and facilitates the

expression of feelings that are in some senses inexpressible. Through creativity a person functions not simply according to reason and rationality, but rather through intuition, feeling and expressions of awe and beauty. As such it provides an ideal context for the expression of spirituality, particularly for people with cognitive and verbal communicative challenges. In particular music and art are important ways in which people with learning disabilities express their spirituality.

### *Spirituality and music*

One carer described the effect of music on her clients in this way:

*Deborah: The people I work with often come in feeling tired or maybe feeling a bit down by their circumstances. Having had a night of singing they go away with their spirits really lifted. And feeling quite energised. That's another word that people have said to me: "I feel quite energised after being here".*

*Interviewer: So inspired?*

*Deborah: Yes definitely. And of course depending on the song it can bring back memories too.*

A young man with severe autism made a similar point:

*Frank: I feel that music is inspired by God in our church but I am not sure how I am affected by it except that I enjoy it. I am convinced it is a vehicle of holiness to the sense of hearing just as the icons are a vehicle of holiness to the eyes.*

*Interviewer: How do icons help you to think about God and worship?*

*Frank: I think that the saints are portrayed to help us understand what holiness comprises. I am even pleased to say that I understand what it is with my eyes so that I don't need to read about it or speak. I see their asceticism and their immense concentration on God and I know what I must achieve to be at all acceptable to God.*

The suggestion that music 'inspires,' 'energises,' 'lifts them up' 'is a vehicle for holiness,' and communicates in ways that words cannot, relates closely to traditional understandings of spirituality. Within certain forms of religion for example, the 'spirit' is perceived as a personal force that interacts with and responds to the life experience of human beings. Common expressions such as: 'her spirits are high;' 'his spirits are at a very low ebb'; 'her spirit has been quenched'; 'I feel inspired (inspired)'; 'he is feeling rather dispirited'; 'she has lost her spirit,' point towards

the ways in which the spirit can be nurtured or quenched in response to human experience<sup>35</sup>.

These participants' observations about the impact that music has on people's spirits are very much in line with this way of understanding. Music becomes a vehicle for enabling spiritual experience and connection.

The suggestion that music brings back memories is also spiritually significant. As we have said, spirituality has to do with connections and wholeness. The experience of participating in the act of creating or listening to music draws the past into the present and reminds people of where they have been. Remembering where a person has been is a vital dimension of understanding who they are now. Thus music can play an important role in consolidating a person's identity and sense of self.

Music provides one mode through which the spirit can be nurtured, particularly for people who find it difficult to communicate in words. Sheila, who is a musician and the mother of Kevin, a young man with profound learning disabilities, described an event that she found engaging and spiritual:

*We had a whole session of an hour a few weeks ago where we were down at the hall with all my gear, my PA gear and my keyboard. We sang for the whole hour. He had his guitar with him and I think this is really important because he bangs away on his guitar. He doesn't know how to play it but he can keep a regular rhythm...at least he can some of the time! But once again the key aspect of participation [was that] he could join in. I didn't mind the noise it made because I was playing anyway through my PA system and he was able to join in on the lines that he could remember. So he was kept on track for a whole hour. He and I together singing. Afterwards I thought it was the best spiritual feeling. He came back home quite high; he couldn't wait to see ---- to tell him what we had been doing. There was lots of verbal communication when we got in the door so again that was very energising.'*

The motifs of energising, accepting, relating, sharing all indicate the spiritual potential of music to take people to areas of expression which reach beyond the verbal and the cognitive and allow expression which may not always be aesthetically pleasing but is nonetheless beautiful and powerful.

## *Spirituality and art*

Art seemed to be spiritually significant on two levels. For some people, interacting with visual images such as drawings or paintings was an important way of connecting with something beyond themselves. One young man responded to photographs of landscapes he had viewed during a television programme:

*Seeing these pictures makes me believe that God exists, the beauty in the world. I mean there is beauty in the world*

Art enabled people to recognise the possibility of beauty in a world that was often profoundly ugly, both in terms of the universal politics of the world and the difficult circumstances of people's individual experiences. Art, whether simply observed or personally created seemed to open up the possibility of space, beauty, calmness and connectedness. As one participant put it:

*“Art and beauty is an expression of peace and calm.... Pottery is making me try to concentrate and make me think about spirituality*

Art provides a way in which people are able to express feelings and experiences that might otherwise go unnoticed and unacknowledged.

### **Ian's story**

Ian is twenty-two years old and has moderate learning disabilities. He finds it difficult to communicate verbally. He can communicate through sign language and gestures, difficult for outsiders to understand, but those close to him can understand and interpret them effectively. Art is very important for Ian, both as a form of personal expression and as a way of communicating and working out his spirituality. He expresses himself in a variety of ways, through clay modelling, weaving, rubbing textures. Not all of his art relates directly to his spiritual journey but one particular expression is worthy of reflection.

Ian has developed a way of praying which combines creative expression with non-verbal spiritual quest. Ian and his carers work through what he wants to pray about. Then his carers write this down on pieces of paper. These are pasted onto tissue paper, material or ribbons. These materials are then pasted onto a cup or a carton that has been covered with clingfilm.

Thus Ian's prayers are layered together onto the cup; once the material has dried he is left with a prayer cup. For Ian this is a potent symbol of the importance of his spirituality and a public recognition that God is listening to his prayers and that God will act on them. This simple creative act enables Ian to express what would otherwise be inexpressible; to reach out from his 'silence' and make a powerful statement about the importance of his spiritual life.

### *Imaginative identity*

Many participants had poor self-esteem and struggled to find a sense of meaningful citizenship that transcended the negative labels they were so often given. Creative activity enabled people to imagine that things might be other than they are. Creative processes were a means of expressing new possibilities for themselves and participants seemed to develop new, more positive identities. This imaginative identity does not simply relate to a person's perception of who they are or indeed other people's perceptions of them. Rather it is a way in which a person can imagine themselves to be. Art and music helped people imagine new possibilities for themselves and the symbols and rituals gave them a way of bringing these imagined possibilities into more concrete existence. Prayer enabled a sense of connectedness with something beyond their present circumstances and offered the possibility of not being alone amid the struggles of life. These new expectations often reached beyond those of carers and support workers. But for those who recognised the significance of creativity and took the time to explore and nurture it, it became a source of revelation and healing.

### *The significance of time*

Before we conclude our reflections on creativity, it is helpful to return to the significance of time and explore it from a slightly different angle. Everything discussed in this section requires time. People with learning disabilities need time to explore the creative dimensions of their lives and to work at the spiritual meanings of their activities. Carers and support workers need to enable and facilitate that time and find time themselves to get to know these inner regions of people's lives.



*Interviewer:* It takes an awful lot of time to think about things and listen and go away and think about it and come back you know.

*Jemma:* Yes.

*Interviewer:* It takes time to really make sense.

*Matthew:* Time is the most important thing.

This raises significant challenges to the ways in which services are currently structured and the way in which care provision is prioritised and delivered. When carers and support workers were alerted to the significance of the issues highlighted in this report, they recognised their importance and wanted to address them. Although it was difficult, people recognised the importance of creating time and space to listen and respond to people appropriately. They recognised the need to think of new and different ways of meeting the spiritual needs of people with learning disabilities.

Over and over again, people stated that time was the most important factor in order to respond to people's spiritual needs. In a professional context where people are still focused on functioning according to tightly-ordered work schedules which are often task-oriented rather than person-centred, serious reflection on the spiritual needs of people with learning disabilities challenges all of us to rethink how we might understand and use time. One carer astutely observed that people might need two or three days to respond to situations, feelings and experiences.

*You need to get away from expecting a 2-3 second response. Don't impose a response, expect a response.*

The suggestion that carers and support workers should expect rather than impose a response is a challenge to all to slow down and begin to reflect on whether current modes of practice that claim to be person-centred actually match our theoretical vision.

If carers and support workers don't have time to listen to people with learning disabilities, then exploring the spiritual dimensions of their lives will not be available. One carer put it thus:

*'The option is not given, the option of choice is not given. It's staffing as well. You've got far less staff, usually about one to four or five people. People are put in situations where they can't really give much of a choice, and freedom of choice. Sometimes staff come in on their own time to try and provide some time. I did that when I was in Coventry. I often went in on my own to try to provide time so they could have their own one to one individual place – spaces. Do you want to go out to the chippie or do you want to go out and enjoy that time. If they wanted to talk about God or their spirituality they could do, or any of their own problems or feeling. That option of spirituality or God has never been given or explained to them.*

Here we see clearly the problem of lack of time and the implications for people's spirituality. Staff coming in on their own time is admirable, but raises questions highlighted previously about professionals offering voluntary friendship. Also, use of staff's own time may serve to cover up fundamental flaws in an organisation or institution.

The importance of time was expressed particularly strongly by carers from multi-ethnic backgrounds. For them the biggest issue seemed to be lack of time due to the pressures of caring in other areas. They felt strongly that the only solution was to bring in extra carers. One mother of a person with severe learning disabilities commented that

*life is too fast; you can only meet physical needs.*

This emphasises again the significant gap between the need to offer care that is holistic, empowering and person-centred and the realities of what people are able to do 'on the ground.'

The multiple levels of disadvantage faced by people from ethnic minorities in their everyday lives exacerbate these realities. In contrast to other groups in society a focus on religious or cultural differences rather than social and health inequalities may obscure concrete and practical forms of social help that are essential in order to achieve psychological and spiritual support. Families experience little formal or informal support leading to stress-related problems, surpassing levels of stress experienced by other carers of people with learning disabilities <sup>36</sup>.

## Section Five:

### Barriers to spiritual care

Throughout the study there was a tension between the importance of spirituality for the lives of people with learning disabilities and the ability of services to provide appropriate care and support. This was not because carers or support workers were disinterested or unwilling to take this area seriously; many were. Nevertheless, it was clear that there were significant barriers to providing effective support for people's spiritual needs.

#### Uncertainty about the spiritual dimension

Many people with learning disabilities who participated in the study had never been asked questions about their spiritual life. This would suggest an inability or unwillingness on the part of carers and support workers to recognise and facilitate this dimension of people's experience. The issue of spirituality may be enshrined within their professional codes but in practice, they get little education or guidance on the subject<sup>37</sup>.

Carers and support workers felt that one reason for downplaying was that care strategies emphasised a functional approach.

*Historically we've always focused on functional ability at the expense of people's emotional life. They [people with learning disabilities] have a spiritual life and, we talk about wanting to give people a good service. But if we're missing that chunk out of their lives, maybe the service we do offer these people is anything but good. Really an indicator for good service will be how well we start meeting and addressing the spiritual needs of people with learning disabilities.*

Part of the problem seems to be a general mystification and lack of clarity about the term spirituality. Although spiritual care is often included in organisational policy, it can be difficult for carers and support workers to articulate what this means in practice. For some the term is nebulous and overwhelming. As one participant put it:

*Spirituality is a vague concept; it's a difficult one. Getting close to people is the main important thing.*

While it is true that getting close to people is the most important thing, in order truly to be with them it is necessary to recognise the actual nature of their experience and be able to acknowledge what is most important to them. Some carers and support workers implicitly demonstrated aspects of spirituality in their work but had difficulty in articulating this and in associating it with their role as professionals. Also, spirituality does not sit easily within the expectations of current patterns of care and assessment. Spirituality is difficult to place within a system that assumes that quantification and definition are the main ways we can validate effective implementation of care.

As one support worker put it:

*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. You'd have to have a sense that this is a person that you are going to try and help in a way that you would maybe try to help a friend or a relative to come to terms with something or explore something.*

In an evidence-based world, it can be difficult to see or to prove the practical relevance of a dimension that refuses to fit neatly into a tick box mentality. Some of the language that carers and support workers used to express this omission of the spiritual dimension of people's lives was quite startling.

*I have some really good friends who have a learning disability. With working with them and their spiritual needs [I have learned that their needs] are as real as mine and their need to express that is as real. I think for some kinds of learning disability that's smothered; it's never been able to come out.*

Two health professionals made a similar point:

*Donna: It is a lot of inner, hidden values or experiences. People are sanctioned. They're not allowed to talk about what they've been carrying around for years and years and years and years and years.*

*Fraser: Services generally don't address that.*

The use of powerful, emotive language such as 'smothered' and 'not allowed to talk about it' indicate that there may be deep flaws within the system's structures, priorities and training programmes that need to be addressed.

It is also interesting to reflect on the suggestion that in attempting to protect clients from abuse, people may be unwittingly denying them something that is of fundamental importance. One support worker made the following observation:

*In the area we live in, religion is something that you really don't want to talk about in the workplace because you don't want to be saying something to somebody that is really against their belief. It's trying to maintain that environment. It's just something that you don't talk about at work. It's not talked about at work. I suppose a lot of us have a fair idea about everybody's background but then again, what we believe about somebody else could be totally wrong.*

Time and again, people with learning disabilities said they wanted religion and spirituality to be a topic of conversation with carers and support workers. However, carers and support workers gave us the impression that sometimes caution about religion and fear of manipulation of vulnerable clients are given greater attention than the meeting of spiritual needs. Getting the balance right here may be difficult but services need to address these issues if they are going to provide the best possible support for people.

### **Role confusion**

Whilst people felt comfortable and confident with standard professional roles, an understanding of professionalism that included the intimacy and openness necessary to explore the spiritual dimension raised problems of self-definition. One carer said:

*The problem with implementing spiritual care is that carers would have to be willing to look at themselves and how they are in relation to their work and most people aren't. It's not in the contract is it. You get together and you talk about the clients, day by day and maybe how you could help them, but there isn't a sort of... it's a job. I mean, there's a very definite distinction between a job and whatever your personal philosophy is if any.*

This statement reflects the tension that was expressed by other carers and support workers concerning the acknowledged importance of spirituality and the perceived need to avoid it within a professional context. Another support worker expressed this tension even more strongly:

*It [spirituality] is not an upfront thing - not thrown in your face. It is difficult to talk about because people are scared of pushing their own beliefs. I think it is illegal.*

For this man there was a conceptual and practical gap between his perception of what he should be as a professional and how he actually experienced the world himself. He did not think that he could be involved in overtly meeting spiritual needs. It was not part of his self-perception as a professional. This raises important questions as to what it means to be a professional. If the accepted role of the professional excludes dimensions of the experience of people with learning disabilities that they feel are of fundamental importance, then there may be a need to re-think our definitions.

### **Lack of time**

This report has emphasised the importance of time in the process of nurturing and encouraging the spiritual lives of people with learning disabilities. Time in health and social services is scarce and workloads are stretched. Functional needs take priority - sometimes exclusive priority - over other significant needs such as spirituality. The people with learning disabilities who participated in this study had often not been given the time or the space to reflect on such needs.

Carers and support workers also suggested that they themselves would benefit from having time to reflect on the spiritual dimensions of their work. As was quoted earlier:

*Unless you're in a situation like this, [an interview situation] you're not really talking about your own spirituality or your own religion. It's just something that you don't talk about at work and is not talked about at work. I suppose a lot of us have a fair idea about everybody's background but then again, what we believe about somebody else could be totally wrong.*

It appeared that carers and support workers rarely got the chance to reflect on their own spirituality, partly because of time restrictions and partly because it was not on the agenda.

Combined with lack of awareness and education in this area, this leads to significant difficulties in dealing effectively with the spiritual dimension of the lives of people with learning disabilities.

### **Religious and cultural barriers**

Whilst some staff were clearly aware of the significance of both religion and spirituality, others were more ambiguous about its value. Sometimes this was expressed directly, but sometimes indirectly through people's assumptions and practices. For example, within one care home carers described the home as having a busy timetable during the week and stressed the importance of service users staying in on a Sunday for chilling out. Attending a service of worship was viewed as an impingement on this time out, therefore residents within that home didn't go to church. This was despite the fact that a number of people living there told us they would like to go to worship on a Sunday. The problem seems to have been that they were never asked and did not feel confident enough to ask.

Carers reported that in some areas there is no budget from social services for staff to take people to places of worship on a regular basis. Lack of money for such simple things as bus fares meant that the staff either could not take people to worship or they were forced to pay for it themselves, which

is clearly inappropriate. Clashes of religion and culture sometimes prevented people with learning disabilities from having their religious needs met. One carer complained that a Moslem support worker refused to take a Christian to church, as she did not feel comfortable about going into a church. Similarly, there were difficulties that moved in the other direction:

Interviewer: *This is really a big issue? You can only go to the Mosque when there are Muslim staff on duty, is that right?*

Christopher: (carer and advocate) *You need some support with the rituals, I think.*

Karl: *Yes that is right.*

Interviewer: *If there was a carer there, you would go every week?*

Karl: *yes.*

Interviewer: *You would like to go regularly?*

Karl: *Yes 'cos I used to. Yes.*

A solution to such clashes was not clear from the interviews. What was clear however was that there was little if any discussion. What there was seemed to focus around disagreements between carers and support workers who carried on their arguments without entering into any meaningful discussion with the people with learning disabilities. When we talked with the people with learning disabilities themselves, it was obvious some wanted at least the option of attending religious worship and were not at all interested in the religious problems discussed by their carers and support workers.

It is clear that many of the ways that faith communities present their teachings and order their communities prevents the full integration and participation of people with learning disabilities. Faith communities must learn to be sensitive to the needs of people with learning disabilities and develop forms of community and ways of teaching that expressly include them. This is important for people with learning disabilities who attend faith communities with other members of their family or with friends. For those who still rely mainly on services for their support, faith communities need to develop strong and trusting relationships with service providers in order to open up opportunities for people to be fully involved and develop long-lasting connections.



learning disabilities may present.

## **Conclusion**

Participants in this study consider spirituality in both its religious and non-religious modes to be important for the quality of their lives. Their comments, reflections and conversations clarified what spirituality is and showed clearly how it can benefit people's lives. However, there are significant barriers to the implementation of spiritual care. These barriers are not caused by bad intentions or malpractice. Quite the opposite, many carers and support workers as well as members of religious communities, agreed strongly that spirituality is important and should be incorporated into care and support strategies. The problem lies in a lack of education and training combined with institutional barriers that prevent people from focusing on this area. We hope that the problems highlighted in this section will raise people's consciousness to the possibility that the spiritual life of people with learning disabilities may not be receiving the attention it should within their working practice and help them think about how this might be addressed.

Finally, it is important once again to draw attention to the issue of human rights and social justice. The expression of a person's spirituality should be recognised as a fundamental human right. It is not something to be thought of just as an additional option. People have a right to have their spiritual voices heard and carers and support workers have a moral and legal obligation to ensure that this is facilitated.

# Recommendations

The research has raised a number of important issues that need to be addressed by those who wish to encourage forms of care and support that are genuinely spiritually informed and authentically person-centred. The following recommendations are intended to help faith communities and service providers at all levels accept the challenges that taking spiritual care seriously will bring. We hope the voices of the people with learning disabilities on whose opinions and experiences they are based will make a difference to the way services are prioritised and delivered and to the way faith communities respond. Then, we believe, people with learning disabilities will have their right to express their beliefs and values truly respected.

## Developing spiritually sensitive services

- 1. People with learning disabilities must be given the opportunity to make informed choices about meeting their spiritual needs. These should be included in person-centred planning.**  
*Action:* Service providers, support staff, service user groups, family carers, faith communities
- 2. People with learning disabilities must be given the opportunity to articulate the importance of spirituality for the quality of their lives individually or in groups.**  
*Action:* Service providers, support staff, family carers, service user groups.
- 3. Proactive strategies need to be developed to foster and maintain strong relational networks for people with learning disabilities. These relationships must be based on meaningful, voluntary friendships.**  
*Action:* Service providers, support staff, family carers, faith communities, service user groups.
- 4. People with learning disabilities should receive appropriate and sensitive support when someone close to them dies.**  
*Action:* Service providers, management, support staff, family carers, self-advocacy groups.
- 5. People with learning disabilities should have the opportunity to create and experience quiet places, where they can explore and develop their spirituality.**  
*Action:* Service providers, management, support staff, family carers.

## Caring for carers and support staff

- 6. Carers and support staff must be given training to understand and work with the spiritual dimension of people with learning disabilities. People with learning disabilities should be involved in the training.**

*Action:* Organisations that provide services, management, professional bodies, training institutions.

- 7. Service providers must learn how to be comfortable with the idea of referring people to individuals and organisations who may be more appropriately equipped to meet clients' spiritual needs.**

*Action:* Service providers, support staff, family carers, service user groups.

- 8. Families must be enabled to have time to support the spiritual needs of their family member.**

*Action:* Social services, faith communities, service providers, service user groups.

- 9. Services must develop strategies to enable carers and support staff to have time to address their own spiritual needs.**

*Action:* Service providers, managers

## Spirituality and Faith Communities

- 10. Faith communities must develop stronger links with other agencies in order to develop a firm and accurate understanding of the needs of people with learning disabilities.**

*Action:* Faith communities, service providers, community liaison bodies.

- 11. Faith communities need to recognise the importance and diversity of faith experienced by people with learning disabilities.**

*Action:* Faith communities.

- 12. Faith communities need to reflect seriously on the quality and commitment of the relationships they provide.**

*Action:* Faith communities.

- 13. Faith communities need to recognise the connection between the experience of friendship in human communities and the ways in which people learn to understand and connect with God.**

*Action:* Faith communities.

- 14. Faith communities, working with people with learning disabilities, need to examine whether their liturgy and teaching is accessible for people with different needs.**

*Action:* Faith communities.

- 15. People with learning disabilities require access to appropriate teaching and learning materials that will enable them to participate effectively and fully in their religious tradition. People with learning disabilities should be consulted about their content.**

*Action:* Faith communities.

## **Implications for management and institutions**

- 16. Systems should be developed which will allow time to deal with the spiritual issues highlighted in this report. Lack of time is a political and management issue and needs to be addressed at that level.**

*Action:* Policy makers, service providers, management, support staff, family carers, advocacy groups.

- 17. There is a need to re-think the role of the ‘professional’ in a way that will enable carers and support staff to incorporate the spiritual dimension as a significant part of their role.**

*Action:* Professional bodies, training institutions, service providers, management, support staff.

## **Implications for policy makers**

- 18. Spiritual care must be recognised as having important political, systemic and institutional dimensions. Policy makers need to incorporate this in planning and commissioning.**

*Action:* Politicians, policy makers, management, service providers, service users groups, disability activist groups.

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# Appendix 1:

## The Research Approach

In the past the voices of people with learning disabilities have frequently been excluded from research. They have been treated as ‘objects’ of research rather than people with valid and important contributions to make. Over the past few years researchers, particularly those with a focus on disability rights, have challenged this approach and called for research which is focused clearly on the experiences of people with disabilities and which have direct benefit to people ‘on the ground.’<sup>38-40</sup> As Taylor puts it, “the perspectives and experiences of people labelled mentally retarded [sic] must provide a starting point for all research and inquiries into the study of mental retardation. [sic]”<sup>41</sup>

The starting point for this research was the perspectives and experiences of people with learning disabilities. They form the basis of the report and make up the major part of the text. However, the report includes the voices of families and other carers and support workers. Although families and carers often reflect different and sometimes contradictory perspectives<sup>42</sup>, they are a vital part of the whole picture and need to be interpreted and understood alongside the experiences and narratives of people with learning disabilities. This is particularly important in relation to people with profound and complex needs who may rely so much more on others to help them communicate.

The study was specifically designed to ensure that people with learning disabilities could be fully included in every dimension of the research process.

There remains an issue about whether or not participatory research can actually be done by those who do not share the experience. Some might object that only people with learning disabilities are capable or competent to carry out research that is genuinely participatory. This raises a number of important issues about how to involve people with learning disabilities in research that are not within the remit of this study. However, by assuming that people with learning disabilities are partners in the research process, we have tried to provide a research context which is owned by the participants, but which also fits credibly within the current boundaries of research. In this way we hope that the results of the project have the potential to affect strategy and policy making and at the same time give a valid voice and authentic perspective on the experiences people with learning disabilities.

### **Participatory Research**

The methodology was based on a participatory approach, incorporating elements of grounded theory<sup>43</sup>, combined with insights from narrative analysis<sup>44</sup>, ethnography<sup>45</sup> and hermeneutics<sup>46</sup>. We also drew from insights provided by other researchers who have been working within the participatory paradigm<sup>47-51</sup>.

As we have said earlier, participatory research assumes that the best people to research a given topic are those with the most experience of it. In line with this, the emphasis throughout was on doing research with rather than on participants. Efforts were made to ensure authentic participation of people with learning disabilities at every level of the study. This included having two people with learning disability on the advisory panel so that they were also involved at the design and management level. Like other members of the panel who did not have a background in social scientific research, these two people struggled with the more technical aspects of the research

process. However, all members of the group made invaluable contributions in different but complementary ways.

### **Promoting participation**

Although we used a number of questions as a loose framework for the interviews, participants were encouraged to share their own thoughts and experiences more broadly. Some of these related directly to the questions, others introduced new and challenging dimensions to our initial understandings. In the focus groups we tried to avoid having people talk on behalf of others. However, it became clear that group members encouraging and supporting each other to speak up was an important part of the research process. It empowered people to express their opinions.

Interviews were wide ranging and conducted with people who had a number of different challenges including people with profound and complex needs, visual and hearing challenges, people who used facilitated communication, communication boards and flash cards. When participants were unable to express their experience fully, they sometimes demonstrated what they wanted to communicate by taking the researcher to places of significance, sharing in activities and sharing objects of value. Some participants chose to sign, sing, draw, write or just look at pictures. Sometimes the interviewer or interpreter drew out the answers during discussion; this helped to focus on the topic and to aid the recall of the participant.

### **The research process**

The study encountered a number of difficulties with standard social scientific research methods. For example, grounded theory requires that there be a written text as the result of an interview, with which the researcher engages at some depth. This method relies on a high level of verbal

ability. This is appropriate for people who can speak but more problematic for those with limited or no verbal skills. We needed to address this issue in devising our research process.

### *A multi-method approach*

Firstly, the research design used a multi-method approach in order to engage people regardless of cognitive and verbal ability. Interviews were supplemented with direct observation and the use of advocates and interpreters. The interpreters and advocates were not necessarily professionals or family carers. They often emerged from the focus groups of people with learning disabilities. It was clear that, given the appropriate opportunity and circumstances, people with learning disabilities are more than able to advocate not just for themselves but for one another.

The diversity of the methods used to collect the data is reflected in the style in which this report is written. We have used reflection on direct quotations from people with learning disabilities, carers and support workers combined with interpreted data drawn from the narratives of carers, advocates and interpreters. In this way we have tried to capture both the words of those who were able to express themselves through language and the interpreted experiences of those who had to communicate through others.

### *The methodological significance of fragments*

Secondly, we had to take seriously the suggestion that it is not the quantity of words that are spoken that was significant, but the quality and inherent meaning. Carers and support workers spoke clearly and often eloquently about their experiences of spirituality and how it relates to their particular roles, as did many people with learning disabilities. However, for others it was only possible to speak a few words. But, these words were often powerful and deeply meaningful. In response to this we have had to reflect seriously on the methodological significance of fragments,

that is, the suggestion that within a participatory research context with people who have limited verbal skills, the researcher must take seriously the importance of the fragments of truth that people offer.

One of the more profound things we learned was the challenge that people with learning disabilities offered to the way we all see the world. They challenged accepted understandings of such things as time, space, acceptance, friendship and indeed the meaning of spirituality itself. Within the context of the research methodology, the participants deeply challenged the way that research should be done and precisely what researchers should take seriously as meaningful data.

### **The interview process**

The interview process comprised of three stages:

1. Sharing the nature and purpose of the research in order to help people understand the issues which would be discussed
2. Discussion about issues of consent
3. Conducting the interview

One of the initial difficulties we encountered was how to communicate the word spirituality to participants within a cultural context where the meaning of the word was so diverse and fluid. This was particularly problematic with people with profound and complex needs for whom language was not their first form of communication. If people were to be given a genuine opportunity to reflect on their spirituality we decided it would be necessary to create basic conceptual parameters within which we could explore the areas that previous research had suggested constituted the 'spiritual dimension.'<sup>52</sup> These parameters were always left open to be challenged and developed by the experiences and feelings of participants, but we needed to define a framework within which the interviews could take place. So we developed an interview

schedule based on the findings of the *Space to Listen* report<sup>53</sup> consisting of the following questions:

1. What is spirituality?
2. What makes you feel good about yourself? (value)
3. What do you like best about your life? (meaning)
4. Are friends important to you? Why? (connectedness/relationships)
5. What do you want to do with your life? (hope)
6. Do you think there is a God? (searching for the transcendent)
7. Why do you think you are in the world? (existential search for identity and purpose)

These questions opened up some fascinating areas of discussion and reflection. Question 1 enabled us to explore what the word spirituality actually meant for people. The following questions enabled us to test and deepen our understanding of the responses to question 1. For people who had no expressed idea of spirituality as a formal concept, the questions allowed the interviews to explore those dimensions of human experience that have been recognised as spiritual and to examine what it meant for different individuals.

### **Individual Interviews**

We carried out 19 interviews with people who have learning disabilities across the UK:

- 6 individual interviews with people with learning disabilities
- 4 with people with high support needs
- 9 interviews with people with learning disabilities and their carers.

Individual interviews took place in a variety of settings including people's homes, day centres, religious communities, care homes, family homes and places of work. Interviews lasted from 20 minutes to an hour and a half. It was sometimes necessary to meet with individuals on more than one occasion in order that their perspective could be fully grasped, understood and properly communicated.

### **Focus groups with people with learning disabilities**

We carried out 10 focus groups - two with professional caregivers, five with people with learning disabilities and three with family carers and relatives. We held one or two sessions per group.

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. The aim of the focus groups was to explore the meaning of spirituality both personally and collectively within a group and to reflect on what this might mean for the lives of people with learning disabilities.

### **Direct observation**

Interviews were supplemented with direct observation. It is important to note that 'direct observation' is not the same as 'participant observation.' Trochim differentiates between the two in this way<sup>54</sup>:

*Direct observation is distinguished from participant observation in a number of ways. First, a direct observer doesn't typically try to become a participant in the context. However, the direct observer does strive to be as unobtrusive as possible so as not to bias the observations. Second, direct observation suggests a more detached perspective. The researcher is watching rather than taking part. Third, direct observation tends to be more focused than participant observation. The researcher is observing certain sampled situations or people rather than trying to become*

*immersed in the entire context. Finally, direct observation tends not to take as long as participant observation.*

Direct observation was very important for this study, particularly in relation to people with limited verbal skills. By observing people within their own context and reflecting on their words and actions, the researchers gleaned vital information that made their process of understanding much clearer and more authentic.

### **Ethical considerations**

We considered ethical issues to be of particular importance, bearing in mind the possibility of inadvertent abuse of a vulnerable population. We used existing ethical guidelines - the principles of respect for persons, autonomy, confidentiality and freedom of choice – to underpin the research process<sup>55, 56</sup>. Great care was taken to ensure that nothing was forced on the participants and that participation in the interview process was voluntary and solely at the discretion of the individual<sup>57</sup>. Participants were encouraged to choose how they would like to conduct the interview and how or if it would be recorded. Levels of consent were constantly monitored, assessed and checked with participants during the interviews.

### **Analysis**

Using an approach based on aspects of the constant comparative method of Strauss and Corbin<sup>58</sup> the analysis commenced after initial interviews were conducted and continued throughout the study. The researchers constantly immersed themselves in the data, searching for themes and ways of understanding what people contributed. By reading the transcripts, listening to interviews/interactions, reflecting on interview details (researcher-participant relationship),



reflecting on the meaning of drawings/posters and critical reflection on field notes, the interviewers were able to gain rich insights into the spiritual lives of people with learning disabilities and to articulate a number of significant themes. The analysis was constantly written and re-written as the researchers engaged more fully with people's experience.

### **Issues of validity**

The question of validity in qualitative research continues to be a matter for debate. It is not possible to review the various arguments here but readers interested in following this up are referred to Koch<sup>60</sup> and Lincoln and Guba<sup>61</sup>. The object of qualitative research is to gain understanding of the experience of research participants, rather than to explain the experience. Consequently, any form of validation needs to reflect this perspective. For the purposes of this study the researchers drew on certain validation processes that are well established and accepted within the literature.

Lincoln and Guba put forward the term 'trustworthiness' to indicate the nature of rigor within qualitative research<sup>62</sup>.

*Qualitative rigor emerges from three components; credibility, auditability and fittingness (whose quantitative analogues are validity, reliability and generalisability).*

In order to be trustworthy in this sense, the study drew upon a number of suggestions in the literature.

*A thick, rich description*

*For the study to attain credibility it must be able to present a thick, rich and recognisable description of the subject matter. A qualitative study is credible when it presents such faithful descriptions of a human experience that the people having that experience would immediately recognise from those descriptions of interpretations as their own. A study is also credible when other people (researchers or readers) can recognise the experience when confronted with it after having only read about it in a study.* <sup>63, 64</sup>

A thick description seeks to capture the essence of a phenomenon in a way that communicates it in all its fullness. It is therefore rich, vivid and faithful <sup>65</sup>. The implications of this for the research process as a whole is that the process of writing, reflecting and accurately interpreting the data is not simply supplementary to data presentation and analysis. It is a crucial part of the process <sup>66</sup>.

### *Participant Validation*

Lincoln and Guba <sup>67</sup> highlight credibility as fundamental to the trustworthiness of a research project. Without such credibility in the eyes of the ‘information sources’,

*the findings and conclusions as a whole cannot be found credible by the consumer of the inquiry report...credibility is crucial and...cannot be well established without recourse to the data sources themselves.*

The transcripts and the interpretation of the data were returned to a sample of the participants for validation. In each case the themes were talked through and any suggested adjustments incorporated in the final text. A vital part of the validation process was the use of participants’ own words and narratives as a prominent aspect of the final text.

### *Independent validation*

The process of independent validation enables the researcher to reflect on and monitor his or her own prejudices and to ensure that the way in which the data is being processed and understood is authentic. The interview texts were read and the themes checked by independent researchers with knowledge of the research process being used. Comments were noted and discussed.

### *Auditability*

Auditability refers to the decisions made by the researcher at every stage of the process<sup>68</sup>. This aspect is achieved when

*another researcher can follow the “decision trail” of a study from beginning to end....In this way, readers of a report may not agree with the author’s interpretations, but at least they should be able to understand how he arrived at those interpretation.*<sup>69</sup>

This means recording the decisions and experiences encountered at each stage of the research process and recording them in the form of an ‘audit trail’ that can be followed through by others<sup>70</sup>. To this end, the researchers kept a close note of the way the process was developing and the reasons behind the various decisions that had to be made along the way.

### *A recognisable final product*

Finally the end product of the research process should be recognisable as reflecting something of the essence of the experience being described<sup>71</sup>. To this end, the final product of this study was fed back to participants for discussion and further reflection<sup>72</sup>.

## Appendix 2

### The Spirituality Committee at the Foundation for People with Learning Disabilities

Lady Euston (Chair) Vice-president the Mental Health Foundation

Rafiq Abdulla Kingston University

Annie Borthwick The Retreat, York

Rev Christopher Brice The Diocese of London

Pat Charlesworth One-to One

Shirley Linden Consultant (formerly The Judith Trust)

Linda McEnhill St Nicholas Hospice, Bury St Edmunds

Su Sayer United Response

Lord Tanlaw

Lama Yeshi Losal

Professor Francis Young The University of Birmingham

Staff members: Hazel Morgan, Amy Sutton and Patricia Umolu

## Appendix 3

### What makes a religious leader?

The following story arose from our conversations with a young man with severe autism. Although it does not represent a major theme in the research, it does raise important issues for religious communities.

Christopher had been, in his words, ‘written off’ by professionals and educational establishments all his life. His mother had always thought that he was capable of more than people assumed, but a stream of professionals and educationalists had consistently insisted that he was not. Sadly they could not find any university in the country who would take him on. Each used the same reason: clearly Christopher could not communicate and it was simply his mother who was speaking for him. However, in 2002, Christopher was accepted as a candidate for distance learning qualification in theology. In May 2002 he successfully completed year one of his programme.

Christopher reflected on his rejection by secular and religious authorities. In particular he found being rejected as a candidate for the priesthood distressing. He recalled his encounter with his assessor who broke the bad news to him:

*I was awfully sad and I felt that he [the assessor] wanted to comfort me. He told me that he wanted me to be a monk and I believed him... But now I wonder if it was hallucination because I have very little hope that any monastery will accept me as I am so handicapped and dependent.*

The fact that Christopher feels that he cannot fulfil his religious longing because of disability and dependency challenges religious communities to reflect deeply on what criteria they may be using to determine who may or may not have a religious vocation. Why would a lack of cognitive capacity prevent a person from becoming a priest? It is not possible to answer this question from the research data. However, the question is an important one. The fact that Christopher felt compelled to conform to this intellectualist demand also raises questions about whether or not

religious communities are willing to accept the challenges that the presence of people with learning disabilities may present.

Interviewer: *I'm just wondering what you want to get out of this course at college?*

Christopher: *I want to be included with others of my age and to be in a non segregated setting and I also think that the clergy will take me more seriously if I have academic qualifications.*

Is intellect the main criteria for the fulfilment of a religious vocation? Does this mean that the only way a person can be taken seriously as a religious leader is by conforming to assumed norms of educational qualifications and intellectual achievement. Christopher's story raises significant challenges to religious leaders and religious communities to think - and perhaps re-think - why people with learning disabilities are excluded from positions of leadership.

