



Religious expression, a fundamental human right:

The report of an action research project on meeting
the religious needs of people with learning disabilities



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Contents

Chapter 1: Background	3
Chapter 2: The project.....	7
Chapter 3: Religion in the lives of people with learning disabilities	17
Chapter 4: How faith agencies respond to people with learning disabilities	21
Chapter 5: How services respond to religious needs.....	24
Chapter 6: Supporting services	29
Chapter 7: Conclusions	43
References.....	47
Appendix 1 The Project Advisory Group.....	50

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This report is part of a series of publications on meeting the spiritual and religious needs of people with learning disabilities. This research report is linked to a training guide: *What about Faith? A good practice guide for services on meeting the religious needs of people with learning disabilities*, by Professor Chris Hatton, Suzie Turner, Robina Shah, Nabila Rahim and Julie Stansfield.

John Swinton has written *Why are we here? Meeting the spiritual needs of people with learning disabilities*. It is accompanied by two information booklets to raise the awareness about meeting spiritual needs, one for people with learning disabilities called *What is important to you?* and one for carers and support staff called *No box to tick*.

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Chapter 1: Background

This report describes a two-year action research project running from January 2002 to December 2003, funded by the Foundation for People with Learning Disabilities. The aim of the project was to work with services to meet the religious needs of adults with learning disabilities, and to discover what worked particularly well. Many positive and creative ideas for meeting people's religious needs came out of the project, which have been put together into *What about Faith? A good practice guide for services on meeting the religious needs of people with learning disabilities* (Hatton *et al*, 2004). This report gives an account of the project on which the good practice guide is based.

Before describing the project itself, it is important to give some background, highlighting why and how the project was done. This includes a discussion of what we mean by religious needs, why we need to take the religious needs of people with learning disabilities seriously, how well services are doing in meeting people's religious needs, and the background to the project.

What do we mean by religious needs?

For this project it was crucial to have a clear definition of religious needs, in particular to distinguish religious needs from spiritual or cultural needs.

Spirituality has defined by John Swinton (2001a) as “that aspect of human existence that gives it its ‘humanness’. It concerns the structures of significance that give meaning and direction to a person's life and helps them deal with the vicissitudes of existence. As such it includes such vital dimensions as the quest for meaning, purpose, self-transcending knowledge, meaningful relationships, love and commitment, as well as the sense of the Holy amongst us”. Spirituality is important to everyone, although different people vary tremendously in how they express spirituality in their lives. Spirituality does not have to involve religion at all.

Religion can be one way of expressing a spiritual need. Religions “provide shared rituals, narratives, symbols and guidance through scriptures, prayer and modes of social support” (Swinton, 2001b). In the UK, people are involved with a huge range of different religions. According to the 2001 Census (Office for National Statistics, 2003), the UK population includes approximately 42 million Christians, 1.5 million Muslims, over 500,000 Hindus, 340,000 Sikhs, over 250,000 Jews and a huge range of less numerous religious communities. Each of these major faiths also has diverse traditions and organisations within them. There are also 9 million people in the UK who say they have no religion.

Within services for people with learning disabilities, needs based on culture, ethnicity and religion are sometimes confused. This might mean that activities based on religious principles (such as halal food or carol concerts) are all assumed to be related to ethnic identity, ignoring their religious significance for the person with learning disabilities. Culture is “that complex whole which includes knowledge, belief, art, morals, custom, and any other capabilities and habits acquired by humans as members of society” (Bolaffi *et al.*, 2003). This complex whole includes beliefs and behaviours related to ethnic identity and beliefs and behaviours related to religion. A person’s ethnicity does not necessarily tell you whether that person will have a religious faith at all or what forms religious faith will take for that person.

Why we need to take religion seriously

There are many reasons why services should regard meeting the religious needs of people with learning disabilities as a fundamental activity.

The first reason is a straightforward human rights issue. As for any UK citizen, people with learning disabilities have a fundamental human right of freedom of thought, conscience and religion, now part of UK law as Article 13 of the Human Rights Act (1998). Services that obstruct these freedoms are open to legal challenge.

The fundamental human right of freedom of religious expression for people with learning disabilities is being increasingly recognised by theologians and faith agencies (Gaventa and Peters, 2001; IMPACT, 2001/2002; Swinton, 2001a). Although there can be religious traditions that exclude people with disabilities (Rose, 1997), there are traditions within almost all religions emphasising inclusivity: “Every religious tradition is pluralistic, meaning that within it can be found a wide range of interpretations of the tradition’s response to persons with disabilities. In most, a perspective that God accepts all, calls all, and can use all exists” (Norman-McNaney, 2001/2002, pg. 10).

These traditions are supported by a view of religious expression that is not only about religious beliefs, because insisting on knowledge and understanding of a set of beliefs may be used to exclude people with learning disabilities (Gaventa and Peters, 2001; Swinton, 2001a). Instead, many religious thinkers place equal emphasis on other aspects of religious expression, such as an emotional sense of having a relationship with a God or gods, praying, and having a sense of belonging within a religious community, including friendships and participation in the activities of the faith agency (Argyle, 2002; Gaventa and Peters, 2001; Swinton, 2001a).

There are also very good practical reasons why services should meet the religious needs of people with learning disabilities (Gleeson, 2001/2002). For example, person-centred planning principles emphasise the importance of meeting aspirations chosen by a person with learning disabilities, with the help of community-based

circles of support (Routledge and Sanderson, 2002). The person-centred planning process should therefore routinely include a spiritual and (if chosen) religious dimension (Gaventa and Peters, 2001). People within a person's religious community can also be useful members of the person's circle of support.

There is increasing research evidence that religious expression can have positive effects on physical and mental health (Swinton, 2001b). Religious expression and religious connectedness can also be an important and positive part of the lives of families with a person with learning disabilities. Religious beliefs help parents make sense of the experience of having a child with a disability and help parents to cope, and religious connectedness can provide families with much-needed support (Bennett *et al.*, 1995; Glidden *et al.*, 1999; Haworth *et al.*, 1996; Heller *et al.*, 1994; Rogers-Dulan, 1998; Rogers-Dulan and Blacher, 1995; Skinner *et al.*, 1999, 2001).

Finally, meeting the religious needs of a person with learning disabilities can be seen as a way of supporting the person achieve a positive and valued lifestyle in areas that services often find difficult, such as independence, meaningful social inclusion, and a valued social role (Gaventa and Peters, 2001; Gleeson, 2001/2002; IMPACT, 2001/2002; Swinton, 2001a).

Are services meeting people's religious needs?

There are strong reasons why services should be meeting the religious needs of people with learning disabilities as part of their routine practice. How well are services generally doing? Apart from services that have a religious or spiritual foundation (such as L'Arche, Camphill, Norwood Ravenswood and Prospects), services for people with learning disabilities generally seem to give religious needs a very low priority. This reflects a lack of policy emphasis on religious needs; for example the White Paper Valuing People (Department of Health, 2001) only mentions religion once in the whole document (page 20), and this mention is within the context of services for people from minority ethnic communities.

Although research evidence is limited, many people with learning disabilities have consistently said that religion is an important part of their lives. However, services are rarely interested in the person's faith and rarely help the person to explore their religion, unless a particular member of staff is interested and motivated (Azmi *et al.*, 1997; Churchill, 2000; Gaventa and Peters, 2001; Minton and Dodder, 2003; Swinton, 2002).

John Swinton (2001a) has suggested four possible reasons why services neglect the spiritual and religious needs of people with learning disabilities:

- communicational barriers that prevent the exploration of the emotional and spiritual aspects of the lives of people with learning disabilities

- assumptions that spirituality and ideas about God require a high level of abstract thinking, leading to decisions as to what the “necessary cognitive threshold” is for the membership of religious communities
- suspicion of the value vase of religion (i.e. that the values and belief systems that are inherent within religious systems will be forced upon people with learning disabilities)
- a general unwillingness to address spiritual issues, which is indicative of a wider failure to address emotional needs in people with learning disabilities.

Background to the project

The action research project was part of a programme of work led by the Foundation for People with Learning Disabilities, which has been at the forefront of efforts to highlight the importance of spirituality and religion in the lives of people with learning disabilities. Following a seminar on spirituality, religion and people with learning disabilities, the Foundation funded a preliminary study to describe the current situation on meeting the spiritual and religious needs of people with learning disabilities, and what needed to be done. This resulted in the report *A Space to Listen* by John Swinton (2001a). Following this, the Foundation funded two research projects to fill some of the gaps identified in this report.

The first project was managed by John Swinton at the University of Aberdeen. This project investigated in depth the spiritual needs of people with learning disabilities, and how these may be met by service providers, faith agencies and other community stakeholders (Swinton, 2004). The second project was the action research project described in this report.

Chapter 2: The project

Design

The overall aim of the project was to discover practical ways that services could meet the religious needs of adults with learning disabilities. Because services for adults with learning disabilities generally give a low priority to religious needs, it was important for the project to support services actively, rather than simply documenting existing good practice. However, it was also important that the active support given by the project was flexible enough for services to develop their own creative ideas for meeting people's religious needs, rather than the project imposing a rigid framework on services. Finally, it was crucial to evaluate what impact, if any, the support offered by the project had on services and service users.

To meet these aims, the project was designed as a piece of action research (Whyte, 1991). In action research, research and action go hand in hand; "the researcher acts as a facilitator or resource, providing information which helps those making decisions come to an informed choice over alternative courses of action. The researcher becomes part of the decision-making machinery, so that research findings are in the form of shared experience." (Uzzell, 1995, p. 311)

Guiding principles

Values are obviously fundamental to any service working with people with learning disabilities. This project was based on some basic principles, which all the participating services signed up to.

- The project starts from the individual religious needs of the person with learning disabilities.

Within any faith, there are big differences in how people understand their faith, what their faith means to them, and how people choose to express and explore their faith. These individual understandings and preferences should be respected rather than assuming that all people with learning disabilities of a particular faith will express their religious interests in the same way.

- The project aims to help services integrate religious needs into routine service practice.

Meeting people's religious needs is not the icing on the cake, only to be tackled when the basics of a service have been sorted out and easily dropped as non-essential when resources are tight. Meeting people's religious needs is a basic, and should become part of what a service does routinely.

The project is designed to help services and staff listen to the religious needs of a person with learning disabilities, rather than making staff religious

experts. Because there are so many religious faiths, interpreted in different ways by different people, it is impossible to expect staff to become experts in all the religions they might encounter amongst people with learning disabilities. It is far more important for staff to know how to listen to a person to find out how they understand their faith and what it means to them, than to apply a textbook knowledge of religion that might not fit the person at all. Staff will then learn about the person's faith in a way that is relevant to the person and that will help staff support the person in their religious interests.

- The project aims to help services meet the needs of people with learning disabilities of any faith.
Services should be willing to work with people of any faith, with no exclusions.

Participants

Within each pilot site, the project aimed to identify 10 adults with learning disabilities to participate in the project. Service professionals were asked to identify potential participants, who were known to have expressed some form of interest in religion. Each potential participant was asked by a member of staff who knew the person well if they were willing to be visited by one of the researchers to discuss the project further. If a person was interested, one of the researchers visited the person, talked through the project with them and a supporter if the person wished, and asked if they were willing to take part. Thorough and accessible informed consent procedures were used to establish if a person wished to participate.

Across the five pilot sites, 42 people with learning disabilities provided their informed consent to take part in the project. Table 1 describes some basic characteristics of the participants with learning disabilities. Table 1 also shows, there was a good representation of gender and age, although religious affiliations were less diverse than anticipated. On further investigation, this was due to the restricted religious diversity of people using the services for people with learning disabilities included in the project. It is common for many minority ethnic communities to be under-represented in services for adults with learning disabilities (Hatton, 2002); this is likely to apply to smaller religious communities too.

As with any action research project, many more people were involved in the project than the participants with learning disabilities. These included:

- senior managers, training departments and staff across North West England who responded to a postal survey (with telephone follow-up) asking about current policy and practice concerning meeting the religious needs of people with learning disabilities within their service and examples of good practice
- 18 people with learning disabilities, 10 family members and 30 staff who participated in separate focus groups in three of the pilot sites at the beginning of the project

- staff and managers across the five pilot sites who were directly involved in managing and organising the project within their service, participating in the project events, and taking both individual and service-level action to meet people's religious needs; for example, 39 staff attended the initial training days across the five pilot sites
- family members who participated in the project events and were directly involved in individual person-centred religious needs planning
- the project advisory group (see Appendix 1)
- people with learning disabilities, family members and staff who were not included in the project at the initial stage, but who became involved in the project during its lifetime within each pilot site.

The project programme

Although the support offered to participating services was flexible, a project programme was used as a general guide. For each participating service, it was planned to offer support according to the following programme:

- Ten adults with learning disabilities who had an interest in religion, and who gave us informed consent to take part in the project, were to be identified by the service.
- Within each service, information was to be gained about what the service was doing to meet the religious needs of service users and what the service should be doing. This might include separate focus groups with people with learning disabilities, family members and support staff, surveys of service managers and support staff, and/or in-depth interviews with the people with learning disabilities taking part in the project.
- Within each service, all the participating people with learning disabilities, support staff working with them, relevant service managers and family members were to be invited to an initial training day. This day was designed to be interactive, flexible to address the concerns of individual services, and fun. Starting soon after the training day, all the services were to receive ongoing support to help them develop person-centred individual action plans to meet the religious needs of all the people with learning disabilities taking part in the project. Services were also to receive support to help them develop more widely. This might include ideas for services to incorporate religious issues into their routine service-wide practices, and using lessons learned from individual work to guide changes in broader policies.
- Continuing support and evaluation was to be offered over the lifetime of the project, finishing with an event at the end of 12 months within each service. This event was to celebrate the achievements of the service, decide what the next steps were, and to evaluate the impact of the project on the service.
- Throughout the project, useful resources were to be lent to each service, together with information on more resources that services could access.

It was initially planned to work with three services for people with learning disabilities in North West England, according to the following criteria:

- Across the three pilot sites, there should be considerable religious diversity.
- The three pilot sites should be three different types of service: short-term support; day service support; and supported housing.
- Senior managers were committed to providing the resources required (in terms of staff time and venues) for the project.

The project began with three participating services according to these criteria. After some time, work was discontinued in one of these sites (a housing service) after several unsuccessful attempts to set up and run the initial training day. The project then worked with two additional sites on a short-term basis; a second day service for six months and a second housing service for two months. Table 1 summarises the activities conducted with each pilot site throughout the project.

Table 1: Summary of participants and activities across the five pilot sites

	Site 1: Short-term support service	Site 2: Day service	Site 3: Housing service	Site 4: Day service	Site 5: Housing service
Participating Service Users					
Gender					
Male	3	7	6	3	1
Female	7	2	6	7	1
Religion					
Christian		Yes	Yes	Yes	Yes
Catholic	Yes	Yes	Yes	Yes	Yes
C of E		Yes			
Methodist	Yes		Yes		
Muslim	Yes				
Hindu	Yes				
Age range	18-70	25-55	17-60	25-60	35-50
Regional survey of senior managers, training departments and staff in North West England					
Pre-Training Day					
Service audit	Detailed audit survey across whole service				Brief audit survey across whole service
Focus groups	Service users Relatives Staff	Service users Relatives Staff	Service users Relatives Staff		
Interviews with service users	In-depth interviews	In-depth interviews	In-depth interviews	In-depth interviews	
Training Day and Reviews					
Training day	Training day	Training day	Two attempts at training day; both failed due to lack of attendance	Training day	Training day
Training day evaluation		Questionnaires	Interviews with key staff	Questionnaires	Questionnaires
6-month review	Regular review meetings	Review meeting	Involvement with site stopped before 6-month review	Review half-day event	
6-month evaluation	In-depth interviews with service users	Questionnaires		Questionnaires	
12-month review	Conference	Review half-day event			
12-month evaluation	Questionnaires & focus groups	Questionnaires			
Ongoing Support					
Loan of resources	Yes	Yes		Yes	Yes
Individual action plans	Regular person-centred planning action group	Support for individual planning		Support for individual planning	
Strategic service	Regular strategic planning group				Informal service-wide religious needs group
Local action pack	Summary of progress for dissemination throughout service	Summary of progress for dissemination throughout service		Summary of progress for dissemination throughout service	Pack for local services: good practice, contacts, resources

The training day

An essential component of the project programme was the initial training day. This was developed according to the project principles, and information gained from the regional postal survey, pre-training focus groups and pre-training interviews with people with learning disabilities. The training day was, however, designed to be flexible to accommodate the individual needs of the pilot sites. More details and practical guidance on running the training day are available in *What about Faith? A good practice guide* (Hatton *et al*, 2004).

The training day was designed to run largely in a workshop format, to encourage active participation and motivation to take action. At least two of the research team ran each training day. It was essential for service users and staff working with them to attend; family members and managers were also encouraged to attend up to a total number of around 25 participants. The training day had the following key objectives

- to improve understanding and increase awareness of the religious needs of people with learning disabilities
- to identify gaps in current practice and understand the implications of not addressing religious needs
- to explore person-centred planning as a vehicle to meet the religious needs of individuals with learning disabilities
- to establish a list of key actions for the service.

Table 2 presents a typical programme for the training day, including the following major components

- an introduction to the training day, including the aims of the day and the basic principles underlying the training day
- an initial training session discussing definitions of religion, spirituality, culture and ethnicity, why the service needs to take religious needs seriously and the positive benefits of religion
- an interactive discussion session with the whole group about what services generally are doing to meet the religious needs of people with learning disabilities, using quotes from focus groups with service users, family members and staff
- exercise 1, designed for smaller groups, to discuss what the service is doing (or not doing) to meet people's religious needs at the moment and what helps or hinders effective support in this area; small groups feed back to the whole group to generate discussion
- exercise 2, also designed for smaller groups, to come with some concrete ideas for what the service can do to start meeting people's religious needs, including ideas about what resources are needed and a realistic timetable; small groups feed back to the whole group and a single set of actions are agreed

- a brief training session to the whole group, discussing the concept of person-centred planning and how this can be applied to the religious needs of people using the service
- exercise 3, for very small groups, to work with individual service users to discover their individual religious interests and preferred religious activities; feedback to the whole group describing the person's religious affiliation, interests and activities, and identifying some actions that can be taken within the next six months
- summing up the training day.

Table 2: Typical programme for the training day

Timings	Programme
9.30	Welcome and introductions Housekeeping
9.45	Definitions of religion, spirituality, culture and ethnicity Aims & objectives of training day
10.00	How are services currently meeting people's religious needs?
10.15	Exercise 1 How does your service currently meet the religious needs of people with learning disabilities?
10.45	Feedback
11.15	Break
11.30	Exercise 2 Assessing and responding to need. Wish list. What changes could be made within the service to better meet religious needs? List key issues.
12.00	Feedback
12.30	Lunch
1.30	Why we need to take people's religious needs seriously. Person-centred religious needs planning.
2.00	Exercise 3 Person-centred religious needs planning exercise.
2.45	Break
3.00	Feedback
3.15	Evaluation
3.30	Close

Resources

At the beginning of the project, a member of the research team conducted an extensive international search of resources that might help services in meeting the religious needs of people with learning disabilities. Resources were ordered and included in the set of recommended resources if they met the following criteria

- accessible to the target person (e.g. person with learning disabilities; staff member)
- age-appropriate
- consistent with the underlying principles of the project.

Resources were lent to participating pilot sites throughout the course of the project, and feedback gained on how useful they were. A final recommended list of resources is available in *What about Faith? A good practice guide* (Hatton *et al*, 2004).

Audit and evaluation

Consistent with an action research approach, methods of auditing services and evaluating the project developed over the course of the project (see Table 1 for a summary of which methods were used in each pilot site). Audit and evaluation methods were designed to gain relevant information in ways that were practically feasible. Several methods of audit and evaluation were used throughout the course of the project; details and examples of most of these methods are available in *What about Faith? A good practice guide* (Hatton *et al*, 2004). A brief description of these methods is presented below.

Regional surveys

Before working with individual pilot sites, postal surveys of senior managers and training departments were conducted across North West England. One copy of each survey questionnaire was sent to every major service supporting adults with learning disabilities, with a telephone reminder once the survey had been sent. Thirteen responses were received. These detailed postal surveys covered the following issues

- major religions in the local area and religions of people using the service
- contacts with local faith agencies
- policies concerning meeting people's religious needs
- training concerning meeting people's religious needs
- examples of good practice in meeting people's religious needs
- attitudes about the religious needs of people with learning disabilities
- challenges to services meeting people's religious needs.

Service-wide audit surveys

Two pilot sites in the project wanted to conduct service-wide audits. In one service, a brief two-page survey questionnaire was distributed to all staff within a large housing service, with only six responses received (an indicator of the low priority of religious needs within the service before the initial training day). With the support of the

researchers, another service developed and distributed a more detailed four-page survey to all staff across short-term support, housing and day services, with 30 responses received. In different levels of detail both audit surveys covered the following areas, with an emphasis on finding examples of good practice;

- religions of people with learning disabilities using the service
- service practices to assess service users' religious needs
- celebration of religious festivals in the service
- service practices to meet service users' religious needs
- service contacts with local faith agencies
- attitudes about the religious needs of people with learning disabilities
- challenges to meeting service users' religious needs.

Focus groups

Before the initial training day, focus group meetings were held in three of the pilot sites. Within each pilot site three separate focus group meetings were held, with service users, family members and staff. Two of the research team facilitated each focus group, with each focus group containing a maximum of 10 participants and lasting for a maximum of two hours. Although there were some differences in emphasis, the focus groups covered similar issues, including

- the meaning of faith and religion to the participant
- the religious affiliation and interests (if any) of the person with learning disabilities
- how those religious interests are expressed by the person with learning disabilities
- religious activities involving the person with learning disabilities and family members or friends
- religious activities supported by the service
- religious activities within the service
- involvement with faith agencies
- the attitudes of other people (including staff, friends and family) to active religious expression by the person with learning disabilities
- obstacles to religious expression, and ideas to overcome them.

In one pilot site a second focus group meeting with five staff was held after the project had been running for over a year. This focus group covered the following issues

- the opinion of staff about the religious needs of people with learning disabilities, and if this had changed over the course of the project
- the impact (if any) of the project on their practice, and which aspects of the project support were most and least helpful
- what messages should be highlighted in *What about Faith? A good practice guide*.

In-depth interviews

In-depth semi-structured interviews were conducted with 29 people with learning disabilities across four pilot sites before the initial training day, and with nine people with learning disabilities in one pilot site six months into the project. All interviews were conducted by one member of the research team at a place and time chosen by the interviewee. Interviews were between 10 minutes and one hour, and were all audio-recorded (see Turner *et al*, submitted, for details).

The interview schedule was developed on the basis of focus group discussions with people with learning disabilities, family members and staff members, previous literature, and discussion with experts in the field of spirituality, religion and people with learning disabilities. There were two parts to the interview schedule, although the interviews were conducted flexibly to follow the conversation of the interviewee. Part I of the schedule consisted of questions around attending a place of worship and descriptions of the interviewee's faith, and Part II consisted of a series of semi-structured questions around topics such as prayer, home visits, service responses to religion, and social life linked to a faith agency.

Evaluation questionnaires

Brief one-page questionnaires were developed for project participants to evaluate the support offered by the project. These were completed by participants in three pilot sites after the initial training day, participants in two pilot sites after six-month reviews, and participants in two pilot sites after 12-month reviews. The questionnaire immediately after the initial training day covered the following issues:

- Did the training day meet the person's expectations?
- What were the most helpful aspects of the training day, and what could have been different?
- Did the training day increase the person's understanding of religious issues and confidence to take action?

The evaluation questionnaires six and 12 months after the start of the project covered the following issues:

- How would participants rate the initial training day at this point in time?
- Since the initial training day, has the service made any changes to policy and practice to meet people's religious needs?
- Since the initial training day, have there been changes to the religious activities of individuals in the service?
- What have the positive and negative aspects been of trying to meet people's religious needs?
- What have been the most useful aspects of project support, and what could be done differently?

Chapter 3: Religion in the lives of people with learning disabilities

As mentioned in Chapter 1, there is some evidence that religion can be important in the lives of many people with learning disabilities. However, barriers to participating in religious activities often stop people with learning disabilities fully expressing their religious interests. This chapter will briefly describe the meaning of religion to the people with learning disabilities who took part in the project, based mainly on the in-depth interviews and focus groups described in Chapter 2. More details of the focus groups and interviews are available in *What about Faith? A good practice guide* (Hatton *et al*, 2004) and a journal article (Turner *et al*, submitted). As all the participants had expressed some interest in religious issues, the purpose was not to try and establish the extent of religious interest among people with learning disabilities: the aim was to discover the meaning of religion for those taking part.

Faith

In both the interviews and the focus groups, participants with learning disabilities were happy to talk about their religion and welcomed the opportunity to do so. Most people expressed a strong and clear sense of religious identity, clearly described their faith, and differentiated their faith from other faiths.

“Faith is what you believe.”

“Religion is a way of life.”

“I go to Church of England.”

“I love being a Catholic.”

“We believe in Allah.”

“It makes me feel happy, makes me feel good in myself.”

“I mean it’s good – God is good for you.”

Many people also showed a clear understanding of some fundamental concepts underpinning their religion, such as religious beliefs or religious practices.

“He came from what is it that...He was born at Christmastime in that’s what they believe...She had him in that foreign country where they’re

fighting, they are all fighting one another. Yeah where he was born they are fighting one another.”

“Yeah. People believe in, people believe in God and...life and problems, and thing if you have problems with religion and that, they go to the priest, go to religion with the church place.”

“It is when people go to Holy Communion and they go to church and they pray to Jesus and they have hymns and they have the Bible about Jesus. I believe in God, the Father Almighty, maker of heaven and earth, Amen. Dear Father in Heaven look down from above, bless father and mother and all that I love. For what we are about to receive may the Lord make us truly thankful. For Christ’s sake Amen.”

“It is about praising Allah.”

Religious practices

Participants in the interviews and focus groups engaged in a wide form of religious practices appropriate to their faith, beyond attending places of worship (this will be discussed in Chapter 4). These religious practices included prayer, religious television programmes, religious duty and religious festivals. The family, including the death of a parent, were identified by some interviewees as important influences on their religious practices.

The concept of prayer was almost universally understood, with only one participant in the interviews not showing an understanding of this concept. A large majority, although not all, participants prayed, mostly alone in a private space.

“I pray, I pray for God to help me.”

“Sometimes before I go bed, you know...I kneel down at my bedside, you know (laughter)... and you know like, and pray to God, it’s alright and say the Lord’s Prayer you know... Our Father which art in heaven hallowed be thy name...”

“On me own, in my bedroom, with my rosary beads.”

“I ask God to make all those sick in body and mind to get well.”

“I pray about it, I just, just think it in my head, don’t I.”

“No, I don’t pray, I watch television all the time.”

Religious television programming was a popular and important part of the religious lives of many participants. Indeed, for some people this was their only opportunity for religious expression apart from private prayers. The BBC Sunday evening show Songs of Praise was mentioned by a number of people, as well as Islamic cable channels showing religious programmes in the first language of the person's family.

“Oh yes, we watch that yeah, she [participant's mother] loves that one.”

“Like watching the mosque on telly.”

A Christian man and a Muslim woman in the project outlined that they felt a religious obligation to help people. Both individuals felt that they wanted a role within their community where they could help others who they saw as being less fortunate than themselves.

“Helping people... like blind people.”

“Urm, sometimes, if I see somebody crying, or if I see someone in trouble I will put my arm round them... helping people.”

Almost all the participants in the project from every religion spoke about celebrating religious festivals.

“[Eid] You keep a fast and don't eat nothing until four, and don't eat nothing before, right. You open it at four, so you can eat now, it is dark, you can eat. In the morning I don't eat nothing.”

“[Eid] Get up at dawn to eat and then open the fast with a date... New clothes, food, relatives come over”

“Diwali – making and sharing 36 different items of food.”

“Christmas fair, like to be involved.”

Families

Participants expressed different opinions on the influence of their families on their religious expression and activities. Many people, but not all, reported that they remembered being involved being brought up within a particular religious tradition. However, a minority of participants only became religious in adulthood or made a conscious decision in adulthood to change their religion.

“Yeah yeah, no no I never been to church when I was a little boy no, only when I grow up like.”

“There isn’t even bread there now, not even a bread, or the wine, not having them in [name of previous church], so I thought blow it I’m going down the Catholic now”.

Some interviewees attended religious ceremonies with other family members or engaged in other religious activities with family members, although even where families have strong religious views there was no evidence to suggest that this had a pervading influence on the religious life of the person with learning disabilities.

“We go for communion me and Mum.”

“Mum and Dad read the Qu’ran to me.”

“No my Mum doesn’t talk about religion.”

Some participants discussed how the death of a parent or parents had affected their religious practice in a variety of ways. Typically, the death of a parent was associated with people continuing to pray for their deceased parents. Over half the service users that discussed the death of a parent and prayer were from a Catholic background, reflecting the Catholic doctrine regarding prayer for the dead.

“My Mum I say prayers for.”

“I said, I said dear Lord, I hope to see my Mum again?”

One person had been excluded from the funeral of his father, although he continued to pray for him.

“No I don’t go in churches with the singing, I just go to funerals by going to the graves don’t I?...We go to my Dad’s grave a few times and we pray to God to him don’t we?”

The family members in the focus groups expressed a wide variety of views, from doubts about the capacity of the person with learning disabilities to engage in religious expression through to extensive support for the person’s religious expression.

“She wouldn’t understand, I teach her what I can.”

“We talk about it: not over-religious, we watch all the religious programmes on TV, Catholic and Protestant.”

“My son has been to Mecca, he knows it is God’s home.”

“Her father is strict, I am more liberal but we both read the Qu’ran to her.”

Chapter 4: How faith agencies respond to people with learning disabilities

Faith agencies played an important part in the religious activities of many, but not all, the participants in the project, with people engaging with faith agencies in very different ways for very different reasons. However, people had very diverse experiences of the inclusiveness (or otherwise) of faith agencies, with some exclusionary practices having a long-term effect on people's religious expression. Again, the information in this chapter is drawn from interviews and focus groups with people with learning disabilities.

Attending a place of worship

Although most of the participants said that they belonged to a religious group, only a minority attended a place of worship on a regular basis. Comparing attendance at places of worship across different religious faiths is impossible because of differences in customs. For example in the Bangladeshi Muslim community women do not usually attend the Mosque; female Muslims from a Pakistani background are more likely to attend the Mosque than their Bangladeshi counterparts but attendance is certainly not obligatory. As children, all Muslims attend the Mosque to learn Arabic in order to read the Qu'ran. Most of the Muslim service users reported not attending the Mosque as children, with only a minority attending Arabic school at a Mosque.

“I talk to my Dad and go to my church with my Dad.”

“Sisters take me to the Mosque.”

“Go to Methodist church to pray to God.”

“Me, I don't go Mosque I've finished.... I liked the Mosque.”

Of those who did not attend a place of worship some people expressed a wish to return.

“I would like to go back into church.”

Of those who attended a place of worship, many people particularly liked aspects of the atmosphere of the place of worship and the religious ceremonies, including the ritual sense of the sacred often present in services and Bible reading, although there were few examples of faith agencies making worship accessible.

“High church and the incense, swinging incense, you know...and the church choir.”

“The songs, the songs we sing, I don’t know what because I can’t read them.”

“I just can’t read them, I can hold the rosary beads with my hands and do it like that, I can’t read the prayer book.”

“Well, I think after Christmas we will be having one of them signed masses.”

Reasons given for not attending a place of worship varied from disliking the atmosphere to having to rely on support from others to attend.

“I don’t like it it’s ... It scares me.”

“No I don’t go into churches, they go too noisy inside, don’t they? ... That’s why I don’t like going in churches, you can hear the music of the instrument but it goes too loud, doesn’t it.”

“Yes I do I go to church if anybody can take me.”

The person within the faith community

There was very little evidence of religious organisations and communities fully incorporating people with learning disabilities by giving them a valued role. One person spoke of his participation at his old church acting as a greeter for the congregation. He had a useful and valued role within his old church but not at his new church, and expressed a wish to once again take on this role.

“...if people are coming in, if people are coming in, I help give books out for them.”

However, many participants reported being involved in and enjoying many other aspects of the activities of faith communities. These included the social aspects of faith communities and other activities such as prayer meetings and Bible study.

“I’ve got friends there,”

“Yes coffee, a drink of coffee and a bring and buy stall.”

“Discos... Dancing.”

“We go to the luncheon club after.”

“Monday night fellowship at the Ministers’ house... Bible study and choir.”

“Easter vigil, Christian Aid week, Children’s first Holy Communion,
Christmas fair, happy hour club on a Tuesday and coffee mornings after mass”

Very few participants reported that a representative from a place of worship visited them at home.

Sacraments and ceremony

Some participants reported sacraments such as communion or confirmation to be a very important part of their religious identity, although other people had been excluded from these sacraments.

“I was baptised at [name of church], a Roman Catholic at [name of town]... I’ve been going since I grew up and made my first communion at [name of church].”

“I got confirmed in a, like in a convent, ...we went there. There was a ceremony and I had a veil on with a white frock on and a veil and white shoes and I had one nun like that” (gestured to her side).

“Well, I did make my first confession... But when my mam was alive the priest come round to the house because I’m Down’s syndrome and that; and he actually upset my mam by saying that I’m Down’s syndrome and I don’t know what... he was saying to my mam that I don’t know about religion... I’d love to make my communion with everyone standing around me the whole family, except my mam who isn’t with me anymore.”

Chapter 5: How services respond to religious needs

As Chapter 3 showed, people with learning disabilities can have strong religious affiliations and interests. Forms of religious expression include but are not confined to involvement with faith agencies, but full religious expression requires support for the person's religious needs to be fulfilled. In this project a large amount of information was collected on the role of services in meeting the religious needs of people with learning disabilities. Sources of information included a regional survey, service audits, interviews with people with learning disabilities, and focus groups with people with learning disabilities, family members and staff (see Chapter 2 for details). These multiple sources of information produced a consistent picture across many different services for people with learning disabilities; that meeting people's religious needs was a low or non-existent priority for services.

Policy, practice and training

No respondents to the regional survey reported that the service had a policy concerning meeting the religious needs of service users. If religion was mentioned, it was within policies concerning meeting service users' cultural needs, reflecting a confusion between ethnicity and religion also expressed by staff in more detailed audit surveys (for example, one staff member described a person's religion as Polish). A similar issue arose concerning staff training. The regional survey revealed very little training for staff in religious issues, with such issues only being mentioned as part of cultural diversity training with reference to people from minority ethnic communities.

Services in the regional survey also reported having little or no information about the religious affiliations and religious needs of the people using the service. One detailed service audit revealed that standard audit and referral systems recorded little or no information on people's religious needs. Furthermore, where information systems did include options to record a service user's religion, these were often left blank: information about religion was only gained informally by a staff member if the person or their family proactively mentioned that religion was important.

Basic audit information on how well services were doing in meeting people's religious needs was very rare, and where this information was available it revealed low levels of service activity aimed at meeting people's religious needs. For example, an audit done by one service in the regional survey found that only 23 of 176 housing tenants and none of 150 users of short-term support services attended a place of worship. Almost all services only celebrated Christian religious festivals, typically Christmas and Easter, with even these festivals celebrated in a largely secular way.

For the people with learning disabilities taking part in the project, services typically ignored religious needs and could even be actively unhelpful; examples of good practice seemed to be isolated and dependent on staff who themselves had religious interests.

“They don’t mention about churches but they let me know when they are going to meetings every time, don’t they?”

“I do it on my own in my room... because it might upset the staff, I go on my own and say a couple of, say a couple of prayers on my own.”

“Some people [staff] stop me.”

“Some staff listen at night and advise on religion.”

“Staff that are religious are more involved.”

“I don’t know what it is, I’d get there before it opens when I lived there [near the church] but I can’t go anywhere now I’m here [new supported living services], I have to get taxi money here.”

Families in the focus groups confirmed this picture of a general lack of service interest in their person’s religious needs, except for basic support concerning those aspects of religious practice seen as ‘cultural’ by services.

“Services concentrate on their own faith and don’t think of others.”

“In day centre environment religions are not taught.”

“Services just never think to offer.”

“Sometimes for specific things like diet and filling forms in.”

Some staff members reported specific examples of good practice in their service, although the general picture from staff was a lack of active support to meet service users’ religious needs.

“We have supported a priest to come in and have a service within the building for a lady who could not get to church.”

“We pray with people.”

“If a Muslim it is done as part of the review.”

“At annual review it’s addressed if a family push it.”

“Sometimes there is a sigh of relief when people do not have any religious needs.”

Barriers to meeting people’s religious needs

Service users, family members and staff all identified barriers to services meeting the religious needs of people with learning disabilities. Some of these barriers concerned a lack of physical resources, staff time or staff knowledge of religious issues.

[Service user] “They don’t have a place there [to pray], do college. I can’t find a place there and I can’t read the namaz and things like that and there is no space there”

[Service user] “Staff do not have time.”

[Staff member] “Resources and staffing levels.”

[Staff member] “Have to know a lot.”

There were, however, more frequently mentioned barriers. For example, staff members had very different views on the role of religion in the lives of people with learning disabilities, with some opinions directly contradicted by the views of people with learning disabilities themselves discussed in Chapter 3.

“Most service users don’t display religion.”

“No idea of what it stands for, no say in it.”

“Don’t have the logic or understanding to change religion, just follow carers or parents.”

“People with learning difficulties do not have limits to spirituality.”

Staff also varied in their views about whether services should be meeting the religious needs of service users.

“It isn’t part of the job in day services.”

“Holy days of obligation – the staff shouldn’t have to take them. It isn’t their responsibility.”

“The service supports are not designed to meet religious needs, they are for basic support.”

“Easy to impose a religious view on others – easily led.”

“Meeting ‘spiritual’ needs is part of staff’s role, like taking people to college.”

“Some things are not negotiable.”

Family members also highlighted some barriers to their involvement in supporting services to meet people’s religious needs.

“Things are so automatic to us we don’t think to tell and they don’t ask personal questions about the way of life, only diet etc.”

“There is a lack of trust of social services from families.”

“Don’t expect them to.”

In fact, the most important barriers to meeting religious needs identified by staff concerned the attitudes of other staff members within services.

“Staff don’t understand and may see it as boring plus don’t want to be bothered.”

“People supporting people with learning disabilities do not understand their faith.”

“A can’t do culture in some services limits people.”

“Direct racism and indirect racism.”

“Fear of asking, upsetting, offending people.”

“Religion not predominant in British culture any more so staff don’t think along religious lines.”

“Other staff can see religions as bizarre.”

Ideas for improving service support

In the focus groups, service users, family members and staff were asked for their ideas about how to improve service support. Ideas for improvements tended to reflect the identified barriers. People with learning disabilities emphasised staff involvement and support, and accessible religious resources.

“People having more time.”

“Time to think.”

“Talking about it.”

“Be talked to more about religions.”

“Helped to join things.”

“Tapes.”

“Reading and pictures.”

Family members emphasised more personal involvement with family members, a person-centred approach and a multi-faith environment.

“Giving people the experience, not just a talk on what a Muslim is and what he does.”

“Services not being afraid to ask.”

“Services being more approachable to learn would help.”

“Treating people as individuals not groups – not ‘Oh this is a Muslim so they need this or this is a Christian and they need that’; there are routines that are individual.”

“Sharing all festivals and parties like Eid, Christmas, Diwali etc.”

Staff suggested similar improvements to those mentioned by service users and family members.

“Love and respect for each other regardless of religion. Having the knowledge and awareness; knowing the basics of religion not stereotypes.”

“Induction training – where religious needs are raised.”

“All people would be offered and facilitated in getting a good person-centred plan.”

“Staff discuss religion with different service users.”

“Festival celebrations – Eid, Christmas, Festival of Lights.”

“Visit places of worship.”

Chapter 6: Supporting services

In keeping with an action research approach, the research team worked with participating services to support them in meeting people's religious needs. Chapter 2 describes the framework used to guide the support offered to participating services. However, the services worked with the research team to develop and pilot innovative ideas. This chapter will briefly describe the main types of support offered by the researchers and the main types of activity that the services engaged in. The impact (or otherwise) of the support offered by the researchers, and the factors that seemed to result in the greatest improvements, will also be discussed in the relevant sections.

The training day

Full training days were conducted in four of the five pilot sites. In one pilot site a full training day was not carried out despite repeated attempts; this pilot site took no further part in the project. In this pilot site a lack of clear organisational support from senior managers led to confusion about who was responsible for organising the day and who was to attend. Two training days were set up in this pilot site, both of which were very poorly attended by staff. These training days then became half-day discussion groups, principally with service users, about their views of religion.

Based on the experience of the research team, the following factors need to be in place for a successful training day to be set up:

- Organisational support from the senior manager responsible for the service where the training day is to take place. The senior manager needs to recognise the value of the training day, establish clear lines of organisational responsibility to ensure that the training day happens and ensure that essential resources are made available.
- A named training day organiser to ensure that the training day goes ahead.
- Essential resources for the training day including a venue, refreshments and lunch, allocated staff time to attend the training day and engage in preparatory work with interested service users and family members, interpreters and supporters if required and transport to enable service users and family members to attend.
- Preparatory work before the training day to identify interested service users and family members, and go through what the training day will be about.
- The attendance of substantial numbers of people with learning disabilities at the training day.
- The compulsory attendance of relevant staff (particularly those who work with service users attending the training day) at the training day.

- An informal and non-judgemental atmosphere.
- A flexible approach to the training day so that the day moves at the right pace for the participants.

Chapter 2 outlines the training day programme (see *What about Faith? A good practice guide*, Hatton *et al*, 2004, for more details). This section describes some of the issues raised in the training days, together with participants' views of their effectiveness.

In the first exercise of the training day, participants in small groups discussed what their service was currently doing (or not doing) to meet people's religious needs and what helped or hindered effective support in this area. In all pilot sites, the issues raised in these discussion groups were similar to those discussed in Chapter 5; a generally low priority given to religious needs with isolated examples of good practice, and resource and attitudinal barriers identified to meeting people's religious needs within the service.

In the second exercise of the training day, participant groups were asked to come up with some concrete ideas for what the service could do to start meeting people's religious needs, including ideas about what resources were needed and a realistic timetable. All participants together produced a focused action plan for the service as a whole. Examples of service-wide actions arising from this part of the training day included

- buying a multi-faith calendar and displaying it in a prominent place, and getting more information on a range of religions
- incorporating religious issues into crafts, music and cooking activities, particularly around religious festivals
- invite representatives of different faith agencies into services to talk to service users and staff
- interested individuals and groups of service users visiting different places of worship to learn about their own and other religions
- using religious resources that are accessible to service users.

In the third exercise of the training day, very small groups worked with individual service users to discover their individual religious interests and preferred religious activities. Both the service user and another member of the group presented these religious interests to everyone, including some ideas for actions to be completed in the next six months. This exercise could be very powerful for both service users and staff: service users often felt empowered to talk about their religion for the first time, and staff often realised that religion was a central part of a person's life that they had not to date taken seriously. This exercise also showed very clearly how individual people's religious interests and preferred activities were. Two examples of these individual stories (with the names changed) follow.

Alfred

Margaret (a member of staff) began by stating how this exercise has completely changed her conception of Alfred's religious needs. As he is non-verbal he often gets left by the wayside at the service. The staff completed the task by asking Alfred questions and he either nodded or shook his head, he also crossed himself and put his hands together in prayer. Margaret stated that she and other staff had always presumed that Alfred crossing himself was simply obsessive behaviour, not an indication of his religious need. Aspects of religion in his life included

- participates in Mass/communion every Sunday
- Roman Catholic church
- important part of Alfred's being
- enables him to socialise with his friends
- music, Boys Brigade linked to the church
- ceremony/genuflecting/praying/singing.

Alfred's action plan:

- To visit a church with others once per month – achieved two months from now.
- Object reference – e.g. photos/Bible/statues/music tapes – achieved in one month, speak to manager to obtain money.
- To attend a concert with religious music.

Paul

Aspects of religion in Paul's life included

- Church of England
- to worship God and partake in communion
- enjoys the rituals of attending church
- social side and meeting different people
- going regularly to places of worship
- observing religious festivals and holidays
- singing hymns
- praying
- Bible readings
- enjoys helping such as handing out the hymn books.

Paul's action plan:

- Paul said that he would like to meet with other people from both day centres to talk about today and give feedback – by three months; staff to co-ordinate with Paul and other service users to ensure it happens; staff to facilitate venue and transport etc.

- Go with service users who are interested to visit Paul's church by minibus – by six months. Speak to vicar for suitable time and date. Christmas may be a good time.
- Paul's vicar to visit the service to see what we do and speak to interested service users – by three months. Staff will liaise with vicar to see if he can attend.

In services where the full training day took place, participants in evaluation questionnaires were generally enthusiastic about the day. Even six and 12 months after the training day, most people felt that it had increased their confidence and changed their practice, although a minority of staff felt that the training day had little impact on them or their practice.

[After the training day] "It gave me the confidence to stand up in front of people and discuss my religion."

[After the training day] "Yes I enjoyed talking to service users and staff."

[After the training day] "Today was a pleasant and informative surprise."

[After the training day] "Enjoyed it very much. I was sceptical at first but all my questions were answered."

[After 6 months] "It has given me more understanding to meet the needs of individuals."

[After 6 months] "I have thought more about the above [religious needs] but got no more confidence."

[After 6 months] "Useful, informative and raised awareness with people."

[After 6 months] "I enjoyed the training day (informality and humour helped). Positive suggestions from tutors were beneficial."

[After 6 months] "I still feel we have a very limited role to play – religious needs should be dealt with in a home environment."

[After 12 months] "It has created a forum for discussion that in the past may not have happened."

[After 12 months] "It has raised awareness with both staff and service users. Not only has it been a theoretical exercise but a lot of practical work has been done."

[After 12 months] “Helped to dispel preconceived notions that we might have held on people’s religious beliefs before the training days.”

Participants in the training days also gave their views on what worked best and what they would have wanted to be different. Aspects of the training day valued by most participants included the mixture of information and discussion, the inclusion of service users as an integral part of the training day and the informal atmosphere.

“The talks and explanations.”

“Good to have service users present and involved.”

“Yes, very positive and a great experience training alongside people who use the service”

“Being with friends.”

“Talking about what we want.”

“Informative in an informal way.”

“Sidelineing my own personal beliefs and looking at the emotional needs/ beliefs of others.”

“Good team work with service users involved.”

“Easy going, encompassing all religions and geared to individual choice – excellent buffet.”

“Non challenging approach, friendly, meeting colleagues from other bases, relevant group discussions, time to listen.”

Participants also suggested some potential improvements to the training day, mainly around inviting more people, giving more information about particular religions and extending the scope of the training to include people with more complex needs.

“More service users here.”

“I would have liked more people to have attended the day.”

“Involvement of carers would have been good”

“To gain more knowledge to present to people with learning disability with less skills.”

“Different religions.”

“Which videos are available, what festivals there are.”

Resources

A member of the research team undertook an extensive search for suitable religious resources (see *What about Faith? A good practice guide*; Hatton *et al*, 2004; for details of recommended resources). Recommended religious resources were lent to participating services throughout the project, according to their needs and activities. In general, religious resources were common for various Christian denominations, and less common for Judaism, Islam, Hindu Dharma, Sikh and Buddhist faiths. Religious resources were identified that were useful for a range of audiences and covering a range of issues, including

- multi-faith resources useful for staff and family members, including multi-faith calendars, resources with basic information on different religions and their festivals, and resource listings of faith agencies in the UK
- multi-faith resources accessible to people with learning disabilities, providing basic information on different religions and their festivals
- resources useful for staff, family members or people with learning disabilities giving more information about particular faiths and particular religious festivals
- resources accessible to people with learning disabilities with practical ideas for activities associated with particular religious activities
- videos and practical guidance on getting involved in places of worship
- song books and CDs of religious songs and music.

Participating services reported that all these religious resources had been useful in different ways, and many invested in their own religious resources throughout the lifetime of the project.

One participating service produced a local resource to share information, examples of good practice and contact details (both staff and local agencies) across the whole service. This local resource included

- information on local faith agencies that were welcoming to people with learning disabilities and their activities
- examples of good practice in local services to meet people’s individual religious needs, with staff contact details for further information and support
- examples of good practice where staff in the service have taken time to find out the religious needs of individuals with learning disabilities, in consultation with them and their families, with staff contact details for further information and support

- details of how religion should be a part of the general person-centred process being conducted throughout the service, with practical examples of how this can be done
- guidance to ensure that people with learning disabilities are included in the funerals of people close to them in ways that are accessible and sensitive.

Incorporating religious issues into routine service practice

As described in the section above, during the initial training day participating services set themselves some service-wide actions, with self-imposed deadlines. Many of these service-wide actions concerned incorporating religious issues into their routine service practice. The research team supported each participating service to take action according to the expressed needs of the service. This support included regular visits to discuss progress, lending relevant resources to the service, discussing obstacles to progress with senior managers and encouraging services by documenting achievements.

In all the pilot sites, service began to incorporate religious issues into some of their routine activities very quickly, particularly when few resources were required to implement change and activities were not tailored to meet the religious needs of specific people in the service. More individually tailored activities (see below), activities requiring more resources (particularly in terms of dedicated staff time) and activities requiring co-ordination across different branches of a service (for example a housing service and a day service) took longer and were more difficult to achieve.

All the services taking part in the project wanted to start celebrating a range of religious festivals, with multi-faith wall calendars a particularly good source of basic information. Rather than aiming to celebrate a wide range of religious festivals, many services found it useful to focus on one festival (such as Diwali or Eid), and use this as a way for everyone in the service to learn something about both the festival and the religion underpinning it. For example, one service in the project included in their arts and crafts sessions some activities around Diwali. Another service arranged an Eid party for everyone in the service. Attending carol concerts around Christmas was another activity engaged in by some services. Other examples included a trip out to a Cathedral at Easter and having a meal in a restaurant to celebrate Eid.

Almost all the services involved in the project started to make contact with people in local faith agencies, usually through the personal contacts of staff, family members and people with learning disabilities in the service. Many services arranged visits of interested service users to diverse places of worship, as many people wanted to find out about religions other than their own. A smaller number of services invited representatives from faith agencies to visit the service to discuss religious issues in a familiar, informal environment, with appropriate training for the representative.

For example, on request from one minister visiting a service, the staff videotaped his session and gave him feedback on making his language more accessible to the people in the service. By the time the project had finished, these contacts with faith agencies were beginning to result in more involvement by service users in the life of local faith agencies, including worship and social activities. In some services, this had included active support by the service for service users to attend funerals of people close to them.

Many services in the project were involved in very creative activities incorporating religious issues into routine service practices, including

- having some questions around religious issues in a weekly quiz
- occasionally hiring videos of films with a religious theme
- making Eid cards
- wall displays of the theme ‘faith and light’
- exploring religious themes in music sessions.

Despite the initial concerns of staff in participating services, there seemed to be little evidence that people of different religious beliefs would engage in conflict with other; instead service users generally wanted to learn about religions other than their own. Services were careful to ensure that service users with no interest in religion were not forced to participate in religious activities, and did not lose out on preferred activities because other people’s religious needs were beginning to be met.

Individual planning

Different participating services engaged in individual religious needs planning to varying extents. Within the project, planning to meet the religious needs of individuals generally took longer than making some changes to incorporate religious issues into routine service practices. The two services who had been supported by the project for 12 months or longer had both engaged in religious needs planning by the end of the project; the three services involved for shorter periods of time showed less evidence of individual religious needs planning.

One service in particular developed very thorough religious needs plans using person-centred planning principles and methods. Facilitators of these religious needs plans were supported by a professional within the service experienced in person-centred planning, and also met each other regularly for peer support. Obviously, the plans by their nature were highly personal, including personal information and pictures of local people, family members and places of worship, making them highly accessible to the service users at the centre of the plans. Because of their personal nature, it is not appropriate to share the plans in their original form. However, some people gave approval for excerpts of writing from their plans recording their current religious activities to be included here; excerpts from three of these plans are given below. Although the examples here all relate to Islam, the principles of person-centred religious needs planning apply equally to any religion.

Plan 1

- I like to watch my mum pray – this is important to me as it helps me to learn and understand my religion.
- I listen to the Qur'an on cassette. The Qur'an is originally in Arabic but is translated into Bangla on tape. This makes it easier for me to understand about what is written in the Qur'an.
- I especially enjoy listening to the Qur'an in the month of Ramadan.
- I also watch religious programmes on the Bangla channel.
- It is my dream to visit Saudi Arabia to see the home of Allah and the resting place of our prophet Muhammad (peace be upon him).

Plan 2

- I pray regularly with a member of staff at home. I recognise the moves and I am able to follow the movements. I also pray at home with my family when at home with them. I have a prayer mat for this purpose.
- My house is completely Halal and no other food is brought in. I eat a varied diet consisting of Asian and British cuisine. All the staff that support me eat Halal when at work and they have learnt to cook lots of Asian foods with me. All food is checked for meat products, gelatine, and alcohol when I am supported to shop.
- I celebrate all the Muslim festivals. Ramadan, Eid-ul-Fitr and Eid-ul-Adha. I am supported by staff to buy presents and cards for my family and friends.

Plan 3

- Salah means prayer, this is done five times daily.
- I can take part in these prayers through a number of ways.
- With the support of my brother we recite verses from the Qur'an. When I am reciting people say I look very happy and content.

At the end of the project, religious needs planning facilitators were asked what advice they would give to other people doing person-centred religious needs planning. The advice they gave is summarised below, grouped into advice about the role of facilitators and advice about the role of managers.

The role of facilitators

- Put your own opinions, religious faith or atheism to one side.
- Be as objective as possible.
- Keep families and those that love and care for the individual involved in the development of the plan.
- Ask lots of questions. It is better to ask than presume and get it wrong.
- Ensure that everyone has the opportunity to see a draft of the plan and make any changes, additions or edits as necessary.
- Remember the plan is going to be 'living'; there will be a need for ongoing revisions once the implementation is in place.
- Make the plan accessible, include as many pictures as you can.

The role of managers

- Managers must be prepared to allow time for staff to develop the plan. For example in a day service setting it will be necessary to allow staff time with individuals away from the rest of the group.
- Funding: it may be necessary to set aside a small fund to cover certain costs. For example people working in a supported house would not have access to photocopying or laminating facilities.
- There needs to be commitment at all levels of the service. For example staff may be keen to take part but it is equally as important for their managers and the head of the service need to be as committed.

Strategic development

So far, this chapter has described project support and service actions based either at the level of individual service users or the level of a particular service participating in the project. Throughout the project, the research team was interested in supporting and documenting any strategic initiatives around meeting religious needs undertaken by the services. In particular, the researchers wanted to know whether the support offered would have wider effects beyond the particular individuals taking part in the project. Pilot sites varied in terms of how much attention they paid to strategic developments, although all the pilot sites who participated in the training day were involved in some activities that went beyond the service users who originally consented to take part in the project. Even in those services where there was no focus on strategic development, the following changes were seen suggesting that the impact of the project was beginning to broaden out beyond the original participants.

- As discussed above, routine service practices began to incorporate religious issues, which were made available to all people in the service.
- Services began systematically to ask all people using that service about any religious affiliations, beliefs, interests or activities they may have.
- Regular review processes began to routinely include religious issues.
- Individual religious needs planning work began to happen with people who were not originally involved in the project.
- Staff not involved in the original training day became involved in later review events.

Although these changes were important, they typically had little impact beyond the participating pilot site. Two pilot sites paid greater attention to strategic issues, driven by senior managers with considerable commitment to the aims of the project. One site, which was involved in the project for a short period of time, began to develop an informal group of managers, staff, service users and family members to raise the profile of religious issues throughout the whole service. This group was to meet regularly, and by the end of the project had set itself a number of tasks including the following

- organising a survey to find out where the service is at concerning religious issues
- developing a local pack to share examples of good practice
- making contact with representatives of local faith agencies
- finding out what religious resources were available and appropriate
- finding out examples of good practice in other places
- looking at referral forms and information systems across the service
- taking the lead in developing person-centred religious needs plans.

The second site set up a more formally constituted strategic planning group, with a membership of senior managers, committed staff and members of the research team. This group had formal terms of reference and was accountable to a senior planning committee within the service. Throughout the lifetime of the project, this strategic planning group had four major aims, which will be outlined in turn.

The first aim of the strategy group was to ensure that the project ran successfully within the pilot site. Strategy group meetings were held regularly, with attendance from relevant people as required, to monitor progress, solve practical problems, and plan the direction of the project as a whole.

The second aim of the strategy group was to apply lessons learned from individual person-centred religious needs planning to the whole service. The process of developing individual plans and putting them into practice identified practical obstacles to meeting people's religious needs, which were brought to the attention of the strategy group. For example, one individual and his family had been requesting for sometime that when Imran (not his real name) attends College the personal care

he receives should be gender specific. At first the College said this was not possible until it became part of his person-centred plan. Now that the College understands the importance of Imran's religion they are meeting his personal care needs as well as other religious needs such as helping Imran say 'bismillah' ('in the name of Allah') before Imran begins a new activity. This is also having an effect on the College's general practices towards other people with learning disabilities.

The third aim of the strategy group was to examine and improve the service's assessment and information systems to routinely and accurately include information concerning religious needs for all people using the service.

The fourth aim of the strategy group was to develop a service policy concerning religious needs. The group felt it was important to develop a religious needs policy for the following reasons:

- highlighting that the service takes people's religious needs seriously
- helping staff across the services get started with some basic information and guidelines
- setting standards so that the service could be held accountable.

A policy concerning religious needs was developed and added to the service's policies on cultural diversity. Beyond the lifetime of the project, the plan was to keep monitoring and revising this policy document: to improve the policy; to adapt the policy to meet new circumstances and changes in services; and to allow everyone in the service to have an input into the policy to increase ownership.

Celebrating achievement and driving improvement

Services taking part in the project found that two types of follow-up event to the training day were useful in monitoring progress and setting new targets for continued improvement.

The first type of follow-up event was a regular, relatively informal event for everyone who has taken part in the initial training day, typically held on a six-monthly basis. These half-day events with an informal atmosphere generated honest reflection on what had been achieved in the service so far, what the problems were, and what the service should do next. Below are some examples (with the names changed) of issues arising in these events, first of all for individual service users. Again, the examples relate to Christianity but the six-month events are equally applicable to any religion.

- Suzanne wanted to go to a specific church. This was made possible for her by formulating it as a day activity and including some other service users. Staff discovered that Suzanne is visited by the vicar and offered communion in her own home.

- Bridget – The vicar left at her old church and they are still waiting for a permanent replacement. Bridget has been kept informed.
- Mike hasn't noticed any difference and would like to be more involved.
- Robert went to church when his brother died and now goes every Sunday with his sister, Winnie. Robert carries the candle flame.
- Brian says that nothing has changed and he would like to go to the remembrance service at his local church.

Services also identified issues at a service level, in terms of activities and meeting the goals of previous action plans.

- There have been some art activities around religious themes. Some resources for embroidery and sewing are on order.
- We have had some discussions regarding what Eid celebrations could take place in the service.
- New people to the service have been asked if they need any help with meeting their religious needs.
- A local church helped service users at time of Albert's death – used church to pray for him.
- Visits to diverse places of worship, including a Mosque, Cathedral, and Church of Latter Day Saints.
- Recognising different religious festivals.
- Our practice has changed over the past 12 months e.g. seeing service users as whole being, holistic approach.
- We have met goals set out 12 months ago but there's always room for improvement.

Finally, services identified priorities for the next six months:

- Would like someone from another religion to come to the service and talk to service users about their religion and help willing service users to celebrate their religious days.
- Learn to recognise different symbols for other religions.
- To visit church at Christmas.
- To watch religious videos.
- Non-Christians to celebrate their special days.
- Christmas carols – singing.
- Steven would like to go to church as he likes the singing.
- Promote what's already been done. Have a coffee morning and invite people from different ethnic and faith backgrounds for discussions.

In addition, one service held a conference just over a year after the initial training day. The purpose of this all-day event was to celebrate the achievements of the service, and to share these achievements with new groups of staff across other parts of the service. Staff and service users together presented their stories about supporting people to meet their religious needs, including positive achievements, difficulties and plans for the future. Some examples of these stories are presented below (all the names have been changed).

- Nasreen wanted to have an Eid celebration with her friends and staff at the gender specific outreach base she attends. Staff made this possible, taking everyone who wanted to attend out to a suitable venue for a meal.
- Sharaf is being supported by a member of staff who is praying with her at home.
- Parveen shared with everyone how much she had enjoyed making Eid cards at the centre.

Chapter 7: Conclusions

This final chapter will briefly summarise some of the major conclusions from the project and reflect on some larger issues coming out of the project to suggest some directions for future work aiming to meet the needs of people with learning disabilities.

Conclusions from the project

The project reported in this final report was an action research project designed to work with services to help them meet the religious needs of people with learning disabilities. By conducting the project it was also hoped to produce creative and practical ideas for other services to use; *What about Faith? A good practice guide* (Hatton *et al*, 2004) is the result of this aim.

The first major conclusion of the project is that many people with learning disabilities have a strong religious identity that they are happy to discuss and share with others. These religious identities, and the interests and activities associated with them, vary tremendously across individuals. However, freedom for religious expression for people with learning disabilities is all too often constrained. This constraint is often imposed by support services, whether through lack of resources, neglect, exclusionary beliefs, or secular service cultures that are hostile to religion. Constraints are also sometimes imposed by faith agencies, including religious services that are inaccessible to people, an unwelcoming atmosphere, and a lack of willingness to integrate the person with learning disabilities fully into the life and activities of the faith agency.

There are, however, a number of levers for positive change within services. These levers include attention to basic human rights, the positive benefits of inclusion within faith agencies and the current focus on person-centred planning and meeting the person's individual aspirations. The project demonstrated that staff in services paying little or no attention to people's religious needs very quickly appreciated the potential importance of religion to service users, and the benefits to be gained by addressing people's religious needs. Understanding religious needs within this framework motivated staff to use their existing skills and apply them to people's religious interests, rather than deskilling staff by making them feel they had to be religious experts before they could do anything.

The second major conclusion from the project is that services can substantially improve service practices to meet people's religious needs in a relatively short space of time, without substantial extra resources. However, support from senior managers is crucial: for ensuring that training events happen; to give staff the time and support to properly develop and implement person-centred religious needs plans; and to link up lessons learned from working with individuals to strategic, service-wide change. Without this

senior management support, improvements are likely to be contained within small parts of the service and initial enthusiasm may not be maintained over time.

Finally, it is crucial to emphasise that for participating services their involvement in the project was only the beginning of their commitment to meeting people's religious needs. Making the meeting of religious needs routine for all who have religious interests is likely to take several years, given the lack of priority given to religion by almost all services for people with learning disabilities. However, this project has shown that services can achieve important gains for people in a short time, forming the foundations for a long-term commitment to meeting people's religious needs.

Issues for the future

The project also raised a number of broader issues that were beyond the scope of the project and signal possible future directions.

Faith agencies and religion

Religious expression is a fundamental human right for everybody, including people with learning disabilities. For services to meet the religious needs of people with learning disabilities, they need support from people in faith agencies who want to include people with learning disabilities. People in the project reported very different experiences of faith agencies, from very welcoming and inclusive agencies to agencies that actively excluded people with learning disabilities from fundamental aspects of religious expression.

This project focused on what services could and should be doing to meet the religious needs of people using the service. It was beyond the scope of the project to work with faith agencies to give similarly detailed guidance on what they should be doing to include people with learning disabilities. Some religious organisations have produced their own guidance to faith agencies about including people with disabilities (see Chapter 8 of *What about Faith?*; Hatton *et al* 2004; for some examples), but these have not been produced for all major religious groups and have certainly not been taken to heart across all people within faith agencies. Services can have an important role in training faith agencies in inclusion principles and practices, and attempts by services along these lines should be encouraged and supported.

Self-advocacy organisations of people with learning disabilities might also want to highlight the right to religious expression, both individually and in bigger campaigns. Although there are some useful resources accessible to people with learning disabilities about religious issues, resources produced by self-advocacy groups could have a big impact.

Religious diversity

Within the project, services were chosen to reflect population areas with considerable religious diversity. However, there was less religious diversity within participating services than in local populations. This is not surprising, as services for adults with learning disabilities are very limited in what they offer to people from minority ethnic communities (Hatton, 2002). It does mean that the religions represented in the project were a wide range of Christian denominations, Islam and to a lesser extent Hindu Dharma, with other major religions such as Judaism and Sikhism not represented. The spirit of the project was very much about encouraging services to listen to people with learning disabilities, learn from people about what religion means to them, and support their individual expression of religious interests. Although the project was therefore designed to be useful for people from any religion, the models of training and support offered in the project have not been tested across all major religions.

A strong theme coming out of the project was that people with learning disabilities were not only interested in their own religion; people also wanted to find out about other religions, including beliefs, practices and festivals. There was no evidence of people reporting conflicts between people of different faiths. This encouraged services to support multi-faith activities, including visits to different places of worship and service-wide activities relating to a range of faiths. Although they require careful planning, these multi-faith and inter-faith activities are invaluable ways to enrich the lives of people with learning disabilities.

Religion and spirituality

It is vital to distinguish religious needs from issues of spirituality. A more detailed discussion of these terms is in Chapter 1; here it is important to emphasise that this project focused specifically on religious needs rather than spirituality. Although not everyone will have religious needs, there are strong arguments for supposing that everyone's life has a spiritual dimension, whether this is expressed in terms of religion or not. Where a person does not express any interest in religion, services should still be actively supporting their spiritual life; John Swinton and colleagues (2002;2004) describe in depth the importance of spirituality to people with learning disabilities.

Religion – a matter of choice?

Particularly before the training days, many staff expressed doubts that people with learning disabilities had 'chosen' their faith, and were reluctant to support religious activities on the grounds that the person did not understand their religion or had been brought up by the family within a particular religious tradition. This seems to set double standards for people with learning disabilities compared to people generally, where choice is not used as a barrier to participation in religious activities. Most people who express a faith express the same faith that they were brought up in by their families as a child, and few people understand all the theological intricacies of their faith.

In the project, all the people with learning disabilities who took part were adults who were able to give informed consent to participate; this helped to counter any objections on the grounds that people were not choosing their religious activities. However, it was beyond the resources of the project to support services in meeting the religious needs of two groups of people where staff objections might be more entrenched; people with high support needs and children with learning disabilities.

For people with high support needs, religion can still be an important part of their lives. Services still need to find ways of identifying religious interests and supporting people in their religious activities, while at the same time not assuming that everyone will be religious. Although some of the ideas arising from this project may help services in this respect, additional strategies and skills will be required that were beyond the scope of the project.

Similar issues arise for children with learning disabilities. For some adults with learning disabilities in the project, childhood religious experiences had a long-term impact on their religious activities in adulthood. For example, to participate in many Islamic religious practices it is vital to have some skill in reading Arabic; if this was not taught the child at school age, then their opportunities for religious expression in adulthood were restricted. Similarly, exclusion from Christian baptism or confirmation could have long-term consequences for later religious expression. While the focus of this project was very much on services for adults with learning disabilities, there is substantial scope for similar work with education services and other services working with children and families.

Meeting religious needs within services

Finally, the project faced a dilemma that is common when trying to help services address a neglected issue; should the services develop special procedures for meeting religious needs, or should the service integrate meeting religious needs into their routine service activities? The position the project took was that services probably need a bit of both approaches. As religion is such a neglected issue in most services for people with learning disabilities, services need to kick-start activity by setting up audits, training days, action groups and individual plans focusing specifically on meeting religious needs. Over time, as meeting religious needs becomes more widespread, the service can move towards including religious issues into routine service activities, such as audits, training events and person-centred planning processes. The view of the authors is that most services are at the point where they need to do something specific about meeting people's religious needs, otherwise this fundamental human right will continue to be neglected. It is the hope of the authors that this project, and the good practice guide arising from it, will play a small part in stimulating services to start this journey.

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