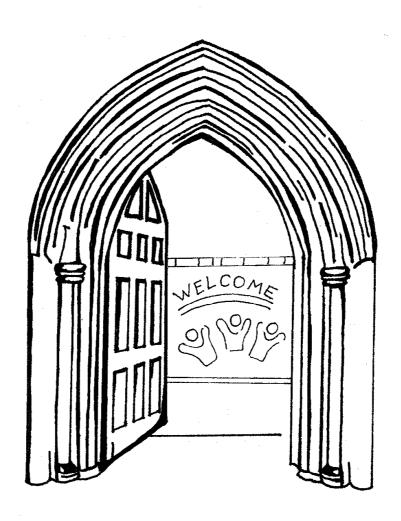
# **Opening the Doors**



Ministry with people with learning disabilities and people on the autistic spectrum

# **Acknowledgements:**

These guidelines have been prepared and contributed to by a number of individuals. Special thanks go to all the people who contributed with their own testimonies and members of the working party:

Staff of the Archbishops' Council:
Philip Maddock – Ministry Division
Christopher Jones – Mission and Public Affairs Division

The Revd. Canon Bob Brooke (Chaplain for people with Learning Disabilities in the Diocese of Ripon and Leeds)

The Revd. Marian Crawford (Methodist Minister, Chaplain to Faith and Light and a Mother to a daughter with Down's syndrome)

Sister Ruth Reed C.A. (Disability Officer and Vulnerable Adults Co-ordinator for the Diocese of Liverpool)

Mrs Sally Hodges (Mother to a son on the autistic spectrum who has severe learning disabilities)

The Revd. Jo Stephens (Curate in the Diocese of Southwell and Nottingham and a Mother to a son on the autistic spectrum)

Additional thanks go to particular advisors and contributors:

Dr Wayne Morris Mrs Ann Memmott Mrs Elizabeth Sandbach The following people and organisations were instrumental and invaluable in the production of the DVD:

Mr Matt Aldred (pointfivemedia.co.uk) Mr John Mansfield (inspiringcalm.com) Mr Peter Renton

Lincoln University
Causeway Prospects (holders of the copyright of the DVD)
Through the Roof

To all the people and groups whom we filmed; it all centres on you and could not have happened without you. Thank you.

Much gratitude is also expressed to Torch Trust for producing fully accessible versions of this report.

### Foreword by the Archbishop of York:

This is not just another set of official guidelines – it is an invitation to the church to walk on holy ground. The stories and sayings here from people with various kinds of disability themselves press home the profound revelation of God's grace in Christ, that true strength and wisdom is to be found in what many would count as weakness and foolishness.

Looking back, my own life and faith has been both challenged and enriched by companionship on the way of Christ with people with disabilities. The World Council of Churches has declared that when people with disabilities are missing from the church the whole church becomes disabled. This is undoubtedly so – but it has taken far too long for a church preoccupied with the intellectual and the rational to warm to the full humanity of the body of Christ as revealed to us in these our brothers and sisters.

We have forgotten that divine wisdom is a gift and not the amassing of information and understanding. As St Augustine of Hippo said, "We come to God not by navigation but by eternal love." The Christian Gospel, after all, is not based on humankind's awareness of God but on God's interest in humankind. For God is not a concept or a symbol, but the God and Father of our Lord Jesus Christ, who is calling us to participate in his life.

When it comes to preparing liturgy that is appropriate, say, for members of the congregation with autism or Asperger's syndrome, or when working out how a woman with Down's Syndrome can be equipped to share in the prayer ministry, this concise resource will both offer suggestions, but also help equip churches to develop their own approach. With the watchword, 'nothing about us without us' thinking and planning will, from the start, look to the gifting of all members of Christ's body.

Not that this is always easy – and there will be those who will read this thinking –" but you haven't met X". What the guidance does is remind us of what we probably thought we knew already, that we are all responsible for one another, and that 'community means you never suffer alone'.

I heartily commend and thank the team who have prepared these guidelines. As the cover picture suggests they have led us to a threshold, and their readers will find themselves both shamed and surprised by grace as they explore what it is to be disciples together with some of the very special people of God.

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### 1. Introduction

In recent years there has been increasing awareness of the need for the Church to respond more adequately to the presence of people with learning disabilities in its congregations. The favourable reception of a parish resource pack on mental health issues prompted the idea that a resource should be produced on the needs and gifts of people with learning disabilities. To this end a joint working party was established by the Ministry and the Mission and Public Affairs Divisions of the Church of England and these guidelines were produced to be presented to General Synod in July 2009.

The main aim of these guidelines is to be a clear and practical guide for parishes and clergy to enable people with learning disabilities to be more fully included in the life and worship of the Church. It is hoped they will also assist in the realization and development of the individual gifts people with learning disabilities bring and will encourage the church to allow **all** people to make valuable contributions to the whole community. In addition, some of the issues referred to in these guidelines concern the preparation of people with learning disabilities for confirmation and reception of the sacraments; consideration of the support to be offered at a time of bereavement and some of the issues raised relating to the question of consent for marriage.

A DVD accompanies these guidelines giving the opportunity for people with learning disabilities to show others what being part of the Church means to them. Through this brief documentary people are also offered a chance to reflect on the gifts that people with learning disabilities bring to the Church.

### 2. A brief definition of learning disability

A person is said to have a learning disability if their capacity to understand new or complex information or to master new skills is significantly limited. A learning disability is not the same as a learning difficulty, such as dyslexia or dyscalculia. It is also distinct from, and should not be confused with, mental illness. However, people should not be defined by their intellect. Throughout these guidelines it is noted that every person is an individual with distinct characteristics and gifts to share with others.

To define somebody by their intellect is, in fact, to use the medical model of disability which defines a person as a patient with a deficit. The medical model can be useful within strictly defined contexts. However, these guidelines encourage ministers to look rather to the social model of disability; a model which encourages us to recognise that people are disabled by society, as the context in which they live with any impairment of their physical or mental functions. 'Nothing about us without us' is the slogan of the social model and thus these guidelines include the words and stories of individuals with learning disabilities throughout.

'The medical model located disability in the individual; the social model in society. The medical model focused on the individual's need to adjust to society; the social model on the need of society to adjust to the presence of disabled people. The medical model saw people as patients; the social model as citizens. The medical model saw disability as deficit; the social model saw it as diversity. The medical model saw the priority as cure; the social model saw it as social change. The medical model saw disability as professionally defined; the social model as self-defined. The medical model said, "This is my diagnosis;" the social model said, "This is my life." The medical model used science; the social model used politics. The medical model was maintained by non-disabled people [sic\*]; the social model by people with disabilities.'

McCloughry & Morris (2002) p.15

<sup>\* [</sup>sic] – This is to indicate that the original quotation has been faithfully reproduced and does not necessarily reflect the use of language in this context today or the views of the Working party.

Rachel is a sensitive, articulate young lady who like any other young adult is enjoying college and time with her friends. Her hope is to get a job, live in her own home and one day to get married. When she was 17 she was confirmed and made a member of the Methodist Church. During the service she gave her testimony telling of her love for Jesus and how Jesus had helped her cope with a difficult year when four people she loved had died. Rachel enjoys being part of the church and sharing in worship through reading a lesson or leading prayers. In a small group she will talk about her concerns for herself, others and the world and is sensitive to need. She is a loved and respected member of her church. Rachel has Down's syndrome.

Jonathan has profound and multiple disabilities. As well as having a learning disability, he is unable to speak and has no sight. He can walk around the house with the help of a Zimmer Frame but for longer distances he needs to use a wheelchair. He lives with three other people with disabilities in a purpose-built and staffed bungalow quite close to his parish church. He enjoys swimming, listening to gentle music and going horse riding. Jonathan and his friends often go with their carers to social events at the parish church and the church has been part of fund raising events for a sensory garden for the house.

David is in his thirties and has Down's syndrome. He works in the kitchen of the staff canteen at a distribution centre for a clothing retailer. He is also a volunteer at a Gateway Club attended by young people with learning disabilities. David lives with his family and has gone to church with them since he was a baby. He went to Sunday school and was a member of cubs and scouts at the church. When he grew up he became a sidesman and a server. When the church council were looking for people to assist with the chalice at the weekly Parish Eucharist they immediately thought of David. With the Bishop's approval David has now joined the team of lay people who administer the chalice on a Sunday.

It must be recognised that many parents find their child defined by the medical model inutero or shortly after birth and thus it is important for a minister to be informed of the medical, as well as the social model. A learning disability may be as a result of a genetic disorder, such as Down's syndrome or Fragile X syndrome,<sup>1</sup> or because of factors such as difficulties in-utero or at birth (for example, cerebral palsy). There are other conditions where the cause is undefined, such as developmental delay and autistic spectrum disorder.<sup>2</sup> A person with one of these conditions may also have a learning disability. In these cases they may have a limited mental ability, or their condition may affect their capacity to integrate with others and thus interfere with their ability to receive education. There are many different conditions which can affect a person's mental ability but in each case it is important to note that each condition affects each individual differently. For instance, one person with cerebral palsy may have a significant learning disability, where another person with the same condition may have a high intellectual ability.

'I smile, therefore you are.'

[Quote 1]

These guidelines stress the necessity for a relationship to be built with every individual, even if only for a limited time. An inability to communicate

does not necessarily mean the person has a low mental ability. Likewise, a person with good vocal and social skills may actually be managing and masking a learning disability which severely hampers their ability to be fully integrated into society. It is also imperative that every minister remembers the slogan 'nothing about us without us.' People with learning disabilities can and do play a vital role in many churches. Their thoughts, desires, needs and gifts must be considered alongside every other individual in the congregation.

[Quote 1] – Quotes 1-3 are taken from the L'Arche Conference at Trosly in 1993 as quoted in Frances Young's Book, *Encounter with Mystery*, (1997).

<sup>1</sup> Fragile X is a genetic syndrome which results in a spectrum (from none to severe) of characteristic

physical, intellectual, emotional and behavioural features.

2 See chapter 9 of these guidelines concerning people on the autistic spectrum.

## 3. Theological Rationale

A statement from the Ecumenical Disability Advocates Network of the World Council of Churches (EDAN) says:

"Members of EDAN believe that all persons with or without disabilities are created in the image of God and called to an inclusive community in which they are empowered to use their gifts. This inclusive community of all the people of God is holy in Christ irrespective of the physical state of their bodies and level of psychological functioning. Through the Holy Spirit, this inclusive community is called to repentance, transformation and renewal (Gen: 1:27 and II Cor: 5:17)."

Any theology that guides the Church's approach to learning disabilities must both be rooted in Christian beliefs about God and be capable of being shaped and challenged by the lives of people with learning disabilities.

Created in the image of God

The starting point has to be that people with

'The persons with mental disabilities, the poor, have the capacity to evangelise us, the intelligent'

[Quote 2]

disabilities are first and foremost human beings. The Bible asserts that all human beings are made in the image of God. This can be understood in various ways, but historically one influential approach taught that the divine image consists of the ability to reason. However, this approach undermines the full humanity of people with learning disabilities, not to mention children and others whose rational capacities are less fully developed. In modern times, being made in the image of God has also been understood as the capacity for relationship. This implies that all people are capable of having a relationship with God and with their fellow human beings and are entitled to be treated with dignity and understanding.

<sup>&</sup>lt;sup>3</sup> Samuel Kabue at the Conference on World Mission and Evangelism in Athens, May 2005 See www.oikoumene.org for further resources

The implications of this truth have often been evaded when human differences have been used as a reason not to accept others as people of equal worth. Some groups, for example, women and black people, have been maltreated in the past as it was believed they did not fully reflect God's image. For people with disabilities, their differing physical and mental characteristics have been taken by others to indicate a deficiency in the divine image, or even to reflect the consequences of sin – contrary to what Jesus says of the man born blind in John 9:3.

However, as a theologian with disabilities herself, Nancy Eiesland, has said, "Our bodies participate in the *imago Dei* not in spite of our impairments and disabilities, but through them." People with disabilities are not incomplete examples of 'normal 'humanity, but are complete persons before God, and their impairments and disabilities are part of their human identity. All assumptions about humanity and wholeness must be informed by the real lives of people with learning disabilities and their experience of the grace of God.

'There are fundamentally no "persons with disabilities" but rather only "people": people with this or that difficulty on the basis of which the society of the strong and capable declare them to be "disabled" and consequently more or less excludes them from public life.'

Moltmann in Eiesland (1998) p.105

#### **Loved in Christ**

These questions are sharpened when they relate to the existence of people with learning disabilities and the ministry of Jesus Christ. Christians believe that Jesus is the definitive embodiment of the image of God in a human life and that in knowing him

<sup>&</sup>lt;sup>4</sup> Eiesland, *The Disabled God (1994)* p.62

anyone can experience the restoration of that image and share in the life of God. In his ministry Jesus made present the divine acceptance and empowerment of those whom others (particularly the religious authorities and the culture of the time) considered unclean, unimportant or unacceptable.

Jesus' approach to people who were despised, overlooked or excluded brings out the distinction, which has been underlined in contemporary thinking, between 'impairment' and 'disability'. Bob Shrine puts it in this way: 'An *impairment* is a stable and persisting defect in physiological form or function. As a consequence of the impairment, a *disability* is a stable and persisting inability or limitation in performing roles or tasks expected of an individual within a social environment. Whether an impairment results in a disability depends on the social context.'5

It could be said that in accepting and empowering people with particular forms of impairment, Jesus was challenging and overturning the disabilities they faced as a result of religious and social stigma – including some which arose from accepted assumptions about ritual purity. On the other hand, the Gospel accounts of his healings of people with physical and mental disorders could be interpreted to imply that God's salvation simply obliterates disabilities, a conclusion which many people with disabilities would find difficult or even hurtful, to accept.

There are a variety of attitudes to healing among Christians with disabilities, and the category of 'learning disability' is not used in the New Testament, but three points may be made in response. First, we should hold to an understanding of healing as being broader than 'cure' in that it opens a person to the total

'We are all only ever "temporarily non-disabled" since at some time in our life many of us will experience one form of disability or another and this could happen at any moment.'

McCloughry & Morris (2002) p.41

effect of God's transforming love. Second, in dealing with people who came to him for healing and help, Jesus often asked them "What do you want me to do for you?" We

<sup>&</sup>lt;sup>5</sup> Theology and Disability: A Liberation Perspective, p.1 by Bob Shrine, Bradford Diocese Disability Awareness Training Paper, 2005. (citing Nancy L Eiesland, *The Disabled God* (1994), p.16)

should avoid imposing our expectations on other people, but should allow space for God's power to work and for people to discover God's way for them in their circumstances. Third, Jesus' acts of power are complemented by his experience of weakness, rejection and loneliness in dying on the cross, and his raising up by God. It is through the whole of his life-story that he relates to people with disabilities, and they to him.

Jesus' ministry, in his life and death, is summed up in the theme of love for those in need. His story fleshes out the character and direction of his love. It is inclusive, compassionate, practical and persistent, but never patronising or oppressive – it gives others space to be and to grow. According to St John's Gospel ch.13, Jesus' disciples are called to love and serve one another in the same manner. The Church is therefore called to welcome, accept and empower people with learning disabilities in ways that are inclusive, compassionate, practical and persistent. They are loved by God and invited to be members of the body of Christ. That means that love must be expressed in the acceptance of **all** people as equal in their difference.

"I have always attended church and was confirmed when I was about 14 with friends from my church in Liverpool. Since coming to Street in 1987 I have been a regular attendee at the Mission Church, one of the churches which form part of Street parish. It has changed a lot from when we first came. It used to be the 'tin church' but that was replaced with a new building with meeting rooms. I used to go to church with my family but since they moved away I have been attending church on my own. I have been a sidesperson at the morning service once a month for about ten years. I welcome people to the service, give out the books before the service and collect them in again afterwards. I sometimes read the lesson. I have been a regular member of housegroups over the years.

I have good links in the church community and have always been made to feel welcome. I feel included in the church and when I see members of the congregation in the street they stop talk to me."

David

#### Gifted by the Spirit

There is one further misconception that must be dispelled. People with learning disabilities are not objects of charity but subjects of the Kingdom of God. The Church's proper relation to **all** people is one of mutuality, not condescension. They are not to be patronised and 'helped' out of pity but to be accepted as partners, as fellow-members of the body of Christ. Another way of putting this is to say that, for people with learning disabilities, as for all Christians, being created in the image of God and loved in Christ is fulfilled in the gift of the Spirit.

'The Church is not sustained by intellect or reason but by grace which is manifested in the various gestures of love and revelation which form the fabric of meaningful community.'

John Swinton (2004) p.7

St Paul's great vision of the body of Christ in 1 Corinthians 12 sets out the gift of unity in difference. The metaphor of the body makes it clear that difference is essential to its effective functioning and unity, since different members have different gifts and callings. At the heart of the chapter is the message that Christians need one another for their own wholeness and mission, and that the parts of the body considered weaker or 'less presentable' are indispensable and should be given the greater honour: all have their distinctive part to play.

This understanding should be allowed to correct the over-emphasis upon the role of intellect and rationality in faith and salvation which has marked many traditional theologies. The result of this is to marginalise people with learning disabilities in the life of the Church. The Spirit is given to all God's people, and the gifts of the Spirit are given for the common good, for building up the body in worship and mission in the way of Christ.

It is in this context that the participation of people with learning disabilities in the life of the Church must be viewed. They are to be welcomed and supported not only because they are created by God and loved in Christ, but because they have a contribution to make to the common life. Elsewhere in 1 Corinthians, Paul highlights the special place of those of low worldly status in God's dispensation: 'God chose what is foolish in the world to shame the wise; God chose what is weak in the world to shame the strong' (1 Corinthians 1:27). Such people are close to Christ in revealing through their vulnerability the power and wisdom of God.

Like other people groups who are stigmatised, overlooked and excluded, people with learning disabilities have a great deal to share and give, out of their experience of impairment and disability. Jesus said, 'When you give a banquet, invite the poor, the crippled, the lame and the blind. And you will be blessed' (Luke 14:13-14). The World Council of Churches has declared that 'When the disabled [sic\*] are missing, the Christian community itself becomes disabled.' Their presence calls the Church itself to learn in mutuality: to adapt its life to their needs and gifts, rather than constantly expecting them to adapt to its own demands. In the process, all people may understand their own disabilities and find new empowerment from God and one another.

The information, advice and guidelines contained herein are an attempt to enable the Church to enter into new understanding and mutual co-operation. If they are acted upon, they will enable us to realise not only that people with learning disabilities are first and foremost made in the image of God; human beings with a life to live, but also that they are gifted by the Spirit to enrich all people's understanding of the Gospel and their mission to the world, sometimes with unsettling and demanding results.

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<sup>\* [</sup>sic] – This is to indicate that the original quotation has been faithfully reproduced and does not necessarily reflect the use of language in this context today or the views of the Working party.

<sup>&</sup>lt;sup>6</sup> Quoted by Bob Shrine, *Theology and Disability: A Liberation Perspective*, p.5 by Bob Shrine, Bradford Diocese Disability Awareness Training Paper, 2005

# 4. The early years of children with learning disabilities and their relationship with the Church

The pathway for children with learning disabilities can differ for each individual in the early years but often, as with any child, their first contact with the local church is through infant baptism. In this event parental preparation and the welcoming of the child into the family of God should not differ from the normative process of the church. However, it should be recognised that if a child's disability is known at birth and the child is thought to be vulnerable, an emergency baptism may take place in the hospital. Churches should thus have well established links with local hospitals so that these children can be welcomed into their local church at an appropriate time; perhaps through a Thanksgiving Service which can include those members of the family and friends who were not able to attend the emergency baptism.

Another possible route into the local church is through Parent and Toddler Groups. Parents may be aware of their child's disability from birth or may become aware of developmental differences between their child and others through groups of this sort. It may be useful to allow for open discussion concerning impairments and disabilities so that the other members of these groups learn to recognise the child first and the impairment second. If a welcome is extended at this time of a person's life, and full acceptance offered, the child and their family will grow up within that community happily and all will feel loved and supported.

For some conditions (such as the autistic spectrum or developmental delay) diagnosis may not be possible at birth. Many conditions cannot be accurately diagnosed until the child reaches a certain age, although the parents or carers may be aware that something is different and they may have anxieties and worries in this connection. When parents eventually receive a diagnosis of a learning disability for their child they

can experience a kind of bereavement where they grieve for the loss of the 'normal' child they were expecting. It may take some time for the parents to come to terms with, and accept, the reality of their child's condition and the uncertain future that now awaits them all. It is very important for the parents to know that the Church and God have always loved and accepted their child, both before and after diagnosis, as the local church community may quickly become the only consistent group of people or institution that that family can experience throughout the child's lifetime.

'Community means you never suffer alone.' [Quote 3]

Sensitivity and the time to listen to parents is an important gift that members of a church can offer. It can also be useful for parents or carers to be linked with others who have a child with the same condition. However, this should not be at the expense of them being integrated into their local community as fully as possible. It is helpful if the minister or church office has information about various support groups in the local area and the Diocesan Disability Officer and Children's Officer will be able to advise in this regard.

'To divide up humanity is to reduce the potential richness of life for every person... The point of liberation is to free each person to attain the fullest satisfaction. This is only possible if each person is freed to belong to a community in which all are included.'

Pailin (1992) pp.24-25

Every minister should also be aware that testing in pregnancy for impairment, the issue of termination and the ethics relating to the treatment (or otherwise) of babies born with major impairments, are all issues which present parents with agonising decisions, both morally and emotionally. Medical advice is not always without bias and members of the church, as well as the minister, can play a vital role for parents as objective listeners. There are also a number of voluntary advice services available and a minister may find it appropriate to refer a couple to these services for additional support.<sup>7</sup>

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<sup>&</sup>lt;sup>7</sup> For example, a minister may refer a couple to the *Down's Syndrome Association* or an agency such as *Care Confidential.* (See chapter 12 - Specialist groups and helpful organisations.)

# 5. Confirmation and admission to communion

It is important that people with learning disabilities are included in the process of preparation for young people or adults to be confirmed or to receive communion before confirmation. If the person has not previously been baptised then this should be included in the confirmation service. In some cases the person themselves, or their carer, may not be certain whether an infant baptism took place and thus a conditional baptism can be offered, as with any adult in a similar situation.

Carers and the people with learning disabilities themselves need to be involved in the discussions about the best way to prepare them as preparation for confirmation will vary according to the individual. Some people can be prepared by being part of the ordinary parish confirmation group supported by someone who knows them, but others may need special preparation. This can be done through courses such as the Confirmation Pack produced by Liverpool Diocese, which is picture based and looks at key gospel events and things that happen in Church. <sup>8</sup>

'Inclusion is God's desire and intention. Inclusion is the resource God has given us to release one another into freedom.'

Lloyd-Williams (2007) p.53

However, any resource may need to be adapted and tailored to the needs and abilities of each individual. Help to understand the best way to communicate with an individual can be sought through their parents, carers and school or support staff. The best course of events will

always be for the minister and leaders to get to know the person as an individual and learn to communicate in the style which best suit them. Whatever the needs and

<sup>&</sup>lt;sup>8</sup> A Resource pack concerning confirmation is available from Liverpool Diocese http://www.liverpool.anglican.org/index.php?p=457

abilities of the people with learning disabilities, it is important to treat all people with dignity and respect and thus some form of appropriate preparation should be offered as it is offered to their peers who have different abilities. Full inclusion should always model as much similarity between all ability groups as possible. For those with very limited abilities, this may simply be a number of meetings with the minister, perhaps in conjunction with their carer, a close friend or their sponsor or god-parent who will support them on their Christian journey.

'The heart of the Eucharist is not found in conceptual awareness but in practice... at the level of being included rather than excluded, some who are handicapped [sic\*] may be helped to discern experientially the reality of God's love for them.'

Pailin (1992) p.144

#### The Service

Prior to the service, it is helpful if the confirming Bishop is made aware of the person with a learning disability in order to help the Bishop conduct the service sensitively. For example, some people on the autistic spectrum<sup>9</sup> can find the laying on of hands difficult. There may be issues about how the promises are made if someone is unable to speak. If a person uses Makaton<sup>10</sup> signing or British Sign Language then that can be used or the promises can be made by the use of picture language boards. If a person with a learning disability also has some physical impairment which makes it difficult for him or

<sup>\* [</sup>sic] – This is to indicate that the original quotation has been faithfully reproduced and does not necessarily reflect the use of language in this context today or the views of the Working party.

<sup>&</sup>lt;sup>3</sup> See chapter 9

<sup>&</sup>lt;sup>10</sup> Makaton is a small but powerful means of communication using key signs combined with speech and sometimes symbols to help convey messages and ideas (both spoken and written) more easily. See www.makaton.org for more details. The necessary software to fully utilize the pictorial element of this communication method may be available through the local special school, speech therapists or the person's carers. It would be worthwhile for a group of churches to invest in purchasing their own software so that Makaton symbols could be utilized in service sheets/signs etc. *Causeway Prospects* produce service sheets for Holy Communion in this format – see www.prospects.org.uk.

her to kneel in front of the Bishop at the place where confirmation normally takes place then it would be better to arrange for the laying on of hands for all the candidates at that service to take place in a more accessible place and for each individual to be able to stand, kneel or sit as appropriate. It is imperative that the person with learning disabilities is given the opportunity to attend a rehearsal before the event, especially if it is to take place in a venue which is new to them.

"Mine was a church that offered communion to children, but the Diocese expected every child to attend catechism classes prior to receiving the elements. My son, James, is autistic and couldn't sit through the classes but he wanted to take communion.

One Easter Sunday he decided that today would be the day he received communion and so we stood in the line before the chancel steps. James was desperately trying to remember the social graces expected of him – "Stand still. Wait. Not first. Need to wait." He found it hard; he likes to be first; he likes to hurry. But he did wait and eventually it was his turn to climb the chancel steps and move toward the communion rail. Suddenly, he collapsed in a lump on the carpet and began to beat his head on the floor.

"James bad" he said. "James bad – Jesus good. James bad – Jesus good – Jesus dead. James bad – Jesus dead. James bad so Jesus dead. Jesus dead because James bad. James bad."

I went up to comfort him but he immediately grabbed my ankles and remained on the floor. I was left standing, unable to pick him up or bend down due to the way I was held. We stood in the middle of the chancel steps; him crying and banging his head; me standing, desperate for help.

People continued to queue; to come up the chancel steps and receive communion. We were obviously an obstruction, but they weren't daunted. They simply gave us a wide berth and walked around us. Going up and coming down, the line of communicants parted around us like the Red Sea – but it was me who wanted to escape.

Eventually, the priest refused to administer communion to anyone else until we were helped. He came over to James and knelt before him, holding him, cradling him, assuring him of God's love. Eventually, James recovered enough to walk and we left. We escaped home and tried to wipe the experience from our minds – busying ourselves with the attempt to locate normality.

To be continued...

...continued from previous page.

The priest phoned in the afternoon to see how James was. "Who was that on the phone?" asked James. "It was the vicar", I replied, "phoning to see how you are." "What do you mean, how am I?" "He saw that you were upset at church today", I said. "I didn't see him", James replied. "Oh James, he came and helped. He cuddled you and assured you of Christ's love." "Oh", James replied, "I thought that was God."

I think James understands communion without taking the lesson.

James' Mum

# 6. Relationships and marriage for people with learning disabilities

#### Relationships

It is very difficult to define relationships in general as they reflect the individuality of the people involved and occur at different levels of intimacy for every couple. However, people need only to look to their own experiences as a reference point, as the relationship of a couple with learning disabilities will be similar in many ways.

Any discussion about the relationships of people with learning disabilities requires each minister to review their own feelings. People often assume that men and women with learning disabilities are not capable of sustaining a meaningful relationship, but this view is not realistic and often based on misconceptions and prejudice. Ministers must therefore be open-minded and prepared for love to come in all shapes and sizes. For instance, a non-verbal mode of communication need not be a barrier to a relationship or marriage.

Some people may be fearful and prejudiced against a friendship between people with learning disabilities developing into a sexual relationship. Sometimes people will try to separate men and women, or dismiss what they are saying about the other person because it challenges preconceived ideas. However, people with learning disabilities have the same ability, desire and need for physical relationships as any other person and should thus be educated and supported to control or explore these desires in the context of a loving marriage.

The minister, along with the support of outside agencies or the appropriate carers, should explore the expectations of each partner with regard to their sexual relationship once married. This could be a subject which has been avoided by many and, indeed, may not have been discussed by the couple themselves.

One couple quickly discovered that their expectations concerning sex were very different. This led to the breakup of the marriage and much heartache. This could have been avoided if open discussion had been facilitated in the marriage preparation.

Specialised help in this regard may be available

through the sex education offered in a local special school or through contacts with support staff.<sup>11</sup>

However, a minister should be aware of the possibility that one or both members of the couple could be unduly influenced by the perceived cultural norm that an adult person should be married in order to fully participate in society. The media constantly provides images of families and couples and this can be misinterpreted by people with a learning disability as a requirement expected of every person in adulthood. A minister should build relationship with each person in order to establish their motivations and explore the core values, expectations and desire for marriage, as with any other couple who require marriage preparation. Carers and parents may be helpful in this regard but ministers should be aware that there may be family tensions concerning the partnership as many parents and carers will be fearful of the consequences of a relationship or apprehensive about losing their role as their child's main carer. It is important that the final decision is that of the couple and they alone have the option to marry, maintain the friendship in its present state or end the relationship. Opinions should not be imposed on them by carers or through cultural influences or practical circumstances.

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<sup>&</sup>lt;sup>11</sup> Every minister must, of course, be cautious in discussing sexual matters with vulnerable adults and must therefore ensure carers or parents are present where appropriate. For more information see Marriage and Relationships section of the Bibliography.

In a society where integration between all kinds of people takes place, loving relationships may develop between someone with a learning disability and someone with no impairment. If approached for marriage by such a couple the relationship should be accepted and welcomed as any other, as long as it is not abusive in any form (for example the able person manipulating the less able). Again, some contact with family, carers, or support workers may be helpful in this regard and any identified difficulties must be sensitively explored by the couple with the help of the minister and/or marriage preparation group.

The couple should always be encouraged to make their own decisions about their relationship but they should be helped to explore the issues and be as well informed and prepared as possible.

Donald and Susan first met in a long stay NHS hospital where they lived for many years. Susan moved out and they lost touch. A few years later Donald moved into a staffed house in the community and started to go to the local church. He was pleased to discover that Susan lived in the same neighbourhood and attended the same church. They both became members of the Faith and Light group that met at the church. Their relationship grew and eventually they were married at the church and moved into a flat in a nearby sheltered housing project.

A minister or the marriage preparation leader may ask a couple who experience learning disabilities whether they have considered their living accommodation after they are married. Many residential homes or wardened accommodations are for single occupancy only and thus a couple may need to be relocated in order to live together. This may be a complication which has not been fully considered and the couple may need the help of outside agencies in order to find a solution.

#### Some facts about people with learning disabilities who marry:

- The rate of marriage breakdown is less than the average marriage breakdown statistic.
- Couples with a member who has a learning disability do not necessarily parent children with disabilities.
- Some of the positive outcomes of marriage for people with learning disabilities (as
  with other marginalised people groups) are that their loneliness will be alleviated,
  they may find some much needed stability and it may be easier for them to integrate
  into society as they will each benefit from the other's gifts.

The Church recognises marriage as a covenant between two people in the sight of God. People with learning disabilities are as capable of entering into that covenant as anyone else.

#### The Marriage Service

When preparing the marriage service for people with a learning disability, many of the same considerations that would apply in relation to other forms of service for them will need to be taken into account. (For example, the liturgy and talk should be kept short and there should be a careful choice of music, with appropriate and simple language being used alongside helpful imagery or symbols.)

Additionally, however, before the marriage service takes place the minister needs to be satisfied that both bride and groom have the legal capacity to marry. That involves their being capable of understanding the nature of the marriage contract into which they are entering, which in turn requires them to be capable of appreciating that it involves the responsibilities normally attaching to marriage. For some people thought may also need to be given to how the expression of consent required in the course of the service itself is to be effectually expressed and communicated.

It may be appropriate to consult family members and professionals working with a couple where one or both have a learning disability, where there is any doubt that either partner has the mental capacity to enter into marriage. This referral might also act as a safeguard in case of later challenges concerning a person's capacity with regard to the validity of the marriage and any related decisions, such as the formation or changing of a will. In some cases it may be a legal requirement, or good professional practice to undertake a formal assessment of capacity where a person's capacity to sign a legal document could later be challenged.<sup>12</sup>

The Diocesan Registrar, the Archbishop of Canterbury's Faculty Office or the local Superintendent Registrar may be able to offer advice on these issues.

<sup>&</sup>lt;sup>12</sup> See The Code of Practice of the Mental Capacity Act 2005 (issued by the Lord Chancellor on 23 April 2007).

### 7. Bereavement and funerals

It is as important for people with learning disabilities to be allowed to grieve as it is for any other group of people as all people have physical, emotional and spiritual dimensions to their being which need to be recognised at a time of bereavement. In the past the need for people with learning disabilities to grieve was not always recognised. Many were excluded from funerals and from sharing in the whole process of grieving. As a result a number of older people with learning disabilities have many problems due to unresolved grief. Sometimes family members will want to protect a person with a learning disability and they may feel that they should not attend the funeral as they will not understand what is happening or because there may be some practical difficulties. It is essential that, whatever their level of ability, people with learning disabilities are allowed to share in the grieving process and are not excluded. The minister will need to approach this topic sensitively with the principle mourners as early as possible in the preparations for the funeral.

Before the death of a family member or a close friend, the person with a learning disability should be encouraged to visit the terminally ill person if they so wish and they should be given the appropriate support needed to enable that. When discussing death with a person with learning disabilities it is important to be open and honest with them and to allow them plenty of time to take in what is being said and allow time for them to respond. They should be given facts and statements in a simple straightforward way using the communication method most appropriate to each individual. The issue of death should not be avoided if it is imminent by easy statements such as; "Oh, he'll be better soon," or "you'll meet up again soon." Words such as *death*, *dying* and *dead* should be used; euphemistic terms such as *passed away* or *gone to Jesus* may be misleading or confusing. It may be necessary to repeat things to make sure the person has understood. It is once again recommended that ministers get to know and befriend the person as much as possible and discover something of their past experience of death. If the person with a learning disability has previously experienced the death of

someone in their family, school or care centre, or has felt the loss of a beloved pet, then this experience can be drawn on in order to ensure the person understands the finality of death.

#### **The Funeral Service**

The person with learning disabilities should be offered the choice of whether or not to attend the funeral and their personal choice should be respected.

In order to prepare each person as fully as possible for the funeral and burial or cremation the minister, a member of the pastoral care team or a carer could look at photographs of the significant places and events that will take place on the day and discuss them with the person with a learning disability. For instance, they could obtain photographs of the interior of the church or crematorium, along with photographs of a coffin and hearse. Alternatively the funeral directors may be willing to show these to the person with a learning disability and even allow them to sit in the hearse before the day of the funeral. Each person should be given ample time to ask as many questions as they need to in order to feel reassured.

Other family members may have some anxieties about how the person with learning disabilities may behave at the funeral and may be so caught up in their own grief that they are unable to look after or support the person with learning disabilities. In such cases, rather than excluding the person with learning disabilities, it is better for a friend or a professional carer who knows the person well to accompany them and support them through the day.

If the body of the deceased is available to be viewed, either at home or in the funeral parlour, it is important to allow the person with learning disabilities the opportunity to view the body and say their own goodbyes if they so wish. Arrangements should be made for them to be appropriately supported by a carer or friend of their choosing. Although it may be painful and possibly frightening, viewing the deceased can help a person to realise that their relative or friend really has died. The sight of the deceased's

body is a visual sign which may communicate what has happened when words have failed to do so. This can aid the grieving process and enable an individual to come to terms with the person's death, as well as prepare them, in some way, for what will happen at the funeral service.

At the funeral service itself it is important to take into account the fact that some people present may not be able to read and may find it difficult to just sit and listen to a lot of words. In the case of a person with a learning disability dying, the congregation may consist of many people with learning disabilities who knew the deceased through their

friendship networks at school or care centres. It is important to keep the language simple and to make it clear precisely why everyone is present at the funeral service and what will be happening. Having a photograph of the dead person in a prominent position can sometimes be very helpful. It may be beneficial for there to be some simple ritual in which everybody can participate; for example touching or placing a flower on the coffin, sprinkling it with holy water or lighting a candle. These physical acts will enable each person to say their own individual goodbyes and take ownership of their own grief. When a person with learning disabilities has died, his or her friends might be able to contribute to the service by bringing forward things that he or she made or enjoyed or photographs of times and events they shared together. 13

'We cannot speak or even think about resurrection without entering into the depth of our grief. Neither Jesus' friends nor the friends of Adam could say, 'Don't cry, he will return.' We needed to cry, to feel his loss, to mourn his passing. Grief is emptiness, darkness, meaninglessness, uselessness, paralysis. Even more it is a gradual dying within us of the loved one who had found a dwelling place in our hearts. Grief is a departing hour by hour, day by day, minute by minute. For a long time we think or act as if he is still there, but at every turn we realize he is gone, for all time.'

'Adam – God's Beloved' by Henri Nouwen (1997) p.103

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<sup>&</sup>lt;sup>13</sup> See the Appendices for a good practice case study concerning a funeral for a person with a learning disability which involved and catered for their peers.

#### **Multiple Losses**

Sometimes the death of a parent or carer may involve multiple losses for a person with learning disabilities as he or she may have to move from the parental home into other accommodation. They may also experience the loss of some personal possessions, of familiar surroundings, neighbours, networks of relationships generally and the loss of familiar and secure routines. These other losses need to be acknowledged. If the person has moved away it is important that they have an opportunity to be involved in the practical arrangements. For example, they may benefit from helping to sort through the deceased's possessions and they may choose to keep an item which is personally significant and valuable. Some people may also need some time and opportunity to say goodbye to their former home and neighbourhood. Church members may be able to offer support to a person with a learning disability by accompanying them back to familiar places during the transition period; by providing transport for relatives as they visit the person in their new situation or simply by being a good listener.

#### **Stages of Grief**

It may be difficult to prepare some people with learning disabilities for the death of a sick or elderly relative or friend. They may have little understanding of the ageing process, and the irreversibility, universality and inevitability of death may be difficult concepts to understand. The death of someone close to them may therefore come as a complete shock and leave an individual in total bewilderment and horror. It may take some people with learning disabilities longer than expected to come to terms with and understand the significance of what has happened.

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<sup>&</sup>lt;sup>14</sup> For specific advice on ministering to people on the autistic spectrum concerning bereavement see 'The management of bereavement in services for people with autism.' (Code of Practice Procedures document 3) (PDF) written by Helen Green Allison and available from http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=364&a=2180

For some, the funeral service may come too soon or it may be too big and too formal an occasion. They may need some appropriate small and simple ritual at a later date to help them say their own individual goodbyes. This can happen in a familiar setting, for example the house where the person lived or a centre he or she attended, and might involve further practical acts such as planting a tree or providing a bench in memory of the deceased.

# 8. Life in the parish setting for people with learning disabilities

#### Worship and Sunday services

After completing a sabbatical exploring the place of people with a learning disability in the life of the Church, a Methodist minister made this resolution:

'Every time I prepare Sunday morning worship there will be some aspect of the service that a person with a learning disability can access easily and so feel part of the worshipping community.'

It is difficult to make all worship accessible for people with learning disabilities but it is relatively easy to include one of the following:

- Simple prayers with a short repetitive response.
- A hymn which has a chorus.
- A simple worship song.
- Use of pictures to illustrate a talk.
- Drama to tell the Bible story.
- Use of Makaton (a sign language developed especially to aid communication with those with a learning disability).
- Use of dance and movement.
- Interactive conversation.

Some people, although they can't read, like to have the books and need help to find the correct pages.

Accept the worship of every individual that is offered. For instance, one gentleman with a learning disability joins in the hymn-singing by conducting the congregation!

"I am 38 years old and live with my Mum and Dad in Liverpool. I also had a brother Paul who died about nine months ago. I attend an Anglican church in Liverpool which I have been part of since the age of three. At my church in Liverpool I help collect stamps for the Leprosy Mission. There is a box at the back of church were people put used stamps. I empty the box and take the stamps home to sort them out. I sort them into groups of English stamps with the Queen's head on them, English stamps with pictures on them and foreign stamps. I then pass them onto someone else in the church who sends them to the Leprosy Mission which helps them raise money."

Keith

#### **Healing services**

Some people assume that the divine image in people with impairments is somehow damaged and that they need healing. Many have supposed that God's image is only fully realised when all impairments have been removed and individuals have become 'normal' (or have become the same as people with no perceived disabilities). Scripture would seem to support this notion in many places as the healing of impairments is often seen as a sign of God's restoration of the created order at the coming of the Kingdom. However, we must also recognise that all people are incomplete and in need of healing and people with impairments are not unique in that respect. Perhaps the best conclusion to reach is that *healing* should not be equated simply with the *curing* of particular conditions but should be understood as growth into wholeness, in relationship with God. What that may mean for each person can only be discovered through the integrity and uniqueness of each individual's experience. It should be recalled that when St Paul prayed for the removal of his 'thorn in the flesh' (whatever it was, it was for him painful and disabling) God's answer was, 'My grace is sufficient for you, for my power is made perfect in weakness' (2 Corinthians 12:9).

People with a learning disability can be very vulnerable and care needs to be taken when including them in healing services. Prayer must not be imposed and neither must it be oppressive with emotional pleas for cures to take place. Consent must be asked for and given with understanding and carers need to be involved where possible. Learning disabilities cannot be cured but a person with a learning disability can respond to prayer for those parts of their lives where there are:

- Feelings of hurt and rejection.
- Fear and anxiety.
- Lack of self-worth.
- Anger.
- The need to forgive.

These are prayers for a life made whole.

However, we must not assume that people with learning disabilities can only be prayed for; many can exercise the gift of intercession and healing themselves for the benefit of others. Do not forget to ask **all** people in the congregation whether they wish to join the prayer ministry team.

One summer I was working with children with disabilities under quite stressful situations. There was one teenage girl with Down's syndrome who would always come to cuddle me when I felt completely exhausted. To be honest, I thought she was the last thing I needed and I was irritated by what I understood as her constant demand for attention. However, after one very difficult morning, whilst I was receiving yet another hug from this girl, I suddenly realized that she was ministering to me. After I had given everything to others she came along, as regular as clockwork, and filled me back up with God's love and comfort. After that I thanked God for her presence every day.

A volunteer

#### **Pastoral Care**

Adults and children with a learning disability have the same right to be included in the pastoral care of a Parish as any other individual, be this through cell groups, pastoral teams, children's activities and youth clubs or through individual ministers. Often it will fall to the minister and the church leaders to lead by example and model the inclusion of **all** people into the church community.

The key to good pastoral contacts is awareness, patience and acceptance of the person just as they are. As in all other pastoral situations, trust and respect need to be built up and dignity needs to be assured. All people have the right to privacy if they so wish it. Other areas of pastoral care may include preparation for baptism and confirmation along with consideration of safeguarding policies and their implementation.

#### Safe practices in Pastoral care with children and adults

Where children are involved, the policy of the Church of England entitled 'All God's Children' should be applied. Where adults are involved the guidance outlined in the document 'Promoting a safe church' should be implemented. <sup>15</sup> These two documents deal with the subject of abuse and how to protect both adults and children from abuse as well as how to protect people from allegations of abuse. Abuse is a highly emotive word but can be summed up in two ways: a misuse of power knowingly or through bad practice against another.

Abuse can be through neglect or can be physical, emotional, sexual, financial, or spiritual and can be perpetrated by any person, including family, friends, neighbours, carers, and church members. It can occur in different settings such as the home, residential placements, workplaces, hospitals, day centres and churches.

<sup>&</sup>lt;sup>15</sup> See http://www.cofe.anglican.org/info/childprotect/ for the Church of England's full Child Protection and Adult Safeguarding Policies.

Many adults with a learning disability will have suffered abuse of some kind in their lives. 16 Ministers also need to be aware that they could have an offender as a member of their congregation.<sup>17</sup>

Here are some examples of bad and good practice in pastoral care:

Bad Practice	Good Practice	
A person with a learning disability is upset in church. They are taken into the vestry on their own by one individual to pray with them. (This is a compromising situation.)	Take the person to a quiet place within the body of the church building or pray with them in private with more than one appropriate adult present.	
The person is not asked if they wish to receive prayer – they are just prayed for without consultation. (This could be seen as spiritual abuse.)	Ask each individual if they would like prayer and ask them what they would like prayer for.	
When an individual tries to explain something they only receive a response along the lines of 'never mind' because their language is not understood. (This shows a lack of respect and is insensitive. It also means genuine support is not offered at a time of need.)	A person should always admit when they can't understand another and apologise. It may be appropriate to ask whether a carer could come and help to interpret or for a meeting to be arranged at a more convenient time, perhaps in a quieter setting.	

See 'Care of adult survivors' in 'Promoting a safe church' (p.19)
 See 'Ministering to known offenders' in 'Promoting a safe church' (p.31) www.cofe.anglican.org/info/papers/promotingasafechurch.pdf

#### Things to remember

- Treat everyone with respect, setting a good example for others.
- Respect personal space and privacy.
- Vulnerable adults should be offered the same level of independence and choice as their peers.
- With children and young people, ensure two adults are present or within sight and hearing of an activity.
- Challenge unacceptable behaviour towards a person with a learning disability.
   Lead by example and confront anyone who is intolerant or disrespectful of another.
- Challenge unacceptable behaviour by people with learning disabilities. Do not
  patronise those with a disability by accepting inappropriate behaviour outside of
  the boundaries set by carers. Deal with situations sensitively and, if possible,
  with the carers' involvement.<sup>18</sup>
- People over the age of 18 who have a learning disability are subject to the same laws of conduct as any other adult. This is an important fact to remember, both for the protection of adults with a learning disability and for defining what is acceptable behaviour within the Church and society.
- Be aware of personal expectations and prejudices which could affect a relationship with a person with a learning disability or the way that particular situations are perceived.
- In pastoral situations it is important that clear communication takes place and the
  person with a learning disability does not simply agree to things in order to
  please others. Ministers should be aware that they can still be perceived as
  powerful figures in today's society.
- Do not put a child, young person or vulnerable adult in a compromising or vulnerable situation. Be attentive to personal vulnerability also.

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<sup>&</sup>lt;sup>18</sup> For information on behavioural issues in relation to children's work see www.scriptureunion.org.uk/YourChurch/SpecialPeople/Behaviour/1800.id

- Do not have inappropriate physical or verbal contact with others.
- Allegations or suspicions of abuse must be acted upon.

Three people came to church together from a local residential home. They sat together for the service and from time to time were quite disruptive with their chattering. People in the church made friends with the three individuals and they then went to sit with their friends in different locations within the congregation. This managed their behaviour and built up relationships.

#### Things to do

- Develop church safeguarding policies for both children and adults and review it regularly.19
- Make sure that everybody who has substantial access to people with a learning disability, both children and adults, goes through the CRB (Criminal Records Bureau) procedure. The Independent Safeguarding Authority will enable checks to be made online. Information is available from the following website www.isa-gov.org.uk.
- Train those involved with vulnerable adults and children with regard to safe practice (e.g. teachers, leaders, youth workers and pastoral visitors). These training materials may be useful:
  - 'Promoting a safe church' (Church House Publishing)
  - 'Safe to belong' (Baptist Union)<sup>21</sup>
  - 'Safeguarding Adults'<sup>22</sup>
- Develop a procedure for handling complaints.
- Record telephone numbers of local Social Services and Diocesan Safeguarding officers.

See Appendix for a summary policy.
 www.cofe.anglican.org/info/papers/promotingasafechurch.pdf
 Available from www.baptist.org.uk/resources

<sup>&</sup>lt;sup>22</sup> Available from www.adss.org.uk

He had been a member of the church for years but no-one had really seen him and what he could give. Seeing him lead prayers in Faith and Light worship led people to recognize his gifts. He's now on the greeting rota as well as being asked to pray. 'I like praying. I'm good at it, yes I am' David said.

David

One good practice is to build up a *circle of friends* where members support each other and the child or adult with a learning disability. The person with a disability is helped to choose a group of people to be part of that circle. The circle meets together periodically to share, to listen to the person with the disability and to make sure that 'all is well'. See - www.circlesnetwork.org.uk for more information.

#### Tips concerning health and safety issues

- When with somebody with a learning disability, ask them how they can be assisted.
- Do not handle a person or their wheelchair without asking or being shown suitable methods.
- Never use flashing lights without a warning as many people with a learning disability have epilepsy and the use of flashing lights can induce a fit (flashing lights also affect some people on the autistic spectrum).
- Safety signs around the property should be in picture form as well as words.

#### Disability Discrimination Act (1995) and the Disability Rights Commission (1999)

Churches should be aware of the requirements of the DDA (Disability Discrimination Act) and that it is illegal to discriminate against children and adults with disabilities. In 1999 the DRC (Disability Rights Commission)<sup>23</sup> issued a code of practice which stated that churches should endeavour to enact the following:

<sup>&</sup>lt;sup>23</sup> The Disability Rights Commission is no longer in existence as it has become part of the 'Equality and Human Rights Commission'.

'Change practices, policies or procedures which make it impossible or unreasonably difficult for people with a disability to use a service (by service the DDA means the facilities and activities of the church).

Overcome physical features which make it impossible or unreasonably difficult for people with a disability to use a service, by providing the service by a reasonable alternative method.

Provide auxiliary aids or services which would make it easier for or enable people with a disability to use a service.'24

Churches need to consider the above recommendations and not wait until somebody with a learning disability enters their building, only to find that the church is not able to meet their needs.

One church found that a young boy with autism was a very enthusiastic welcomer. He ran up to everyone he saw with an order of service and a radiant smile. Through his ministry of welcome people felt accepted and loved before the service had even begun.

#### Gifts and ministry

As with any other group of people, gifts, interests and abilities vary enormously. The important message is don't overlook anyone.

Some people with learning disabilities may be gifted as welcomers at the door or can write and lead prayers, read the Bible, be servers and sidespersons or be pastorally sensitive to others. Some people can bring the Gospel to life through drama and dance, some enjoy bell ringing and others can bring a greater depth of meaning to the word 'offering' as they bring up the gifts to the communion table with great reverence.

<sup>&</sup>lt;sup>24</sup> Bass (2003) pp.47–48

In other words, **all** people are gifted, no matter what their intellectual ability. A person with a learning disability may be able to serve the church in a number of different ways – just as any member of the church.

However, some people with learning disabilities also bring greater gifts which can challenge a church congregation. Their vulnerability can help others to admit their own personal vulnerability. The gift of spontaneity can encourage others to try new things. The gift of honesty and openness can help others to see how easy it is to hide behind masks. The gift of eagerness to participate can encourage others to join in and a willingness to sit on the front pew will be an encouragement to any minister.

#### Blessed are you

For you carry well your disability
In the face of a world that would handicap you.

For in your 'lightness' of spirit,
In the courage of your heart
In your very being is the essence of God.

Blessed are you

For you stand with people who carry disabilities.

You help them to walk the way of life more fully.

As these friends of Jesus

Give life to you

So will you taste the abundance of life.

The Revd. Bill Anderson

## 9. People on the autistic spectrum

Autism is a lifelong developmental disability that affects the way a person communicates and relates to people around them. Children and adults on the autistic spectrum are unable to relate to others in a conventional way and their ability to develop friendships may be impaired as they may find it difficult to understand others' feelings or the required social etiquette of any given situation. People on the autistic spectrum can be quiet and reclusive or overly enthusiastic and uncontrollable. It is important to recognise that there is a broad spectrum to autism and the things that challenge people with this condition can vary dramatically.

Many people on the autistic spectrum suffer anxiety as they find it difficult to make sense of the world and the people around them. Many will understand what is said to them in a very literal sense and most dislike change or the lack of routine. They may have accompanying learning disabilities and people with severe autism may have very limited communication skills. Many are particularly hypersensitive to touch, sound and lighting and may hear things louder or see things in more detail than most people would experience.

The minister should get to know the individual on the autistic spectrum and their family or carers as well as possible, in order to establish the most effective way to communicate with them and the best way to integrate each person into church life. The *National Autistic Society* has local branches in most areas and can provide further information through their website - www.nas.org.uk. There are also some good resources available specifically concerning the spiritual growth of people on the autistic spectrum and the Diocesan Disability Officer should be able to help in this regard.

#### Imagine a world where you can't imagine -

Where everything is completely literal, where there is no understanding that things might be make-believe or abstract.

The other day I watched a DVD about a young man who dies alone in the wilderness. I spent days and nights afterwards terrified that I too was going to die alone. In great fear I reached for my Bible and read, 'Jesus loved them [his disciples] to the end.' I drew comfort and calmness from the promise that although I was convinced I was about to die, Jesus would love me and be with me to the end of my life. With the comfort came some balance in my mind; some perspective and reassurance that in reality I was not about to die.

I am an autistic person living in a non-autistic world. It's a world where, unless I am on my own in silence, I know little else except confusion and fear. The outside world with its business and relationships feels completely disordered, a jigsaw thrown into the air. It's fragmented and bewildering.

But Jesus steps into this chaos with me. I find great joy and light when I talk to Him. I know that when I lay any situation before Him, He makes the jigsaw pieces into a whole picture and I feel then I know what to do or say or where to find help. His strength and faithfulness let me not only live in the community, but also to teach people in my home, maths and the piano.

A long time ago, when I first met Jesus, He gave me this verse: 'I can do all things through Jesus who strengthens me.'

On the good days it feels like we swap: Jesus takes my suffering and panic and I take His peace and love. His peace and love are like white stepping stones across the swirling, rushing river of my life. His strong arms are around me to steady me and show me the next step.

**April Cherry** 

A useful book is Barbara Newman's book 'Autism and Your Church – Nurturing the spiritual growth of people with Autism Spectrum Disorders. <sup>25</sup> A further resource has been produced through the Diocese of Oxford and has been written by Ann Memmott, who has Asperger's syndrome herself. It is entitled 'Welcoming those with Autism and Asperger's syndrome in our Churches and Communities. Ann Memmott has also prepared the following 'Instant Autism Disability Access Checklist' and suggests ten 'Quick Low Cost Things to Make a Difference.'

- 1 Check the **lights in each room**, especially fluorescent ones any flickering ones? Please replace them. (This also helps people with epilepsy.)
- 2 **Noise** levels anything unexpected in today's service/meeting? Can it be changed easily? Can you just warn us? (This also helps people with mental health conditions and those who are deaf.)
- 3 **The Building**. Do we know what it looks like, and what the **layout** is like today? Is information on a simple website, perhaps? (This also helps people who have visual impairments or those who are nervous of attending somewhere new.)
- 4 **The Order of Service** really clear **instructions** for us, e.g. where to sit, when to stand and sit, what to say at each point? Either write it down or get someone to be with us to quietly and say what to do, please. (This also helps those new to church.) Different coloured paper may help some to read service sheets, e.g. light blue paper rather than white.
- We are very **literal** and our minds may see pictures, not words. If you need to use complicated language, can someone be available to explain it afterwards if we need it, maybe by email? (This helps those who find reading more difficult too, which is one in every five people in the UK.)

To be continued...

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<sup>&</sup>lt;sup>25</sup> See Bibliography for further details

<sup>&</sup>lt;sup>26</sup> Available online at http://www.oxford.anglican.org/social-justice/just-care/welcoming-those-with-autism-and-asperger-syndrome-in-our-churches-and-communities.html

#### ...continued from previous page

- **Physical events**, e.g. shaking hands? Water being splashed about? We may find this physically painful as we are hypersensitive. Please warn us what will happen and avoid physical contact unless we offer first. (This also helps those with arthritis and those who are nervous of being touched because of memories of violence.)
- **Rest** area somewhere quiet to go if we need to, please. Or don't worry if we wander outside for a while. (This also helps people who have chronic fatigue illnesses and mental health conditions, as well as those with back problems who may need a quick lie down on a bench.)
- **Socializing.** Be aware we find it difficult and exhausting as we cannot 'see' or hear you that well. Our **body language** can be different to yours and we may not make eye contact. Please don't think we're rude. (This also helps people who are more introverted.)
- **Be clear and accurate.** If you say you'll do something, please do it. Those on the autistic spectrum will always find it very distressing if you promise to help and don't, or promise to phone at a certain time and don't, or if you use expressions like 'I'll be back in five minutes' when you mean 'I'll be back some time this afternoon.' If you need to change arrangements, please just let us know.
- **Support.** Find a quiet caring person to be aware of us, someone ready to lend a little assistance if we need it. Brief others well and please respect our confidentiality and privacy.

Ann Memmott

### 10. Parents and Carers

The early years of a person with learning disabilities and the possible impact and grieving process that parents will go through when they receive a diagnosis of a disability have already been considered in these guidelines. However, it should be noted that this sense of loss can be felt at many occasions during a person's life, especially at times of transition; perhaps as their peers move on to secondary school or college or when the person fails to obtain or retain employment. There can be many significant times of loss when a parent and child can be impacted by their difference or inability to perform normal tasks at unexpected moments. For instance, perhaps there is a sudden realisation that they will never learn to drive or perhaps they are too vulnerable to manage their own money or bank account. A minister will never know when these traumatic moments will arise but they can always offer an open door and a safe place in which the parent, carer or child can share their sorrow and fears as these times of sadness arise.

It is important that the whole family is welcomed, including the person with a learning disability. Every person should be treated with dignity and respect; adults should be treated as adults and children as children, whatever their abilities or roles as carers.

"I went to the church Youth group from the age of 14-18 and made some really good friends there some of whom I am still friends with today. I am now a Youth Group leader and I help out each week on a Thursday evening. Some of the activities we do are: football in the spring and summer, indoor hockey, volleyball, pool, playstation and Wii computer games. One of my jobs at the Youth Group is to run the tuck shop. I set up the shop before people arrive and then when we have our break I serve in the shop. We sell lots of drinks – coke, water, Dr Pepper and sweets – wine gums, galaxy and lots of different chocolate bars. When the Youth Group has finished I put away the tuck shop and help to tidy up the equipment. So that I could be a Youth Group Leader I had to fill in a CRB form and send it to the diocese and I have had to do this twice."

Keith

Once again, the only true way to ensure that the church loves and supports a family who has a member with a learning disability is for the minister and members of the church to get to know each individual personally. It is also important that each parent is given the opportunity to explore their faith and gifts as an individual and support should be offered to ensure they do not always need to care for their child alone through services or meetings.

Indeed, for many parents and carers their constant prayer is for a little help in caring for their child with a learning disability, especially during the Sunday morning service. Patience, a good sense of humour and the empathy/understanding to intervene at the right level when required are the only core gifts necessary for a volunteer. However, if there is really no one within the church family who can help, it may be possible to apply for a volunteer from a

Stanley Hauerwas suggests, 'at the very least, the Church should be the place where parents and mentally handicapped children [sic\*] can be without apologizing, without being stared at, without being silently condemned.'

Hauerwas in Swinton (2004) p59

care organisation, such as the *National Autistic Society* or *Mencap*,<sup>27</sup> or for the church to offer to contribute to the cost of a carer.<sup>28</sup>

Perhaps there are members of the congregation who do not think they could help as a carer but could offer more practical assistance such as gardening, ironing or housework. Try to make offers of help specific – not just 'let me know if you need any help' but rather 'could I collect your ironing on Tuesday afternoon and get it back to you Wednesday night?' Of course, any minister needs to be sensitive to offering help and not patronise a particular family or treat them as a 'charity case.' However, the vast

<sup>\* [</sup>sic] – This is to indicate that the original quotation has been faithfully reproduced and does not necessarily reflect the use of language in this context today or the views of the Working party.

<sup>&</sup>lt;sup>27</sup> See chapter 12 Specialist Groups and Helpful Organizations for details

<sup>&</sup>lt;sup>28</sup> It is possible that the family already employ a carer through the Direct Payments scheme or Individual Budget. In this event there may already be a fully qualified helper who could care for the child and release the parents' time in order to attend an Alpha course or a parish weekend etc.

majority of families need more assistance of a practical nature and are offered very little help from relatives or social services.

It would benefit many people with learning disabilities if there could be an area of the church where it is ok for people to stand up or walk around if they need to, or where any noise would not be so disturbing, and thus embarrassing, for the family. However, a minority of people will not be able to remain in a large, noisy building with lots of people for the whole duration of the service and so a separate lounge area with appropriate soft furnishings and resources<sup>29</sup> or a garden with benches and a covered area for bad weather would be helpful.

It is imperative that the family are reassured that any noises or disruption to the service are acceptable, whilst at the same time offering help and assistance to make the time in church an enjoyable and relaxing experience for everyone.

It may be that the person with a learning disability would be happier if they were involved in the service in some way, perhaps helping with the collection or being a member of the choir. It is important to remember that every person is an individual and each has a different gift to offer. Many people have been surprised by some of the special gifts on offer, including those gifts offered by family members or carers. It should not be assumed that people will not volunteer simply because a member of their family has an impairment. Many carers have gained great skills in tolerance, patience and organisation through the necessity of their caring role and these can be valuable gifts to be shared with the wider community. If there are a number of people with learning disabilities in the local church it would be a good idea to ensure this group of people and their carers are represented on the PCC to ensure their needs are met and their gifts are being fully utilised.

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<sup>&</sup>lt;sup>29</sup> Making a room into a temporary multi-sensory area is a relative cheap and easy thing to establish through the use of blacked out wall dividers or blackout curtains, bubble tubes and different lights – such as tube lights and disco balls. Help and advice would be available through the carers of the person with a learning disability or through your local Diocesan Disability Advisor.

If the person with a learning disability is of Sunday school age then the leaders must liaise carefully with the parents or carers to ensure their child is fully integrated at the appropriate level for them. One-on-one support should be offered, where necessary, rather than this being provided by the parents or carers on a regular basis. It is possible that assistance with their child on a Sunday morning may be the only help they get through a stressful week and this time of respite could be a great blessing to them.

The minister or the pastoral care team should offer space to listen to the personal concerns of any parent, carer or sibling and, where appropriate, they should offer to pray with them. Concerns will be many and varied but they may pertain to fears for the future, health issues or financial matters. It is also noteworthy that a person with a learning disability may be aggressive toward their parent, carer or sibling on occasion. Ministers should be aware of this and offer a safe place in which a person can share this experience in confidence. Ministers must also be prepared to respond to difficult questions, such as 'Why did this happen to us?' or 'Should I pray for my child to be healed?' In addition they must not avoid preaching on matters of disability when it is addressed in scripture.<sup>30</sup>

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<sup>&</sup>lt;sup>30</sup> Kathy Black's book '*A Healing Homiletic'* (1996) is recommended as it offers a fresh approach to some of the healing narratives.

Training for the minister, leadership team, welcome team and PCC members should be available from the Diocesan Disability Officer or such organisations as *Through the Roof* and *Causeway Prospects*.

# 11. Some terms to use when referring to people with disabilities

Try and avoid referring to a person solely by reference to their impairment. For instance, Sarah may be a 20 year old young lady with long brown hair and beautiful blue eyes. She may work in a local shop, help arranging the flowers on a Sunday and enjoy going to the cinema. She may also have a learning disability.

However, where necessary the following terms are appropriate:

Don't use the terms 'handicapped person,' 'cripple' or 'invalid'	⇨	Use the term 'a person with a disability' or 'a person with an impairment'
Don't use the terms 'mentally retarded' or 'mentally handicapped'	$\Rightarrow$	Use the term 'A person with a learning disability'
Don't use the term 'spastic'	$\Rightarrow$	Use the term 'A person with cerebral palsy'
Don't use the term 'mongol'	$\Rightarrow$	Use the term 'A person with Down's syndrome'
Don't use the terms 'suffering from' or 'victim of,' or 'afflicted by'	$\Rightarrow$	Use the term 'A person with'
Don't use the terms 'confined to a wheelchair' or 'wheelchair-bound'	$\Rightarrow$	Use the term 'A wheelchair-user'

Most importantly always refer to the person before the disability.

# 12. Specialist groups and helpful organisations

Being a welcoming and inclusive church means being aware of the needs of the people who are part of the community and thinking about the accessibility of building, liturgy and activities. However, it does not mean that all services and activities need to be appropriate for people with learning disabilities all the time. In addition to what the local church can offer there are some specialist ministries for children, youth and adults with learning disabilities. These offer groups and Christian services where there is time to listen, learn and share at a simpler and slower pace. As can be seen through the section entitled 'Gifted by the Spirit' in Chapter 3, such groups are vital for the church to be whole. For instance, one church has a monthly lunch and Bible study group led at an appropriate level whilst other churches have started groups with the help of either Faith and Light or Causeway Prospects. Some people may say 'our church doesn't need a special ministry because we have no one in our church with a learning disability' but one church saw their congregation grow from two people in the congregation with a disability to 25 who are now welcomed to a regular Faith and Light group. Many churches have discovered that as a group gathers the message spreads that an accessible church has been found and this has a consequent impact on the missional and evangelistic life of the whole church family.

A group was founded in 2002 after an approach to the Church from a local care home for people with learning disabilities. Over the years since there has been a gradual acceptance of the members of the group by the Church family which has been accompanied by a realization that people with learning disabilities have much to contribute to the life of the Church and to society in general.

The group has 18 members at present and there is a philosophy of focusing on what people with learning disabilities CAN do. There is some integrated worship and also opportunities for occasional services to be modified to make them more inclusive of the group. An important feature of the worship is the item in the some services which allows members of the group to contribute directly to the corporate worship. A very special funeral service was arranged recently when a member of the group died. (See appendices).

The leaders of the group make a point of getting to know the members as individuals by listening carefully to them and wherever possible making sure that members have a real choice in decisions that affect them. Individuals are encouraged to make personal contributions to the worship items such as drama or prayers. The leaders also, where possible, offer support to some of the carers of the members of the group.

The contribution made by the members of the group is two-way: the Church is enriched by them and they grow in their Christian understanding by their participation in its life and worship.

'Friends of Jesus' Holy Trinity Church, Redhill

#### Faith and Light

Faith and Light began in the early 1970's growing out of a pilgrimage to Lourdes organised by Jean Vanier, the founder of the L'Arche communities. A family with two sons with learning disabilities who had suffered rejection and isolation from their parish were the catalyst for the pilgrimage when 8000 people from 15 countries spent Easter together. The groups that travelled together became the first Faith and Light communities on their return. There are now more than 1500 communities in 85 countries including people of all Christian traditions. The communities, which are for people with a learning disability, their families, friends and helpers, meet monthly to enjoy friendship, worship and activities. Communities also get together for bigger celebrations and retreat, recognising that they belong to an ecumenical, international organisation. See the Faith and Light website (<a href="https://www.faithandlight.org.uk">www.faithandlight.org.uk</a>) for details of local groups or for a contact who can advise on starting up a new Faith and Light community.

Some comments from people who are involved with Faith and Light:

'I have been waiting 30 years for something like this to happen.'

A mother

'You won't stop me coming will you? I have been banned from everywhere else. I wish Faith and Light happened every week.'

Susan who has autism

'I had no experience but believed God was asking me to be involved. It has been a sacred place and I thank God for the group and what it has meant to me. It's also lots of fun!'

A helper

#### **Causeway Prospects**

This is another Christian voluntary organisation which values and supports people with learning disabilities so that they have the opportunity to enjoy life to the full. Tony Phelps-Jones, the director of mission and ministry says, 'We think of Causeway Prospect as a mission to people with a learning disability. They need to know Jesus loves them. We provide advice, training and resource material to equip churches for effective ministry and outreach.' Groups meet regularly for Bible study, prayer and friendship. There are also regional celebrations and holidays.

Causeway Prospects 69 Honey End Lane Reading Berks RG30 4EL

Tel: 0118 950 8781

Email: <u>info@prospects.org.uk</u>
Web: <u>www.prospects.org.uk</u>

Working with adults with learning disabilities – good resources

#### **SPRED**

SPRED stands for Special Religious Education. This organisation was created in Chicago in the 1960's when it was recognised that the way the Church was teaching faith did not work for people with a learning disability. SPRED works through a system where a community is built up between people with a learning disability and their friends. They listen to the word together and share food and activities either weekly or biweekly. This system is based in the Parish system so it enables SPRED members to be linked to the Parish church.

#### **SPRED**

20 Robroyston Road Glasgow G33 1EQ Scotland

Tel: 0141 770 5055 Web: www.spred.org.uk 'Susan is a person with autism that prevents her from normal communication and relationships. Susan is the eldest of four children living at home with parents Anne and Paul, her sister Marie is around a lot to help with Susan's life style. Susan is a very beautiful person, able-bodied and perceives your heart. With the special help from being a SPRED member Susan is a very happy and joyful friend.

Susan was born in September 1961 and got baptised at the parish church which we regularly attended. When Susan was 12 years of age I was approached by a member of the SPRED group and because of this group Susan was able to make her first Holy Communion.

Whilst she was in residential care Susan went to Lourdes with a SPRED group. She has been back home with us for 12 years and, because we are a very spiritual family, going to church and prayers have become a very important part in Susan's life. Since Susan has started the SPRED group I have observed how happier Susan is now she is with this group. She looks forward to her meetings every fortnight.

Susan has built up a great friendship with the whole group, but there is one special friend that Susan has bonded with and her name is Bridget. Whenever her name is mentioned Susan's face lights up and she rubs her hands, gives a little giggle and we know she is happy. Many times when Susan is low before going to the meetings she always comes back a lot happier, often singing.

Susan went to Lourdes last year with the SPRED group and me and my daughter went with her. We noticed how beautiful the friendships she has are and how close as a group they are, almost like a little family.'

Marie

## Other useful websites and organisations:

Disability-related organisations – <a href="https://www.makoa.org/org.htm">www.makoa.org/org.htm</a>

The UK's leading disability site – www.disabilitynow.org.uk

The Equality and Human Rights Commission – <a href="www.equalityhumanrights.com">www.equalityhumanrights.com</a> Tel. Helpline: 0845 604 6610

#### **Care Confidential**

Clarendon House, 9-11 Church Street, Basingstoke, RG21 7QG

Tel: 01256 477300 or 0800 028 2228 Email: <a href="mailto:careconfidential@care.org.uk">careconfidential@care.org.uk</a> Web: <a href="mailto:www.careconfidential.com">www.careconfidential.com</a>

#### **Down's Syndrome Association**

Langdon Down Centre 2a Langdon Park Teddington TW11 9PS

Tel: 0845 230 0372

Email: <u>info@downs-syndrome.org.uk</u> Web: <u>www.downs-syndrome.org.uk</u>

#### **Evangelical Alliance Disability Forum**

186 Kennington Park Road London SE11 4BT

Tel: 020 7207 2100 Web: <u>www.eauk.org</u>

Umbrella organisation for Christian disability organisations.

#### Foundation for people with learning disabilities

9th Floor Sea Containers House 20 Upper Ground London SE1 9QB

Tel: 020 7803 1100 Email: fpld@fpld.org.uk

Web: www.learningdisabilities.org.uk

#### Livability

50 Scrutton Street London EC2A 4XQ Tel: 020 7452 2000

Email: <a href="mailto:info@livability.org.uk">info@livability.org.uk</a>
Web: <a href="mailto:www.livability.org.uk">www.livability.org.uk</a>

Creates opportunities for people with disabilities and offers residential care for adults, wheelchair-accessible housing, respite care, accessible holidays and support services.

#### **The Makaton Charity**

Manor House 46 London Road Blackwater Camberley Surrey GU17 0AA Tel: 01276 606760

Email: <a href="mailto:info@makaton.org">info@makaton.org</a>
Web: <a href="mailto:www.makaton.org">www.makaton.org</a>

Communication signs and symbols often used for those with learning disabilities.

#### Mencap

123 Golden Lane London EC1Y 0RT

Telephone: 020 7454 0454

Fax: 020 7608 3254

Email: help@mencap.org.uk Web: www.mencap.org.uk

Mencap states it is the voice of learning disability. Everything it does is about valuing and supporting people with a learning disability and their families and carers.

#### The National Autistic Society

393 City Road London EC1V 1NG

Autism Helpline: 0845 070 4004

Tel: 020 7833 2299 Email: nas@nas.org.uk Web: www.nas.org.uk

Information, advice and support for people on the autistic spectrum and their families,

#### **Positive Parenting Publications and Programmes**

109 Court Oak Road

Harborne

Birmingham B17 9AA Tel: 0845 643 1939

Email: <u>info@parenting.org.uk</u>
Web: <u>www.positiveparenting.info</u>

Information, workbooks and courses specifically formulated for parents of children with special needs and challenging behaviour.

#### **Scripture Union**

207-209 Queensway

Bletchley

Milton Keynes

Buckinghamshire MK2 2EB

Email: <u>info@scriptureunion.org.uk</u> Web: www.scriptureunion.org.uk

Help with matters of inclusion for young people in church, excellent practical guidelines and resources.

#### Through the Roof

Global House PO Box 353

**EPSOM** 

Surrey KT18 5WS Tel: 01372 749955

Email: <u>info@throughtheroof.org</u> Web: <u>www.throughtheroof.org</u>

Training and raising disability awareness among Churches and Christians and equipping people with disabilities for leadership

#### **Torch Trust**

**Torch House** 

Torch Way

Market Harborough Leics LE16 9HL

Tel: 01858 438260

Email: <u>info@torchtrust.org</u> Web: www.torchtrust.org

Christian literature, fellowship and personal support for all blind and partially sighted

people.

All ministers should be in contact with their **Diocesan Disability Officer**, **Diocesan Secretary and the Diocesan Safeguarding Officer for children and vulnerable adults** who will be able to give pertinent advice concerning the local area or assist in locating an appropriate outside agency.

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http://www.oxford.anglican.org/social-justice/just-care/welcoming-those-with-autism-and-asperger-syndrome-in-our-churches-and-communities.html

**Promoting a safe church** - The House of Bishops' policy for safeguarding adults in the Church - (www.cofe.anglican.org/info/papers/promotingasafechurch.pdf)

**Protecting All God's Children** – The Child Protection Policy for the Church of England (www.cofe.anglican.org/info/papers/protecting\_all\_gods\_children)

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## Marriage and relationships

The only resources the working party is currently aware of which deal specifically with marriage and sexual health advice for people with learning disabilities are those resources provided by the Brook Advisory Centres (www.brook.org.uk). Brook is a national voluntary sector provider of free and confidential sexual health advice and services. Two publications particularly recommended are 'Living your Life' and 'Young Disabled People Can' (available through their website).

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## **Appendices**

#### A case study of bereavement work with adults with learning disabilities

The list below outlines the various steps taken following the death of a member of the 'Friends of Jesus' Group; a group of people with learning disabilities who meet in Holy Trinity Church, Redhill.

- The person who informed members of the group of the death of their friend was someone they knew well. The same person subsequently kept in close contact with the members of the group, informing them of the date and time of the funeral service etc. The aim was to avoid confusion and to provide simplicity and clarity of communication.
- 2. All meetings with members of the group were by appointment, so that they knew in advance that the leader of the group and one or two helpers would be visiting them.
- 3. Time was given to cover the same ground more than once, and to check at intervals on what had been heard and understood. It was, for instance, important in the first place to check that each person had understood at least in part the reality and finality of the loss.
- 4. Time was given to listen with care to different members as they began to express their thoughts. We needed to notice non-verbal communication, and provide feedback, (for example, "Jane, you are looking very worried. Can you tell us what you are thinking about?"). We encouraged each person to express their thoughts and feelings about the loss and their personal memories of their friend, Stephen. This was a significant part of the whole process and was repeated at later stages.
- 5. It seemed to be helpful that we stressed both commonality and difference: that many of us, both members of the group and helpers, experienced the same feelings of disbelief, shock and sadness, and at the same time we each had our individual memories and feelings.

- 6. We prayed together, asking Jesus to help us in our sadness and to give us His peace. We thanked God for Stephen and for our happy memories of him.
- 7. In all of this, we spoke of being both sad and happy: sad for ourselves, because we would not see Stephen again here, sad that he had been so ill; happy for Stephen that he was no longer ill and that he was safe and well with his friend Jesus.
- 8. Members of the group, especially those who lived in the same care home as the deceased, were offered choice about participating in the funeral service. A number opted to play an active part in the service. Some shared the Bible reading; others played their instruments or signed the actions to the songs from the front of the chancel. They seemed to benefit from this involvement, which focused their attention.
- 9. In preparation for the funeral, we spoke about the service as a time to say "goodbye" together to our friend, to share our memories of him, to comfort each other and to thank God for him.
- 10. We explained exactly what would happen in church, describing how the coffin would be carried in at the start of the service and then taken away at the end.
- 11. The funeral service was tailored to the needs of the group members. The minister who led the service and gave the address was well known to them.
- 12. The minister spoke to the group in a personal manner from the front of the chancel. The tributes included mention of the group, and some of the members' individual thoughts and memories. The address included a simple visual aid a two-sided face, one happy, one sad, reflecting and reinforcing much of what had previously been said to the group.
- 13. The four-page service sheet included a portrait on the front and an activity photo on the back.
- 14. The Act of Committal took place outside the church, rather than in an unfamiliar crematorium. The inclusion in the service of many familiar elements was found to be helpful.

- 15. The service was attended by regular members of the congregation. Members of the group were treated by them, and by others, as the principle mourners, and they were well supported.
- 16. Photographs of the deceased, both on his own and with his friends, were on display in the Church Centre where refreshments were served.
- 17. Feedback. Several members of the group said later that it had been good to be there together. The service undoubtedly helped them to experience both the reality of loss, and also the love and compassion felt for them. Two members, who had previously been very fearful about attending a funeral, seemed much more at ease.

At all times, the desire was to treat group members with respect, and make the occasion both dignified and memorable.

NOTE: In this instance, the deceased had no known family. The leader of the church group was therefore encouraged by the care staff to take responsibility for the pastoral care of the group and plan the funeral service.

On a previous occasion when another member of the group had died, it had been important to work with the relatives of the deceased. It was still possible to make the content of the service appropriate for this group, and to allow them to lead a part of the service and choose hymns and songs with which they were familiar.

## **Model Safeguarding Policy**

Taken from the Church of England's Adult Safeguarding Policy 'Promoting a safe church.' www.cofe.anglican.org/info/papers/promotingasafechurch.pdf

## Summary of the Safeguarding Policy

- We are committed to respectful pastoral ministry to all adults within our church community.
- We are committed, within our church community, to the safeguarding and protection of vulnerable people.
- We will carefully select and train all those with any pastoral responsibility within the Church, including the use of Criminal Records Bureau disclosures where legal or appropriate.
- We will respond without delay to any complaint made that an adult for whom we were responsible has been harmed, cooperating with police and the local authority in any investigation.
- We will seek to offer informed pastoral care to anyone who has suffered abuse, developing with them an appropriate healing ministry.
- We will challenge any abuse of power by anyone in a position of trust.
- We will care for and supervise any member of our church community known to have offended against a vulnerable person.