

Forgotten People – Examining issues of justice and social inclusion with respect to people with intellectual disabilities.

Sheila Hollins

Introduction

Adults with intellectual disabilities are arguably the most vulnerable, impoverished and socially excluded group in society. This is true in all cultures and throughout the world. After more than one hundred and fifty years of institutional care in the western world, community care is being developed in many countries with the intention to provide more humane support to people in their daily lives. Sadly human rights abuses and inequalities remain hidden in our societies.

The author draws on her professional and personal experience in the field of intellectual disability, reflects on the opportunities and experiences of intellectually disabled people as members of church communities, and considers how far Catholic Social Teaching has impacted on people's lives.

Drawing on sociological and anthropological insights and research into the quality of life of institutionalized people, the paper will also consider the responses of other members of society to people perceived as different or 'other'.

Despite the clear reminders in Catholic Social Teaching that every human being has the same value in God's eyes and belongs to society, the way in which this is interpreted in practice in both secular and church society, falls far short of these aspirations. Solidarity with our neighbour should include promoting equality of rights and opportunities, and at the very least the chance to enjoy an 'ordinary life'. But in the Western World, some householders will campaign to prevent a home for people with intellectual disabilities from being built in their street. It seems as if being a successful contributor to economic growth is often

valued more than being a member of a family and a neighbourhood.

The author will explore ways in which people with intellectual disabilities are both included and excluded by local communities, including church communities, giving examples mainly from the UK. She will suggest that some of the well-intentioned approaches to meet the perceived needs of disabled church members may serve to disadvantage them further, and will conclude with some ideas about how the church could modernise its thinking and influence for this diverse group of disabled people.

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Principles

Gaudium et Spes (1965) emphasised some principles about human dignity which have also become or are becoming, enshrined in International Human Rights legislation and within some government policies.

...There is a growing awareness of the exalted dignity proper to the human person, since he stands above all things, and his rights and duties are universal and inviolable. Therefore, there must be made available to all men everything necessary for leading a life truly human, such as food, clothing, and shelter; the right to choose a state of life freely and to found a family, the right to education, to employment, to a good reputation, to respect, to appropriate information, to activity in accord with the upright norm of one's own conscience, to protection of privacy and rightful freedom. even in matters religious (GS 26).

These are Catholic, Christian and universal principles. They are applied in society, by governments as well as at the level of communities and families, to varying extent. What communities tend to have in common, however, is that such principles are not extended to all equally. Some minority groups tend to be considered sufficiently different from other community members, such that they are not treated equally. However, the 2nd Vatican Council laid stress on a reverence for humanity:

... everyone must consider his every neighbour without exception as another self, taking into account first of all his life and the means necessary to living it with dignity, so as not to imitate the rich man who had no concerns for the poor man, Lazarus. (GS 27)

So does this really apply to everyone? Are there any exceptions? How far do we live out the aspirations of *Gaudium et Spes* in reality? What about people with serious intellectual disabilities? How far is intellectual ability seen as an essential component of personhood?

The intellectual nature of the human person is perfected by wisdom and needs to be, for wisdom gently attracts the mind of man to a quest and a love for what is true and good. Steeped in wisdom, man passes through visible realities to those that are unseen.

Our era needs such wisdom more than bygone ages if the discoveries made by man are to be further humanized. For the future of the world stands in peril unless wiser men are forthcoming. It should also be pointed out that many nations, poorer in economic goods, are quite rich in wisdom and can offer noteworthy advantages to others. (GS 15)

Is the full humanity of people with intellectual disabilities recognised, supported and fulfilled? How far is wisdom equated with intellect and to what extent is emotional intelligence recognised? If not fully recognised, are we aware of the shortcomings in the responses of our own communities, and what are we doing about them? Should our responses be restricted to Catholic circles or should we share our insights with the world at large and how effective will we be?

The size of the ‘problem’

What is Intellectual Disability? The definition¹ includes the presence of:

? *A significantly reduced ability to understand new or complex information, and to learn new skills (impaired intelligence)*

? *A reduced ability to cope independently (impaired social functioning)*

? *That started before adulthood with a lasting effect on development.*

This definition encompasses people with a broad range of disabilities. The presence of a low intelligence quotient, for example an IQ below 70, is not, of itself, a sufficient reason for deciding whether an individual should be provided with additional health and social care support. An assessment of social functioning and communication skills should also be taken into account when determining need. Many people with intellectual disabilities also have physical and/or sensory impairments. The definition covers adults with autism who also have intellectual disabilities.

The current prevalence of intellectual disability is between 2.5 and 4% of the population, the majority of whom have mild intellectual disabilities. Evidence suggests that the number of people with severe intellectual disabilities will increase by around 1% of this total per annum as a result of:

? increased life expectancy, especially among people with Down’s syndrome

? growing numbers of children and young people with complex and multiple disabilities who now survive into adulthood

? a rise in the reported numbers of school age children with autistic spectrum disorders, some of whom will have intellectual disabilities

Policy development

Respect for individuals with disabilities or with mental health problems is the main value underpinning some of the most progressive government policy initiatives. In Britain, ‘Valuing People’ - (a new cross government White paper on intellectual disability in England), as one such

policy initiative, has aspirations to support the inclusion, rights, choices and independence of people with intellectual disabilities. Implementation of this policy has also drawn attention in many circles to the need for people's spiritual needs and church membership to be considered.

How did such humane policies develop in practice and what lessons can we learn from the processes involved?

In 1999 I was invited to play a key role in an International Policy Academy hosted by the President's Committee on Mental Retardation to be held in Washington, DC. Eight US state teams, two teams from Native American Tribal Groups and two international teams were invited. Each team was asked to ensure that the members would include legislators, service users, family members and service providers. The England Team comprised 16 people and among them were three women who themselves had intellectual disabilities, and four members who were themselves family members whilst also having professional contributions to make. My role was to attend to the group dynamics and support the team leaders, but I was also called on to share my experience as the mother of a young man with severe intellectual disabilities.²

The five-day Academy proved invaluable in determining the way in which new policy on intellectual disability was later developed in England. The inclusive way in which our discussions proceeded, and the often-painful way in which we learnt to listen to the intellectually disabled members of the team, had a profound impact on everyone. We also heard from other US teams about the ways in which they had made progress in developing inclusive approaches to supporting people with intellectual disabilities and their families in their everyday lives. By the end of the week we were ready to return to the UK with the building blocks of a new policy. The then Minister of Health was ready to listen. Perhaps one key factor was his personal experience of having had a child with a severe disability himself. He formed a 'Minister's Advisory Group' which included most of the members of the Washington 'sixteen'. By May 2001 he was ready to launch his new policy. I will quote from some sections of the report to illustrate

the exciting way in which I think the influence of *Gaudium et Spes* can be recognised.

For example as the Prime Minister, Tony Blair, said in his introduction to the White Paper:

People with intellectual disabilities can lead full and rewarding lives as many already do. But others find themselves pushed to the margins of our society. And almost all encounter prejudice, bullying, insensitive treatment and discrimination at some time in their lives. Such prejudice and discrimination – no less hurtful for often being unintentional – has a very damaging impact. It leads to your world becoming smaller, opportunities more limited, a withdrawal from wider society so time is spent only with family, carers or other people with intellectual disabilities.

Gaudium et Spes emphasised the principles of human dignity

Later on the White Paper refers to the social change needed to ensure that people with intellectual disabilities have a chance to be treated as equal citizens:

1.14 Too many people with intellectual disabilities and their families still lead lives apart, with limited opportunities and poor life chances. To maintain the momentum of change we now need to open up mainstream services, not create further separate specialist services. People with intellectual disabilities should have the same opportunities as other people to lead full and active lives and should receive the support needed to make this possible.

It also addresses their health needs:

Many people with intellectual disabilities have greater health needs than the rest of the population. They are more likely to experience mental illness and are more prone to chronic health problems, epilepsy, and physical and sensory disabilities. The Government's objective is to enable people with intellectual disabilities to have access to a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard and with additional support where necessary. We will ensure that people with intellectual disabilities, including those from minority ethnic communities, have the

same right of access to mainstream health services as the rest of the population.

Many of the changes identified start with addressing the attitudes towards, and the opportunities available to children:

3.3 Three main messages have come out of consultation with disabled children:

*? treat us more like our brothers and sisters
? we want to do the things other children do, not always 'something special'
? give us a chance to be independent, get a job and have a home.*

An Easy Read version of Valuing People was also produced – probably the first widely accessible government policy.³

Learning from experience

A visit to Africa

Some years ago, the supervisor of a religious order came to see me to discuss issues of justice as they apply to people with intellectual disabilities. Her order had come to a similar conclusion: people with intellectual disabilities are probably one of the last groups in society to have their essential humanity recognised. The Sacred Heart Sisters in Chigwell in England have established working communities in Zambia and the Philippines amongst other places, where their social action includes providing teaching and social care for disabled children and adults.

Following a visit to one of their Zambian projects, I co-authored an editorial⁴ about their successful work in developing inclusive education for severely disabled children living in a shantytown. A major barrier to achieving the international goal of universal primary education (UPE; UNESCO 2001) is the fact that those children who do not attend primary school are overwhelmingly from poor households in poor countries. In 1998 UNESCO's Education for All (EFA) 2000 Assessment⁵ estimated that one child in five was not enrolled in school. The vast majority (nearly 87%) of these children lived in just three regions: Sub-Saharan Africa, South and West Asia and the Arab States and North Africa.

The World Health Organisation (WHO) estimates that one in 10 children in developing countries have special needs in education. Children with intellectual disability are not the first priority when educational policy is being made in any part of the world, and yet there are pragmatic reasons why it is fruitful to remember them, perhaps especially so in Africa. Many disabled children in Africa are orphans because of the impact of the AIDS epidemic in their parent's generation. Many more are separated from their extended families because of famine, war or the migration of their parents to the cities in search of work. A child who is slow to develop and who has extra care needs is harder to support in these circumstances. Consider the challenge of a floppy baby with no head control who cannot be carried safely on her sister's, mother's or grandmother's back. Her carer will be unable to work unless she can find another caregiver. But disabled children are still objects of fear in many parts of Zambia, and some families hide their disabled children, perhaps feeling shame for their child's difference.

The sisters are making a significant local contribution towards the UNESCO aim of Education for All by 2015. The school is an integral part of a mainstream 'Open Community School' (a no-fee school catering for orphans and vulnerable children), in a shantytown in the capital. The special classes started in 1997 following a survey in the Compound (population 40,000) to try and find the 'hidden' children. The survey was conducted with the help of the children already in school, in identifying their disabled brothers, sisters and neighbours. 110 children and young people with special educational needs were found, from 18 months to 24 years, many of whom were orphans and who put an additional strain on an already stretched extended family. Before the survey there were no disabled children attending the school. By 2003, 70 children were regularly attending the special school which provided classes from pre-school up to age 15, as well as a 16+ training programme. Inclusive approaches such as these help to break down attitudinal barriers in the wider community, and enable disabled children in sub Saharan Africa to enjoy their right to education.

Living and working in London

In my work as a psychiatrist and psychotherapist I have direct clinical contact with

people of all ages and all degrees of intellectual disability, their families, and carers. As a university teacher and researcher I have an opportunity to teach the next generation of health care professionals and to identify and address research questions which might make a difference to people's lives. I want to describe some key lessons that I have learnt from my clinical and university experience. I also have some important personal, family and community experience to reflect on and share. In some instances, it is the combination of my personal and professional insights that has been called on to inform policy and practice, both at government level and to a limited extent within church organisations.

A Diocesan initiative

Thus, for example, one diocese in London had obtained a grant to review the needs of disabled members and to consider how best to meet their pastoral and spiritual needs. I was invited to join and sometimes chair a steering group for the project. The researcher visited and reviewed different models of provision and drafted a detailed report, concluding with an option appraisal. The options ranged from the more traditional approach of offering an occasional, segregated 'special' Mass for people with intellectual disabilities, to a community development approach that aimed to include people as visible and equal members of the church community. The latter option was chosen and seemed very much in line with the emphasis on inclusion and choice which government policy in the UK was also beginning to embrace.

The diocese then employed two workers to develop this vision, rather optimistically, since there are dozens of parishes in the diocese. The purpose of the project⁶ was described as to bring about change at parish level to promote the full and active participation of disabled people in the church and in the community. The work aims to ...“create an awareness of the needs and gifts of disabled people, and to develop the sensitivity, confidence and expertise of clergy and laity, thus enabling parishes to welcome and accept disabled people as fellow-members of the Church.”

Consider the following experiences:

? A boy with cerebral palsy was denied membership of a church scout group because it wouldn't be 'fair' on the other boys

? A middle aged woman with Down's Syndrome was refused a blessing by a Eucharistic minister

? The mother of an autistic teenager was advised not to bring her son to church because of his disturbed behaviour

And more positively (also see Hollins & Grimer, 1988)⁷:

? A mother of a non-verbal girl was encouraged to bring her to the altar for her first Communion when she judged she was ready – this welcoming approach recognising the lack of an inclusive first Communion programme in the parish, and affirming her mother as her child's first teacher.

? L'Arche communities are acclaimed for offering 'a sign of hope' by enabling people with and without learning disabilities to live together in Christian community.

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Painful secrets

Jean Vanier's writing, personal example and leadership, particularly through the work of L'Arche internationally, has been an inspiration to many. The last time I came to Rome was to speak at an International Federation of L'Arche Communities about the needs of families with a disabled child. In preparing for that occasion I defined some developmental factors that I consider are particularly important in the lives of young people with intellectual disabilities as they are growing up. I called these factors 'the three secrets'. Since then, they have been further developed with my colleague Dr Valerie Sinason, into the **five mutative factors**⁸. These are the secrets of disability, sexuality, mortality, dependency and the fear of being killed.

So how do these issues relate to our theme for this conference? I am going to suggest that people with intellectual disabilities are often aware from infancy that their very existence may provoke feelings of rejection and hostility, and even their families may wish they were dead. We do not know how often death is hastened for children and adults with severe disabilities.

Our insights also suggest, for example, that an individual's disability will be kept from him or her, and that she/he will be treated as an eternal child and not helped to understand inevitable aspects of the human lifecycle. A reluctance to offer sex education to children is even greater when the child or teenager is disabled. These are vulnerable children and research shows that they are much more likely to be abused- usually by someone known to them- before they reach adulthood. Instead of preparing them carefully so that they might be able to protect themselves better, they are often left in ignorance. In my clinical practice I hear stories of incest or of abuse by trusted community members. In one recent example, a priest in an African town is alleged to have abused two disabled girls. Those involved believe that the priest was acting on the local myth that sleeping with a virgin will cure a man of HIV infection. The teacher who supported the girls' parents has allegedly been threatened with the sack.

... while human progress is a great advantage to man, it brings with it a strong temptation. For when the order of values is jumbled and bad is mixed with the good, individuals and groups pay heed solely to their own interests, and not to those of others. Thus it happens that the world ceases to be a place of true brotherhood (GS 37).

Last year a woman came to see me who discovered when her father was dying that he had abused her two sisters as well as herself. She had thought she was the one with the 'special' relationship with Dad. These deathbed revelations have shattered this devout catholic family. Earlier this year another woman came for therapy who had 'got' incest. She didn't know what incest was, but said her children had been taken into care so that they wouldn't catch it. She didn't know whom the fathers of her children were - but said her father, uncle and brothers had all been asked to have tests. She said she had been told that it wasn't OK to have sex with family members in England, but her family had said that that didn't apply to her father and his brothers because they were Indian and it was normal in their country.

With colleagues at St. George's I have been carrying out research to try to understand more about how to recognise signs of abuse and how to help people recover from the psychological trauma of being abused⁹.

Bereavement

The concepts of life and death are difficult for all of us to understand, but so much harder if one is unable to read and has to rely on visual and sensory clues to help make sense of the world. My research has explored how people with intellectual disabilities react when they are bereaved, and how well social and religious institutions respond to these needs. One small study compared how far the funeral rituals of six different religious groups in South London were able to include people with intellectual disabilities¹⁰. None of the religious leaders interviewed had even considered the matter, and most of these church leaders concluded that people with intellectual disabilities should be left out of the funeral arrangements. But our most significant study found that failing to support people with intellectual disabilities following a parental bereavement leads to serious mental health consequences¹¹.

Our next study was conducted jointly with L'Arche UK¹². It was a very successful study in which we compared two different interventions designed to improve the mental health and behaviour of bereaved people with intellectual disabilities, one delivered by L'Arche assistants who knew the individual well, and the other by volunteer trained bereavement counsellors from external counselling agencies. To our surprise the intervention delivered by L'Arche assistants was unsuccessful in that no demonstrable change in behaviour or mental health was found. This was despite the fact that many people living in a L'Arche community home are also accompanied by long term friends of the community, including former assistants, or by local church members. The on-going training and formation of 'accompaniers' includes aspects of loss and bereavement as well as issues related to supporting the spiritual needs of the person being accompanied. The behavioural and mental health measures used in our study showed significant change for those receiving targeted counselling, but those not offered counselling by an outside agency did not show any improvement. This does not mean that the attention to these issues within L'Arche is unnecessary, but rather that, sometimes professional external interventions are also needed to achieve the best outcome for an individual. L'Arche remains unusual in recognising and attending to the spiritual and emotional needs of both residents and staff and offers an example of good practice in this area.

Relationships and community

An insight that has been extensively addressed by Jean Vanier¹³ relates to the essential interdependence of each one of us, but also draws attention to the difficulty experienced by most people with intellectual disabilities in being able to develop exclusive intimate relationships. *Gaudium et Spes* says:

But God did not create man as a solitary, for from the beginning "male and female he created them" (Gen. 1:27). Their companionship produces the primary form of interpersonal communion. For by his innermost nature man is a social being, and unless he relates himself to others he can neither live nor develop his potential.

Assistants living in community with people with intellectual disabilities learn about mutual dependence and about the challenge of celibacy. One assistant in explaining her role to others in a training session simply said ... "there are nine of us in our house, six of us have disabilities and three of us do not".

The latest on human rights

The United Nations Committee negotiating the treaty on persons with disabilities is currently discussing individual rights and freedoms. Meeting for its fifth session in earlier this year, the General Assembly Ad Hoc Committee concluded its session in February by discussing draft articles addressing equal recognition before the law, liberty and security of the person and other individual rights.

During the 5th Ad Hoc Committee, state parties with input from civil society organizations, reviewed and amended Articles 8 through 15 of the draft text. The draft text along with the background documents for the 5th session are available on the United Nations Department of Economic and Social Affairs website www.un.org/esa/socdev/enable/rights/ahc5.htm.

These include: Article 8 – Right to Life; Article 9 – Equal Recognition as a Person Before

the Law and; Article 15 – Living and Being Included in the Community;

Article 11: On freedom from torture or cruel, inhuman and degrading treatment or punishment:

State parties are to take measures to prevent persons with disabilities being subjected to such treatment or punishment. In particular, they are to prohibit medical and scientific experiments without the consent of the person concerned and to protect disabled persons from forced interventions or institutionalization.

Article 12: On freedom from violence and abuse:

States are to take measures to protect persons with disabilities from all forms of violence, injury, abuse, neglect, mistreatment or exploitation.

However, it was reported that

... participants were split on whether to have a provision on the need to educate families and/or caregivers to prevent and address situations of abuse.

At the Conclusion of the 5th Ad Hoc Committee, Diane Richler, President of Inclusion International commented on the challenges ahead.

...There continues to be a lack of understanding by State Parties and other Disability groups of the issues affecting people with intellectual disability and second, there is even less understanding or acceptance of the role that families play in promoting the inclusion and human rights of people with intellectual disabilities. Our job is to articulate to all those involved in the Convention process the nature of the exclusion faced. The Convention is an opportunity to go beyond institutionalizing existing practices but rather to advance a vision for the future that takes seriously the inclusion of all people with disabilities in society.

The 6th Ad Hoc Committee Meeting will

take place in August 2005 and the Articles that remain to be negotiated are Articles 15-25. Key issues include Articles on Education, Children and International Development.

These 'new' demands were anticipated by the Council fathers and although diversity of talent was recognised, interestingly they did not mention disability:

True, all men are not alike from the point of view of varying physical power and the diversity of intellectual and moral resources. Nevertheless, with respect to the fundamental rights of the person, every type of discrimination, whether social or cultural, whether based on sex, race, colour, social condition, language or religion, is to be overcome and eradicated as contrary to God's intent. For in truth it must still be regretted that fundamental personal rights are still not being universally honoured. (GS 29)

Research experience

Let me give some more examples from our research. The UK is not unusual in having provided institutional care for people whose families were unable to continue to care. The history of our institutions goes back to the Poor Law in 1601, when 'paupers and the insane' were accommodated in workhouses within each parish, and perhaps even further back into the Middle Ages when monasteries often provided care for people excluded from the mainstream of society. Deinstitutionalisation has gained momentum in the West in recent years, and in England we expect all of the long stay hospitals for people with intellectual disabilities to have been closed by 2006. From 70,000 people in such hospitals 40 years ago, now less than 1000 people remain.

About seven years ago I recruited Jane Hubert, a social anthropologist, to find out more about the lives and behaviour of 16 men with severe intellectual disabilities and challenging behaviour, who were living in a locked ward in one of these long stay hospitals¹⁴. The men were to move into the 'community' and the hospital wanted to know more about them, and their likes and dislikes, and then to follow them into their new homes. She spent 300 hours 'living' in the ward with the men and movingly describes how she came to know and understand them. Few of them had any speech. All

had been admitted as children, and most had lost contact with their families. What is disturbing about her research however is the way in which these small boys became dehumanised in the eyes of their carers and of society. Each day she documented petty and thoughtless abuses. For some of them more serious abuses were documented in their notes. One of the tragedies of care for some of these individuals was the way in which an innocent child was abused or traumatised such that his own behaviour became socially unacceptable. Outsiders could be forgiven for seeing these children, now grown into adult men, as challenging and 'bad'. And yet the damage they do to other residents and staff derives from their own trauma. The struggle they face in overcoming such unsocial behaviours requires skilled and intensive supports, which unfortunately are rarely available. Groups of people such as these are truly scapegoated and excluded.

The Problem of Empathy

René Girard's insights may be helpful here and made more accessible in Kirwan's new book, *Discovering Girard*¹⁵. He explained that firstly we are mimetic creatures, and secondly, that all cultures use similar mechanisms for resolving tensions in communities. For example, communities exclude a scapegoat, who often later is found to be innocent. He suggests that we can either respond against a person who is different, or with the person. The compassion needed to be with such a person is surely what Christ called us to. He goes on to explore the uncommon nature of empathy as written about by Girard. This has been explored previously, for example in Edith Stein's classic discussion about the problem of empathy, and more recently by Martha Nussbaum.

Conclusion

My professional experience will be unfamiliar and even shocking to many readers. Typical responses to hearing of these issues are to want to distance oneself from them. In our churches we hear such people and their problems described as 'the handicapped' or 'the poor' – not as people first. I suggest that our church leaders, lay and religious, need to learn about people with intellectual disabilities in their early training and formation, and one model for such training is described in *A New Kind of Trainer*¹⁶. Pastoral workers need to confront their fears about people who may at first sight seem very different or 'other'

to themselves. By understanding more about them as people first, they will be able to share more positive attitudes and develop adequate communication skills in order to be truly inclusive. However I consider that to have any chance of achieving change, the principles espoused in *Gaudium et Spes* also need to be taken up within secular government and community policies. Our role must include strong advocacy in public life and a commitment to social action and justice.

NOTE:

¹ *Valuing People: A New Strategy for Learning Disability for the 21st Century*. (London: HMSO, 2001)

² TOWELL, D. (2000) "Achieving Positive Change In People's Lives Through The National Learning Disability Strategy: Lessons from an American experience" *Tizard Learning Disability Review* 5, (3), 30-36.

³ Department of Health, *Nothing About Us Without Us* (London: Department of Health, 2001)

⁴ Dawson, E., Hollins, S., Mukongolwa, M., Witchalls, A. Editorial: "Including disabled children in Africa." *Journal of Intellectual Disability Research*, 47(3), 153-154.

⁵ UNESCO, *Education for All 2000 Assessment, Statistical Document. World Educational Forum* (Paris: UNESCO, 2000).

⁶ Archdiocese of Southwark, *A community development project for the inclusion of people with disabilities into the life of the church*, (Tooting, London: Christian Education Centre, 1998).

⁷ Hollins, S. & Grimer, M. *Going Somewhere: People with mental handicaps and their pastoral care*. (London: SPCK, 1988).

⁸ Hollins, S. & Sinason, V. "New Perspectives: Psychotherapy, Learning Disabilities and Trauma." *British Journal of Psychiatry*, 2000, 176, 32-26.

⁹ Sequeira, H., Howlin, P., Hollins, S. "Psychological disturbance associated with sexual abuse in people with intellectual disabilities: a case control study." *British Journal of Psychiatry*, 2003, 183, 451-456.

¹⁰ Raji, O., Hollins, S., Drinnan, A. "How far are people with learning disabilities involved in funeral rites?" *British Journal of Learning Disabilities*, 2003, 31, 42-45.

¹¹ Hollins, S. & Esterhuyzen, A. "Bereavement and grief in adults with learning disabilities." *British Journal of Psychiatry*, 1997, 170, 497-501.

¹² Dodd P., Dowling S., Hollins S. "Review of bereavement: emotional, psychiatric and behavioural responses to bereavement in people with learning disabilities." *Journal of Intellectual Disability Research* (In press).

¹³ Vanier, J. *Man and Woman He Made Them*. (London: Darton, Longman and Todd, 1985).

¹⁴ Hubert, J. *Madness, Disability and Social Exclusion: the archaeology and anthropology of 'difference'*, (London: Routledge, 2000).

¹⁵ Kirwan, M., *Discovering Girard*, (DLT, 2005)

¹⁶ Owen, K., Butler, G., & Hollins, S. *A New Kind of Trainer: How to Develop the Training Role*, (London: Gaskell, 2004).