

PROVIDING CARE AND SUPPORT: SOME REFLECTIONS ON DISABILITY AND SEXUALITY

LYNDA FISHER



Lynda Fisher is Assistant Director for Adult Support Services with The Shaftesbury Society.

LYNDA FISHER WORKS FOR THE SHAFTESBURY SOCIETY, A LEADING UK CHRISTIAN CHARITY THAT WORKS WITH DISABLED PEOPLE AND LOCAL COMMUNITIES TO ACHIEVE SOCIAL INCLUSION, EMPOWERMENT AND JUSTICE, HAVING PREVIOUSLY BEEN REGIONAL MANAGER IN THE SOUTH AND WEST. Her background has predominately been in both the health and social care and the voluntary sector. In this article she reflects on some interesting and potentially difficult situations that she and her colleagues face in their role as providers of care and support of disabled people, with particular reference to disabled people as sexual beings.

WHAT WOULD YOU DO?

A disabled man wanted to buy pornographic magazines from the local shop but could not reach the shelf because of the restrictions of his wheelchair. Another wanted a nightdress for his birthday present and other items of women's clothing. He wanted his carer to take him shopping for women's shoes. A man with learning disabilities wanted to go to a hotel with his girlfriend for the weekend but he needed help with booking the venue and transport to get there. A parent wanted her daughter to be prescribed contraceptive pills by the local GP. Even though her daughter was not involved in and did not desire a sexual relationship, she wanted to make sure her daughter never risked becoming pregnant. Two disabled people with physical impairments wanted to spend the night in bed together but had to have staff's help to achieve this because of the nature of their impairment. A woman with learning disabilities liked having a bath with the other lady with whom she shared a house.

The majority of the population are not subject to third party scrutiny of our relationships, unless we occupy a place of media exposure. However, for disabled people, the nature of their impairment constantly exposes them to the attention of others. James Overboe writes from personal experience: "Given our subordinate position in our interaction with the non-disabled we fear the negative consequences of 'speaking our mind'. Or a disabled person may not want to speak because the lines of communication may not be open to them. For example, the linear rationality of the able-bodied subject has difficulty in understanding a somewhat chaotic communication that is informed by the 'disruptive' embodiment of a disabled person."¹

The social model of disability, developed by disabled people themselves, asserts that all disabled adults and children have a right to belong to and be valued in their local community. The focus is not on a specific

“Where do the faith and values you hold personally conflict with societal and cultural norms?”

► impairment as the problem, but rather the way in which society inhibits disabled people from full participation as members of a community. If our body or mind is limited in its functioning, it does not make us any less human, it is simply an impairment to our ability to live in a society which is often discriminating in its acceptance of others.

Disabled people, unless their disability is non-visible, cannot escape from the daily challenge of being seen and related to as being different. This is especially true for people, who through circumstance and through the requirement of their needs for care and support find themselves in institutional care. Even with the emphasis since the last decade on care in the community, if someone is dependent on others to support their everyday life needs, they are seen as outside of the individualistic, self-determined nature of the rest of society in this country and, by default, different. Disability may come outside of our paradigm of experience. The consequences of this are that not only may a person be deprived of intimacy, sexual expression and relationships that many of us take for granted but they may be entirely dependent on others for any opportunity to experience intimacy or sexual expression.

A disabled person seeking some acknowledgment of his or her sexual needs may conclude that the truth is that many able-bodied people do not know what to make of disabled people with regard to sexuality. He or she is probably right. It's not a question that probably occurs to most of us as being important or significant in our own lives. However, for people faced with the day to day realities of living with or working with disabled people, it is still a question which can and often is avoided. To question and to seek to understand one's own thoughts and feelings, inevitably involves pain. Rowan Williams describes it thus: “Authentic religious (in this case, Christian) practice begins in the attempt to attend to the moment of self-questioning – to refuse to cover over, evade or explain the pain and shock of whatever brings the self into question, to hold onto the difficulty before the almost inevitable descent into the pathos and personal drama begins.”²

Is it alright to enable someone to buy pornographic magazines? Is it acceptable to sort out hotel bookings and transport for someone to go away for the weekend with his girlfriend? What are the legal implications if someone's parent insists you take their daughter to the GP to be prescribed a contraceptive? Where does your responsibility begin and end if you enable consenting

adults to sleep together who otherwise would not be able without your assistance? Where do the faith and values you hold personally conflict with societal and cultural norms?

WHAT WOULD YOU DO?

Although organisational policies, procedures and knowledge of the law can help to inform decision-making, so often personal values and life experience have an overriding effect on the way we relate to others and interpret our faith. This struggle is particularly true in relation to disabled people as sexual beings. Christian faith and action do not come into conflict where disabled people are perceived as being in need of care. However, where carers are challenged, especially when they hold deep-rooted beliefs, is in the recognition that disabled people are just like every other human being; they have sexual needs as well as physical, emotional, intellectual, spiritual and social needs. “What we believe about the ultimate nature of reality will influence how we think about sexuality and what kind of practices are encouraged or forbidden.”³

Being prepared to enable a disabled man to buy women's shoes incurs huge personal conflict. Carers can choose to avoid the public reaction by refusing to take him. In their professional role as the provider of a disabled person's needs for care and support, carers can choose to ignore needs. But would a severely disabled man, dependent on others for his daily life-needs to be met, make a complaint about their refusal to take him shopping? Agreement means to stand by him, to witness and be a part of the stares, the expressions of horror, the sly grins, towards a male wheelchair user. It means to override one's own feelings and possible prejudice for the sake of another. As a Christian, it provides an opportunity to be touched by the loving compassion of our Lord in standing by another in their ridicule. In the particular example cited, it was part of enabling a confused man to find his real masculinity and sexual identity through the journey that many of us have been free to explore during childhood and adolescence.

My own experience suggests that where carers are enabled to share the daily experience of caring for disabled people in an environment of trust, where their commitment and desire to recognise and meet the needs of disabled people can be acknowledged, then the expression of their faith in God is developed in the light of their experience and relationship with the disabled people to whom they provide care and support. Talking

NOTES

1. James Overboe, “Difference in Itself: Validating Disabled People's Lived Experience”, *Body & Society* 5.4 (1999), pp. 17–19.
2. Rowan Williams, *Lost Icons: Reflections on Cultural Bereavement* (Edinburgh: T&T Clark, 2000), p. 149.
3. Morton Kelsey and Barbara Kelsey, *Sacrament of Sexuality* (Rockport, MA: Element Books, 1991), p. 45.
4. Robert Murphy, *The Body Silent* (London: Phoenix House, 1987), p. 83.

with professional carers, enabling them to voice their real care and concerns, can elicit some unexpected and poignant experiences.

Sadly, the wider Church is not united or indeed that compassionate about the quality of sexual relationships, which exist outside of the standard of lifelong committed relationship of one man to one woman, within a legally recognised marriage. Within residential care homes, many carers have seen it as their professional duty, re-enforced and encouraged by the views of parents, to protect the “innocence” of disabled people from any acknowledgement of their sexual identity. Robert Murphy, a disabled writer finds: “The sexual problems of the disabled are aggravated by a widespread view that they are either malignantly sexual, like libidinous dwarfs, or more commonly, completely asexual, an attribute frequently applied to the elderly as well.”⁴

However, whatever outside agencies’ perceptions are of disabled people and the questioned reality of their wholeness as sexual human beings, working in the context of a Christian organisation, I find that professional carers are prepared to struggle with all their own preconceptions, with the bombardment of media influence, with the current focus on service user’s rights and with all that it means to be an employee.

If the gospel message is about the redeeming love of God as shown through the life of Jesus rather than the legalism of good works, the only answer in the face of deep and complex human needs is to seek God’s grace. We constantly need to ask him to give us the love and compassion that on our own we cannot contrive. It is to see Jesus in the humanity of another human being. It is to be prepared to allow him to transform our expression of faith through our experience of coming alongside another. As Henri Nouwen found, living in the L’Arche Community, spiritual brokenness can be healed in the presence of and relationship with people usually marginalised and disregarded by society. It is to recognise and embrace that we are all made in the image of God, with all that it means to be a human being, whatever our level of impairment. ■