The sexual health needs of people with learning disabilities

Paul Cambridge, BA, *is senior lecturer in learning disability, Tizard Centre, University of Kent at Canterbury*

People with learning disabilities tend to rely on specialist sex and safer sex education, as social and economic exclusion often makes it difficult for them to access sexual health information and services. Paul Cambridge explores the strategies required to enable people with learning disabilities to lead healthier sexual lives

KEY WORDS

Learning disability
Sexual behaviour
Sexually transmitted infections

The sexual health of people with learning disabilities raises important management and practice issues for health services, and should be examined in the context of the current policy emphasis on advocacy, person-centred services and social inclusion (Department of Health, 2001).

People with learning disabilities may have limited access to mainstream health services, and sexual health and genitourinary medicine (GUM) services are no exception (DoH, 2001; 1998). They are often excluded from society, either because they are 'segregated' within specialist support services in the community or because they live in isolation with carers, and health and social care models do not always join up locally to meet their needs.

Although there are some excellent sex and safer sex education initiatives and resources for people with learning disabilities, such interventions may be poorly developed and evaluated.

Acknowledging diversity In general, sexuality and sexual health initiatives and resources for people with learning disabilities have failed to address the realities of HIV risk in the context of homosexuality or, indeed, heterosexuality and gender. Mainstream sexual health and health promotion activities in the mid-1990s tended to de-homosexualise HIV, and men with learning disabilities who have sex with men have been particularly disadvantaged by this change (Cambridge, 1997a).

Evidence suggests that sex between men with learning disabilities and other men is a relatively common behaviour (Cambridge and Mellan, 2000; McCarthy, 1999). The risks of HIV are exacerbated by the fact that many men with learning disabilities who have sex with other men do not identify themselves as being gay. They are therefore likely to be excluded from formal and informal safer sex education.

Of even greater concern is evidence that many men with learning disabilities who have sex with men are also likely to be having sex with women and men with learning disabilities (Cambridge, 1996). A resource pack on HIV, sex and learning disability (Cambridge, 1997b) has been produced in response to this.

It is important to consider the politics of disability and the social and political disadvantages learning disability brings. The reality is that those who are least powerful in society are the most economically disadvantaged, disempowered and excluded. Collectively, these factors mean that both women and men with learning disabilities are at greater risk of HIV infection than other groups.

Factors contributing to HIV risk include limited access to sexual health information and resources, and a reduced capacity to translate knowledge into safer sex practice. It is, for example, evident that people with learning disabilities from minority ethnic groups are likely to be doubly disadvantaged by virtue of culture or language. More broadly, religion can also influence attitudes to sexuality and condom use by people with learning disabilities (Malhotra and Mellan, 1996).

This picture of disadvantage is supported by sex education work with people with mild to moderate learning disabilities (McCarthy and Thompson, 1994). Despite understanding the issues surrounding safer sex and HIV risk, and being able to articulate this and demonstrate how and when to use a condom, it is frequently reported that safer sex is not practised in real life sexual encounters.

This knowledge-practice gap consequently puts people with learning disabilities at increased risk. Contributory factors include low self-esteem, poor negotiating skills, language and communication difficulties, and acquiescence. Together, these factors often mean that women and men with learning disabilities end up in unsafe situations, for example, having receptive vaginal or anal sex that is unprotected. This may also occur in circumstances where personal safety is compromised.

Consent Critical consideration should be given to capacity to consent (Dye et al, 2003; Wheeler, 2003) and, although outside the remit of this article, consent should be central to safer sex education. The nature of learning disability varies among individuals, as do their sexual lives and experiences, and therefore the capability to respond individually in sex education groups as well as in one-to-one sessions is crucial. For example, people with profound and multiple learning disabilities, autism or challenging behaviours may interact with others and their environments in very different ways and require very different educational responses (Stewart, 1997; Downs and Craft, 1996).

In some cases, this aspect of the person's life will be 'hidden', and the professional will need to develop the trust essential for safe disclosure. Examples include men with learning disabilities who have sex with men, and women with learning disabilities who sell sex.

Both behaviours are, of course, also linked to a high-risk of sexually transmitted infections (STIs) and HIV (McCarthy, 1999). There are also issues of personal safety, as sex may happen in places such as public toilets, where assault and arrest are more likely. Women with learning disabilities who sell sex may also be vulnerable to exploitation.

REFERENCES

Cambridge, P. (1996) Men with learning disabilities who have sex with men in public places: mapping the needs of services and users in south east London. *Journal of Intellectual Disability Research;* 40: 241–251.

Cambridge, P. (1997a) How far to gay? The politics of HIV in learning disability. *Disability and Society;* 12: 3, 427–453.

Cambridge, P. (1997b) *HIV, Sex and Learning Disability: A staff training and sex education resource for working on HIV and with men with learning disabilities who have sex with men. Brighton:* Pavilion.

Cambridge, P., Carnaby, S. (2000) *Making it Personal: Providing intimate and personal care for people with learning disabilities.* Brighton: Pavilion.

Cambridge, P., Mellan, B. (2000) Reconstructing the sexuality of men with learning disabilities: empirical evidence and theoretical interpretations of need. *Disability and Society;* 15: 2, 293–311.

Department of Health (2001) *Valuing People: A new strategy for learning disability for the 21st century.* London: DoH.

At the other end of the continuum of dependency may be someone who relies on staff for intimate and personal care, and who would benefit from understanding the differences in types of touch, consent to touch and the significance of gender in caring relationships (Cambridge and Carnaby, 2000). Moreover, it should be recognised that all people with learning disabilities, regardless of severity, are vulnerable to sexual abuse and exploitation and, consequently, at risk of STIs.

Testing for STIs Informed consent to have an HIV test is likely to be more difficult to ascertain in a person with a learning disability, who may be less able to make the link between sexual behaviour that places them at risk of infection, long-term consequences and the need for drugs or medical treatment.

What is evident is that the perceived interests of services for people with learning disabilities are often at odds with the interests and rights of service users, and this is reflected in the conflict between protection and empowerment. In extreme cases, this has resulted in restrictive and punitive interventions, which are difficult to defend ethically, and are illegal. While HIV risk management raises various legal considerations (Gunn, 1997), it is central to the issue of human rights in sexual health provision (Keywood, 2003).

Considerations for practice Evidence from sex and safer sex education, clinical and therapeutic interventions and research suggests a number of considerations for sexual health promotion work with people with learning disabilities.

Matching the educator to the person's gender, culture, race or sexuality is important. For example, in providing safer sex education for men with learning disabilities who have sex with men, it is important that the health professional understands their feelings and experiences, the nature of homosexuality, types of sex and where sex can happen. All educators need to be able to identify with the person and their behaviour, and respond in a positive and constructive way.

Same-sex education groups are an important starting point (unless there is a specific reason for teaching mixed groups). The need for longer-term work, and the links between group and individual work should be acknowledged. Many people with learning disabilities will only benefit from sustained and consistent support in a safe environment and trusting relationship. Education about the body and sex should also be available for children with learning disabilities (Stewart, 1997).

The accuracy and simplicity of the message is another key consideration, which is why many sex educators in learning disability use line drawings and simple video portrayals. Many also focus on the most unsafe sexual behaviours and relate this to HIV, such as receptive and insertive anal and vaginal sex, rather than oral sex.

However, given the rapid increase in the prevalence of STIs, such as syphilis, chlamydia and antibiotic-resistant strains of gonorrhoea among gay men, educational strategies and individual advice require ongoing review.

Plain language and unambiguous images of unsafe and safer sex should be used, and cultural appropriateness considered – for example, a white European image may not be appropriate.

It is essential to recognise and respond to the realities of the lives of people with learning disabilities. Most women with learning disabilities report that they do not enjoy sex with men, either with or without learning disabilities, that they often experience anal sex and that this is usually unprotected (McCarthy, 1999).

They put up with this because they value the status a relationship brings. Many women with learning disabilities have a poor self-image and body image (McCarthy, 1998), which is also an important focus for safer sex education.

Conversely, many men with learning disabilities who have unsafe sex with men without learning disabilities report that this is 'good' and enjoyable, although a feeling of a lack of control is greater than when sex is with a woman with learning disabilities (Thompson, 2001). The challenge is to promote a positive and assertive homosexual identity in the context of safer sex and choice (Edmonds and Collins, 1999).

Conclusion The sexual experiences of people with learning disabilities should inform the baseline to safer sex education work and support aimed at empowering this group to develop positive sexual identities and safer sexual behaviours (Johnson et al, 2002).

Perhaps one of the greatest challenges is to bridge the sexual health gap between mainstream heath promotion activities and GUM services, on the one hand, and specialist sex education and sexual health work in learning disabilities, on the other. Both need to be integrated at a local level.

More radical approaches include introducing gay advocates or outreach workers for men with learning disabilities who have sex with men, education for women who sell sex, and targeted sexual health outreach projects. Developing wider networks of support in the community will also promote the sexual health of people with learning disabilities, their social inclusion and sexual rights. ■

REFERENCES

Department of Health (1998) *Signposts for Success in Commissioning and Providing Health Services for People with Learning Disabilities.* London: DoH.

Downs, C., Craft, A. (1996) Sexuality and profound and multiple impairment. *Tizard Learning Disability Review;* 1: 4, 17–22.

Dye, L. et al (2003) Factors impacting on the capacity to consent in people with learning disabilities. *Tizard Learning Disability Review*; 8: 3, 11–20.

Edmonds, C., Collins, A. (1999) Using social and educational approaches to enable a man with learning disabilities to develop his sexual identity and orientation. *British Journal of Learning Disabilities;* 27: 4, 127–131.

Gunn, M. (1997) *The law, HIV and people with learning disabilities.* In: Cambridge, P., Brown, H. (eds) HIV and Learning Disability. Kidderminster: British Institute of Learning Disability.

Johnson, K. et al (2002) Living safer sexual lives: research and action. *Tizard Learning Disability Review;* 7: 3, 4–9.

Keywood, K. (2003) Supported to be sexual? Developing sexual rights for people with learning disabilities. *Tizard Learning Disability Review*; 8: 3, 30–36.

Malhotra, S., Mellan, B. (1996) Culture and race issues in sexuality work with people with learning disabilities. *Tizard Learning Disability Review;* 1: 4, 7–12.

McCarthy, M. (1999) *Sexuality and Women with Learning Disabilities.* London: Jessica Kingsley.

McCarthy, M. (1998) Whose body is it anyway? Pressures and control for women with learning disabilities. *Disability and Society;* 13: 4, 557–574.

McCarthy, M., Thompson, D. (1994) *HIV/AIDS and safer sex work with people with learning disabilities.* In: Craft, A. (ed) Practice Issues in Sexuality and Learning Disabilities. London: Routledge.

Stewart, D. (1997) *Sex education for students with severe learning disabilities.* In: Cambridge, P., Brown, H. (eds) HIV and Learning Disability. Kidderminster: British Institute of Learning Disability.

Thompson, D. (2001) Is sex a good thing for men with learning disabilities? *Tizard Learning Disability Review;* 6: 1, 4–12.

Wheeler, P. (2003) Criminal law,