Challenges for safer sex education and HIV prevention in services for people with intellectual disabilities in Britain

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SUMMARY
This paper reviews progress and competence in HIV prevention work for people with intellectual disabilities in Britain. It identifies key challenges for specialist residential support and sex education services for people with intellectual disabilities, as well as for mainstream health promotion services. The discussion is informed by research and practice evidence and explores ways to develop competence in safer sex education, offering suggestions for HIV risk assessment and risk management. While the paper demonstrates that the politics of sexuality and HIV are difficult for services to manage, the rights of people with intellectual disabilities to information and support for sexuality and sexual health should be put first.

Key words: HIV; prevention; sex education

INTRODUCTION

For too long, support services for people with intellectual disabilities have failed to respond adequately or effectively to sexuality and personal relationships and this is now reflected in responses to HIV and AIDS. ‘Normalisation’ and ‘Social Role Valorisation’ (Wolfensberger, 1980, 1984) and related principles such as ‘An Ordinary Life’ (King’s Fund, 1980) and the Five Accomplishments (O’Brien, 1987) have provided philosophical and practical direction in services for people with intellectual disabilities, valuing people with intellectual disabilities as equal citizens and highlighting their rights to community integration and participation. Conversely, they have been less robust in incorporating and responding to the diverse and often exploitative sexual realities experienced by people with intellectual disabilities (Brown and Smith, 1992). Research has demonstrated the high incidence of sexual abuse of people with intellectual disabilities (Turk and Brown, 1993; Brown et al., 1995) and the high risks of HIV infection for some men with intellectual disabilities (Cambridge, 1996a). Sex education has highlighted the special and ordinary needs of women and men with intellectual disabilities concerning mutuality, negotiation and consent (McCarthy, 1994; Thompson, 1994). The task facing services for people with intellectual disabilities is to respond in effective and valued ways to a diverse sexual reality and to the sexual disadvantage experienced by people with intellectual disabilities. Such questions are highlighted by the challenges posed by HIV and AIDS.

OVERVIEW

Until relatively recently, a structured approach to sex education had been lacking for people with intellectual disabilities. Attitudes changed with the pioneering work of Ann Craft and colleagues (Brown, 1980, 1987; Craft, 1983, 1987, 1991; Dixon, 1991), which recognised that people with intellectual disabilities had a right to sexuality and sexual expression. People with intellectual
disabilities had traditionally been denied the right to sexual expression or relationships, being perceived as perpetual children who did not need to know about sex, or, as dangerous, because they were unable to control their sexuality (Kempton, 1982). The pathological view of sexuality and intellectual disability is one where risk management means excluding people with intellectual disabilities from sexual opportunities and policing rather than supporting sexuality. Such aversive views were rife in institutions with their congregate and segregated environments, but isolation in the community can also lead to neglect, sexual abuse and exploitation. Negative attitudes to the sexuality of people with intellectual disabilities still remain and show up in a failure to recognise and respond adequately to issues such as contraception, parenting, homosexuality between men and combating the risks posed by HIV and AIDS.

Staff and carers often comment that people with intellectual disabilities need protecting from sexual risks, such as HIV infection, without acknowledging their sexual rights and responsibilities and the alternatives of knowledge and empowerment. Service users will be reluctant to disclose sexual behaviours for which they have been penalised in the past or which they have been socialised into thinking are wrong. A collection of sexual behaviours have been labelled as challenging, such as masturbation in a public place, homosexuality, sex for money or in a public place, without guidance to appropriate sexual expression, such as masturbation in a private place, consenting same-sex relationships or work on self-esteem (Cambridge, 1997a). Articulating the rights and responsibilities of service users and the responsibilities of support services (McCarthy and Cambridge, 1996; Cambridge, 1996b) can help identify and address conflicting attitudes between carers, relatives and support staff, and provide for consistent educational responses developed from a recognition of the rights of service users to safer sexual expression. The development of policies on HIV in services for people with intellectual disabilities (Cambridge, 1997b) can similarly set a standard for HIV risk assessment and risk management responses. Peer education and self-advocacy (see, for example, People First, 1994; Lawnmowers, 1994; Barber and Redfern, 1997) also offer a way forward and can help mend the neglect and damage inflicted by a pathological view of intellectual disability and sexuality by a therapeutic approach:

The threat of annihilation experienced by people with learning disabilities has particular significance for the responses of people working with them, especially in the field of sexual health counseling and psychotherapy. . . . Several of my clients in their weekly psychotherapy sessions talked about this and revealed how aware they were about the wish of many in society to eradicate difference which manifests in the form of handicap. (Morris, 1997)

The overwhelming impression when undertaking sex education in an individual or group context is of the silence and guilt of people with intellectual disabilities about sex. Masturbation is usually seen as a bad thing and homosexuality between men, although known to be a common behaviour (Thompson, 1994; Cambridge, 1994) is usually denied, whereas abusive sex with women with intellectual disabilities is more readily admitted (Brown and Thompson, 1997). The risk of HIV has also helped reinforce a pathological view of sex between men with intellectual disabilities as well as homosexuality more widely (Cambridge, 1996c). This is mirrored in issues of gender. The sexual realities experienced by women with intellectual disabilities related through sex education, indicate that they often experience sex as something done to them and which hurts but which they tolerate for the sake of the contact or relationship (McCarthy, 1994, 1997).

Such considerations raise questions about the abuse and exploitation, and responses to sexual abuse can help inform responses to HIV risk. The work of Hilary Brown and colleagues (Turk and Brown, 1993; Brown et al., 1995) has helped demonstrate the lack of power and control many people with intellectual disabilities have over their lives. The findings of such work have fed through to inform service responses and are increasingly recognised in policies and guidelines on sexuality and sexual abuse, often developed on an inter-agency basis (Greenwich Social Services Department, 1993).

Informed or valid consent to sex can be assessed using the model provided by Turk and Brown (1993). This asserts that sex is abusive if the person:

(i) did not consent (even if they were in an ongoing sexual relationship);
(ii) could not consent (this might be because they could not understand what was being
asked or had little or no expressive communication to be able to say no or let their feelings be known; or
(iii) was pressured into consenting (by a figure of power or authority, be it a familial or caregiving relationship, or with force or threat, such as pressures or bribes).

The last point is critical because many people with intellectual disabilities have been socialised into acquiescence. They may also find it difficult to make sense of what has happened to them or appreciate the consequences of particular sexual behaviours. An assessment of the implications of having sex also makes this model helpful for ascertaining informed consent in relation to HIV risk and provides a factor for helping assess informed consent for an HIV test (Cambridge, 1996c).

Sex education work has also indicated high levels of abusive and non-consenting sex experienced by women and some men with intellectual disabilities from more able men with intellectual disabilities (McCarthy and Thompson, 1996). One of the tasks of sex education is to help people understand the possible consequences of saying yes to sex, give them the assertiveness to say no to sex they don’t like, help them obtain and negotiate the use of condoms or provide the language required to disclose sexual abuse or high-HIV-risk behaviours.

The social care market and mixed economy of service provision in Britain has imperfections (Wistow et al., 1994) and also brings disincentives for best practice in sexual health and intellectual disability. Consequently, it has been observed that good inter-agency working and the incorporation of sexual health in market management and quality control is needed to develop sexual health promotion services for people with intellectual disabilities:

there are likely to be longer term and more peripheral considerations relating to the impact of . . . policy on the wider service system and market. These include the relationship between service commissioning and providing, such as quality audit, inspection, contract specification and performance monitoring, liaison with other agencies and providers and input to joint working through community care planning and to care management through assessment and individual service planning. (Cambridge and McCarthy, 1997)

Service commissioners have a responsibility to develop mainstream competence in sex and safer sex education in support services for people with intellectual disabilities. This requires initiatives which address sexuality through the contract or by broader collaboration with service providers in developing policy and practice guidelines (see Cambridge and McCarthy, 1997, for a case study of issues and process). Commissioners should also specify and develop specialist services in sexuality and intellectual disability, such as counselling, therapeutic interventions and dedicated sex education services. These should be free to providers or service users with access based on need, funded by top-slicing the general intellectual disability (or health promotion) budgets as a way to circumvent market disincentives. This is a similar model to the operation of the ‘Sex Education Team’ (originally at NW Hertfordshire Health Promotion Unit, but now Horizon NHS—intellectual disability—Trust) (McCarthy and Thompson, 1994). Services are provided at no direct cost to recipients and regardless of agency or sector (although staff training is charged for), but are unable to reach out beyond their area. In contrast with this is the market model of ‘Respond’ in London (Morris, 1997), which grew from the work of committed individuals who saw the need for counselling and therapeutic interventions within a safe space. It charges for its services on a commercial basis, although local commissioners have funded projects such as sexual health outreach (see Cambridge, 1996d).

CHALLENGES FOR SAFER SEX EDUCATION

Recognising HIV risk

With the benefit of hindsight one can only conclude that the de-homosexualisation of AIDS has led directly to the marginalisation of gay mens’ unparalleled experience and contributions to fighting the epidemic and has ultimately exacerbated the harmful effects of the epidemic on those most at risk. (King, 1993)

King was arguing for the re-homosexualisation of AIDS in recognition that between 60 and 70% of those affected by HIV and AIDS in Britain (reported cases of AIDS and known HIV infections) are gay men or men who have sex with men. The latter include men with intellectual disabilities, and there is direct and indirect evidence to support this observation.

Sexual health outreach work (Jones, 1993) has identified men with intellectual disabilities who
‘cottage’ (have sex with men in public toilets), and mainstream sexual health needs assessment (Taylor-Laybourn and Aggleton, 1992) identified HIV risk to young men with intellectual disabilities. Needs assessment in HIV and intellectual disability in SE London (Cambridge, 1996a), identified high-HIV-risk sexual behaviours of men with intellectual disabilities, with deficits in staff training and educational interventions. Sex education work (McCarthy and Thompson, 1994) provides evidence of HIV risk behaviours and poor knowledge and practice of safer sex, and the experience of specialist services working with men at risk of HIV and exploitation (Morris, 1997) also indicates high HIV risk, along with sexual health outreach projects in intellectual disability (Cambridge, 1996d).

Although little is known about the epidemiology of HIV infection in the population of people of intellectual disabilities (Simonds and Rogers, 1992), there is evidence that people with intellectual disabilities have become infected with HIV (Kastner et al., 1989, 1992; Marchetti et al., 1990). The reality and location of HIV risk in the population of people with intellectual disabilities therefore needs to be recognised when prioritising and targeting HIV prevention and safer sexual health outreach projects in intellectual disability (Cambridge, 1996d).

Representing homosexuality

HIV prevention programs are bedeviled [sic] by their own success. There is no praise for seroconversions that do not happen, for lives saved or communities protected. The reward for success is, rather, to be accused of scare-mongering, of demanding special treatment, of foisting a gay liberationist agenda in the guise of health promotion. (Davies et al., 1993, p. 173)

Davies et al. (1993), identified the political difficulties associated with HIV prevention activities. A related problem in arguing for sexual health promotion initiatives in intellectual disability is that relatively expensive and continuing educational campaigns carry longer-term benefits which are likely to impact on the budgets of other agencies or interests, such as the NHS or GP fundholders.

Cambridge (1996c, 1997c) references the absence of images or reference to homosexuality in most early sex educational materials produced for people with intellectual disabilities (Craft, 1991; Dixon, 1991) and the marginal representation of homosexuality in relation to safer sex, despite evidence of where HIV risk lies (McCarthy and Thompson, 1992). The video resources available are better, but poorly target HIV risk. My Choice, My Own Choice [South East London Health Promotion Service (SELHPS), 1992], follows ‘Eileen’ through a week in her life, using actors with intellectual disabilities. It focuses on personal and social relationships and their social context. Two gay men with intellectual disabilities act as role models, but it needs to be added that most men with intellectual disabilities who have sex with men are not gay-identified (Thompson, 1994).

Piece by Piece [West London Health Promotion Agency (WLHPA), 1994], uses large puppets. It has sequences on social context, personal hygiene, heterosexual sex, sex between two men and sex between two women. There is an explicit representation of a vagina and penetrative sex in the heterosexual sequence, with the use of condoms demonstrated, but pretend penetrative sex and avoidance of representing the anus for the homosexual sequence. The Australia video, Feeling Sexy, Feeling Safe [Family Planning Association of New South Wales (FPANSW), 1993] uses actors for representing homosexual and heterosexual sex, but the former sequences are less explicit although positive in image. A major challenge for HIV prevention in intellectual disability is to construct accurate and valued images of homosexuality and safer sex. This was one of the aims of a specialist safer sex education resource for men with intellectual disabilities (Cambridge, 1997a). Without these, safer sex education in intellectual disability will continue to mis-target high HIV risk.

Sexual identity and behaviour

Post-Normalisation critiques are needed to determine interventions and support grounded in the diverse sexual realities experienced by people with intellectual disabilities. Adopting a feminist discourse on power and people with intellectual disabilities, Brown and Smith (1992) acknowledge the failure of Normalisation to recognise structural inequalities:
The difficulties of implementing high quality services for people with intellectual disabilities are not just practical, as is often suggested, but may be rooted in the theory’s [Normalisation’s] failure to address alternative routes to empowerment for groups of people who, for different reasons and with different consequences, find themselves living on the margins. (Brown and Smith, 1992, p. 149)

Most men with intellectual disabilities who have sex with men do not have a gay identity (Thompson, 1994, 1997; Cambridge 1994, 1996c) and remain isolated compared with the political and social identities lesbians, bisexuals and gay men have constructed through self-organisation and political action. There are important differences between homosexual behaviours, homosexual identities and homosexual lifestyles (Richardson, 1981) and it has been argued that homosexual identity was a construct of the lesbian and gay liberation movement, which succeeded in establishing the concepts of homophobia and heterosexism (Cruikshank, 1992). This forced the shift from defensive to offensive politics which is continuing in relation to the fight against AIDS.

Yet the value of uniform sexual identities has been questioned from the viewpoint of cultural and ethnic diversity and increasing gender conflict (Seidman, 1993), and this post-modern interpretation could be extended to encompass the sexualities of people with intellectual disabilities which cannot readily be described as heterosexual or properly defined as lesbian, gay or bisexual. Moreover, families of people with intellectual disabilities from cultural, ethnic or religious minorities may not accept homosexuality or will associate the use of condoms with contraception, raising dilemmas for services and sex education (Malhotra and Mellan, 1996). The issues associated with the development of gay and lesbian identities by people with intellectual disabilities are only beginning to be explored (Corbett, 1994; Davidson-Paine and Corbett, 1995). One of the reasons advocacy and peer sex education services in intellectual disability have been limited is because of a lack of common identity, although outreach and befriending projects by gay men may help to explore the productivity of such links.

**Reality and explicitness of image**

Safer sex is viewed as unerotic or unexciting by many people. To maximise the impact of safer sex information it is clearly necessary to move from communicating about sex as a biomedical issue, to a position where safer sex is presented in explicit and erotic ways . . . to emphasise the erotic potential of safer sex. (Deverell and Rooney, 1994, p. 7)

The use of erotic images in the context of safer sex education for gay men and other groups consequently raises a challenge for sex education and HIV prevention work with men with intellectual disabilities. While eroticism is a rational strategy for sexual health promotion for gay men (Deverell and Rooney, 1994), safer sex education in intellectual disability and for other groups such as young people works to different demands and using eroticism could lead to the safer sex message being misread or the educator could find the material offensive. Images need to be accurate but also culturally appropriate, reflecting the reality of the sexual experiences of people with intellectual disabilities and their identity. What is culturally appropriate to gay men may not be to men with intellectual disabilities who have sex with men.

Ideally, sex educators and sex education resources should also use people’s own words or language they understand and are comfortable with, not those most acceptable to educationalists or professionals working in services. The latter has often predominated, with practitioners using medical terms which are alien to people with intellectual disabilities. This tendency remains discernible in some sex educational resources (FPANSW, 1993), while others use direct and plain language (SELHPS, 1992; Cambridge, 1996e, 1997a), which is particularly important for clarity about HIV risk behaviours and safer sex. Messages such as ‘avoid the exchange of body fluids’ or ‘use protection for penetrative sex’ are meaningless for people with intellectual disabilities who do not have good receptive verbal communication.

**Complexity of message**

The simplicity-versus-complexity debate, although evident in all HIV prevention and safer sex education work, is particularly pertinent for work in intellectual disability. Such resources in Britain have tended to prioritise safer sex messages for penetrative anal and vaginal sex (McCarthy and Thompson, 1992; SELHPS, 1992) whereas others, such as in Australia (FPANSW, 1993), provide consistent messages about using condoms for oral as well as anal or vaginal sex. In helping find solutions, we need to
consider the standards we set for people with intellectual disabilities in relation to wider norms in HIV risk behaviour. While protection from HIV infection is also a priority for people with intellectual disabilities, they also need to be empowered to make more informed choices about the practice of safer sex, part of which is choice about taking lower-order risks such as those associated with unprotected oral sex.

Parallel considerations are apparent in relation to explaining the differences between HIV and AIDS. For some people, the temptation may be to simply link unsafe sex with death, but this is potentially dangerous for many people with intellectual disabilities. If they have unsafe sex and are well weeks later the impact of the message could be diluted. The fear and guilt generated could also exert a form of aversive control. Moreover, it is difficult to envisage informed consent for an HIV antibody test without a basic understanding of the differences between HIV and AIDS and the implications of being HIV negative or positive (Cambridge, 1996c). Similar arguments need to be addressed to reinforce responsibilities to others who may be less able or powerful, and a basic knowledge of how HIV is transmitted and causes AIDS is needed to achieve this—a particularly pertinent point considering that it is often the most able and mobile men with intellectual disabilities who are at the highest risk of HIV infection and who may have a number of sexual partners outside and within services (Cambridge, 1996a).

CONCLUSIONS

There is a risk that the above agenda will appear radical and uncompromising, but research, policy development and staff training activities identify the critical need to acknowledge and respond to the sexual health needs of people with intellectual disabilities in ways grounded in the realities of their sexual lives and experiences. Sexuality and sexual health can act as a catalyst for wider personal and political issues and have the potential to generate conflicts of interest within and outside services for people with intellectual disabilities. Staff attitudes and personal experiences combine to make work in sexuality and HIV particularly challenging in services, with new agendas emerging in relation to ethnicity and culture (Senker, 1997). In addition, we are only beginning to develop techniques for working on sexuality with people with severe intellectual disabilities or challenging behaviours who are usually excluded from opportunities for group or individual sex education (Downs and Craft, 1997).

Many parents have had a long battle protecting their children from discrimination and fighting for better services, but concern needs to be balanced with personal development and protection balanced with encouraging independence. Good services should tackle issues of sexuality and the risks which go with sexual activity through policies, procedures and individual programmes (Cambridge, 1997b). There is legal as well as social discrimination against gay men and homosexuality in many Western countries and this will directly impact upon the quality of support men with intellectual disabilities who have sex with men will receive and, hence, the effectiveness of HIV prevention work. Moreover, there remain special laws which apply to the sexuality of people with intellectual disabilities generally (Gunn, 1996) and potential legal considerations in relation to HIV risk management in particular (also, see Gunn, 1997, for an articulation of these considerations in relation to English law). HIV risk management in services will need the capacity to respond to these demands whilst recognising the sexual rights of people with intellectual disabilities (Cambridge, 1996b). The duty of care of services to protect users from undue risk, including that of HIV infection, requires careful prioritisation in relation to rights (Cambridge, 1997b). Moreover, the risk assessment skills needed to formulate risk management responses depend on a depth of knowledge and understanding grounded in a respect for service users and minority sexual behaviours which may also be of high HIV risk. Developing such a culture in services or staff teams will require intensive management intervention (Davies, 1997), which is costly for many services to construct.

Fighting HIV and AIDS requires an openness and honesty about sexuality and a supportive non-judgemental approach in intellectual disability. This needs to be reflected in the nature and content of safer sex educational and staff training resources, effectively targeted on HIV risk and the social and sexual realities experienced by people with intellectual disabilities.
REFERENCES


**HIV prevention for people with intellectual disabilities**


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