



Kent Academic Repository

Cambridge, Paul (2012) *Promoting rights and protecting vulnerabilities and people with learning disabilities: developing evidence based practice and policy in sexuality and adult protection*. Doctor of Philosophy (PhD) thesis, University of Kent.

Downloaded from

<https://kar.kent.ac.uk/94256/> The University of Kent's Academic Repository KAR

The version of record is available from

<https://doi.org/10.22024/UniKent/01.02.94256>

This document version

UNSPECIFIED

DOI for this version

Licence for this version

CC BY-NC-ND (Attribution-NonCommercial-NoDerivatives)

Additional information

This thesis has been digitised by EThOS, the British Library digitisation service, for purposes of preservation and dissemination. It was uploaded to KAR on 25 April 2022 in order to hold its content and record within University of Kent systems. It is available Open Access using a Creative Commons Attribution, Non-commercial, No Derivatives (<https://creativecommons.org/licenses/by-nc-nd/4.0/>) licence so that the thesis and its author, can benefit from opportunities for increased readership and citation. This was done in line with University of Kent policies (<https://www.kent.ac.uk/is/strategy/docs/Kent%20Open%20Access%20policy.pdf>). If you ...

Versions of research works

Versions of Record

If this version is the version of record, it is the same as the published version available on the publisher's web site. Cite as the published version.

Author Accepted Manuscripts

If this document is identified as the Author Accepted Manuscript it is the version after peer review but before type setting, copy editing or publisher branding. Cite as Surname, Initial. (Year) 'Title of article'. To be published in *Title of Journal*, Volume and issue numbers [peer-reviewed accepted version]. Available at: DOI or URL (Accessed: date).

Enquiries

If you have questions about this document contact ResearchSupport@kent.ac.uk. Please include the URL of the record in KAR. If you believe that your, or a third party's rights have been compromised through this document please see our [Take Down policy](https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies) (available from <https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies>).

**Promoting Rights and Protecting Vulnerabilities
and People with Learning Disabilities: Developing
Evidence Based Practice and Policy in Sexuality
and Adult Protection**

Volume 1

Section 1: Summary and Supporting Statement

**Section 2: Sexuality and Learning Disability with a focus on Men with
Learning Disabilities - Commentary on Exhibited Material (Appendix 1)**

Paul Cambridge BA

Senior Lecturer in Social Work

University of Kent at Medway

Submission for the Degree of Doctor of Philosophy in Social Work under

Staff Regulations

School of Social Policy, Sociology and Social Research

University of Kent

March 2012



F 225648

This PhD is dedicated to my mother, Marjorie Betty Jordan (née Spratt) who was born in the village of Stockbury in Kent on 22 May 1914 and died in Pilgrims Hospice in Margate on 5 April 2000. She continues to be an inspiration for me morally and emotionally.

Acknowledgements

I would like to thank my supervisors Alisoun Milne and Sarah Vickerstaff from the School of Social Policy, Sociology and Social Research for their guidance and support, Kim Robinson for her encouragement in getting me going and Chris Hale for supporting and facilitating this submission.

I also owe a debt of thanks to my partner David Carter and our close friend Paul Sims for their positive encouragement and tolerance of my moods.

ABSTRACT

This thesis examines components of my research and published work in sexuality and adult protection and the connections between them in the context of policy, management and practice in services and support for people with learning disabilities. The first section of my thesis on sexuality focuses on HIV, homosexuality and the sexuality of men with learning disabilities. Using a mix of quantitative research and interpretative analysis I examine HIV risk management in services for people with learning disabilities, finding a lack visibility and recognition for the needs and experiences of men with learning disabilities who have sex with men. The accounts and exhibits provided also chart the development of specialist sex and safer-sex educational resources designed to address this neglect, with my wider work on the development and implementation of sexuality policy used to contextualise and generalise applied learning. Hidden issues such as sexuality in the provision of intimate and personal care are also exposed and a rights based approach to supporting the sexual fetish of men with learning disabilities is articulated. This body of work served to strengthen policy, service management and practice in services for people with learning disabilities by drawing on Queer theory and a radical political discourse on sexuality, masculinity and homosexuality. The second section of my thesis focuses on adult protection and learning disability. I use qualitative data from an inquiry into the abuse of people with learning disabilities to construct a theoretical framework which articulates the characteristics of an abusive culture, strengthening our understanding of the aetiology of abuse in community settings. This is interpreted in the context of theory and practice, including recommendations for service commissioning and providing. Evidence from a quantitative study of adult protection referrals in two local

authorities is also discussed and exhibited. Patterns of risk related to the sexual abuse of people with learning disabilities are identified and discussed, with more general learning for effective adult protection data recording and analysis provided. Experience from adult protection training and qualitative evaluations of the specialist adult protection co-ordinator role and intimate and personal care is also exhibited and discussed, including evidence on the effective targeting of adult protection resources, the conduct of adult protection investigations and the visibility of adult protection in intimate and personal care. This body of work has served to inform national adult protection policy and the enhancement of management and support competence in services for people with learning disabilities. Finally, the conceptual and practice relationships between sexuality and adult protection are explored with observations offered relating to the construction and review of policy and the role of individual person-centred work with people with learning disabilities.

Promoting Rights and Protecting Vulnerabilities and People with Learning Disabilities: Developing Evidence Based Practice and Policy in Sexuality and Adult Protection

CONTENTS

Volume 1

Section 1: Summary and Supporting Statement

- 1.1 Personal Account (page 2)
- 1.2 Rationales and Influences (page 7)
- 1.3 Methods and Approach (page 13)

Section 2: Sexuality and Learning Disability with a focus on Men with Learning Disabilities - Commentary on Exhibited Material (Appendix 1)

- 2.1 Mapping Needs and Developing Theory (page 3)
- 2.2 Using Evidence to Inform Practice (page 9)
- 2.3 Strengthening Service Management and Policy (page 14)

Appendix 1: Exhibited Material for Section 2

Volume 2

Section 3: Adult Abuse and Protection and People with Learning Disabilities – Commentary on Exhibited Material (Appendix 2)

- 3.1 Interpreting Evidence from Inquiry (page 3)
- 3.2 Implementing and Reviewing Policy (page 10)

3.3 Promoting Evidence Based Management and Practice (page 16)

Section 4: Concluding Account and References

4.1 Summary Overview (page 2)

4.2 Personal Reflections (page 8)

4.3 Concluding Observations (page 12)

References (page 17)

Appendix 2: Exhibited Material for Section 3

ABSTRACT

This thesis examines my work in sexuality and adult protection and the connections between these themes in the context of policy, management and practice in services and support for people with learning disabilities. The published work exhibited in this thesis reports and interprets evidence from research and inquiry and experience from training and service development to extend conceptual understanding and identify applied learning. In the area of sexuality (Section 2) I develop a radical rights based perspective which is linked to a radical discourse on homosexuality and in the area of adult protection (Section 3) I construct a theoretical framework from inquiry which is utilised to inform research and the interpretation of research findings. The material exhibited and accompanying discussion therefore explores the connections between these two strands of work – promoting the rights and protecting the vulnerabilities of people with learning disabilities - in what were both political and intellectual campaigns. I chart the genesis, evolution and relationships between these related streams of work and provide an account of how research and publication led to externally facing activities such as staff and management training, contributed to policy development and informed practice innovation including the production of educational resources for people with learning disabilities and individual work with men with learning disabilities. The premise underlying this thesis is that policy should be informed by evidence, demonstration and practice innovation, with individual person-centred work with people with learning disabilities argued to have the capacity to meet the dual objectives of promoting the rights and protecting vulnerabilities.

Section 1: Summary and Supporting Statement

1.1 Personal Account

1.2 Rationales and Influences

1.3 Methods and Approach

This section contextualises this submission in my wider work and publications and locates and connects the different elements of the work exhibited in the main body of this submission (Sections 2 and 3).

1.1. Personal Account

The personal influences on my work in sexuality and adult protection in learning disability, although complex in space and time, can be reduced to three key themes:

Having a family member with a learning disability

My uncle Arthur Spratt, who had Down's syndrome and was severely disabled, was the first person I knew who had what was then called a 'mental handicap'. He moved into Leybourne Grange Hospital near Maidstone following the death of my grandfather in the early 1970s and on the closure of the hospital, was moved to a home care placement on the isle of Sheppey by the *People to People* project. After being admitted to Minster Hospital we were informed by his placement officer that he had eaten a poisonous plant in the carer's garden – an incredulous account given he was unable to feed himself – although the explanation later changed to a serious allergic reaction to medication. Social services refused my request for information on his medication or an allergy test and during a hospital visit his consultant expressed the opinion that Arthur's injuries were consistent with being placed in a scalding hot bath, so I contacted Sheerness police. Arthur died in hospital two weeks later after being in continuous pain. At the inquest the pathologist described him as a '*low grade Mongol*', although the coroner recorded an 'open' verdict.

These events happened before the development of national adult protection policy (*No Secrets*, Department of Health, 2000) and although there was no practice or policy language to contextualise what had happened to my uncle, this experience starkly focused my thinking and attitudes to disability, my understanding of how the abuse and neglect of vulnerable adults occurs and how society de-criminalises offences committed against people with learning disabilities (see Sobsey, 1994 and commentary in Section 3.1).

My sexual identity

My involvement in work on sexuality and learning disability was heavily influenced by my sexual experiences and identity as I have always been 'out' as a Gay man in my employment and dealt with the resultant pressures and opportunities (Weeks, 1990). The first consultancy project I undertook when I joined the Tizard Centre in 1992 was to develop a series of HIV learning sets for learning disability service providers in the south-east. Working closely with South East London Health Promotion Service (SELHPS), I became aware of the location of such HIV prevention work in a radical-humanist model (Nichol, 1997). The most pressing issue at this time, given recent experience with the Gaying of HIV and AIDS by right-wing politicians and the tabloid press in the 1980s (King, 1993), was to develop and provide safer-sex education and support for men with learning disabilities who had sex with men, raising political and support issues paralleling those Gay men were experiencing (King *et al*, 1992). This is the point where the dual emphasis of my work on protection (from HIV and sexual exploitation) and promoting rights (sexual choice, informed consent and autonomy) first emerged, re-emerging as a driving factor in recent individual work with men with learning disabilities (see commentary in Sections 2.2 and 4.2).

My insights into institutionalisation

My uncle lived in what was euphemistically called a *villa*, in the grounds of Leybourne Grange Hospital and although this presented as a *physically* separate space, it occupied the same *social* space as a conventional *ward* in a traditional long-stay hospital block. When visiting him by arrangement, he was invariably wearing a shirt and tie and was cleanly shaven. However, when I called unannounced, he was never wearing his own clothes and was usually unwashed and dishevelled.

I started work as a Research Fellow at the Personal Social Services Research Unit (PSSRU) at the University of Kent in 1986, moving from an in-house Research Officer role with Somerset Social Services. My work for Somerset had included involvement in the closure of the county's three mental handicap hospitals (Sandhill Park near Taunton, Norah Fry in Shepton Mallet and Selwood near Frome) and the development and in-house evaluation of replacement services in the community, facilitated by the transfer of funds from the NHS to local government (see model described in Cambridge *et al*, 1994). The new community services were based on the concept of small group homes in core and cluster networks and although later developed into a supported living model with person-centred planning and individualised communication (Dick and Purvis, 2005), remained aligned with the principles embodied in an *Ordinary Life* (King's Fund, 1980).

Somerset was included as one of the 28 *Care in the Community* pilot demonstration projects and my subsequent work at the PSSRU at the University of Kent which I joined in 1986 as a member of the *Care in the Community* team. The PSSRU held responsibility, under a central grant from the then DHSS, for monitoring and evaluating the Government's *Care in the Community Initiative* (see genesis outlined in Renshaw *et al*, 1988). It was in

this role that I became fascinated with the processes which underpinned the development of effective community based services, later expressed through my interest in care management and macro-organisation (see for example chapters in Knapp *et al*, 1992). The original evaluation (Knapp *et al*, 1994), led to new projects examining outcomes and costs for people with learning disabilities *Five Years On* (Cambridge *et al*, 1994) and for people with learning disabilities and mental health problems *Twelve Years On* (Cambridge *et al*, 2006 for example).

Through this work I observed the association between institutionalised practices and abusive and neglectful cultures, reframed and reinterpreted in my later work in adult abuse and protection (see exhibits and commentary in Section 3). I consequently offer some stark images from Time 1 of just one long-stay mental handicap hospital (see Plates 1 to 3) which in my mind, represent an enduring symbol of the social tyranny exercised towards people with disabilities. They serve to remind us of the ongoing fight to protect the vulnerabilities and promote the rights of people with learning disabilities, now conducted in community settings. This is why I now consider deinstitutionalisation, taken as a whole, the most successful social policy initiative in post-war Britain. The challenge now remains to make people safe in various family and community support settings, a struggle succinctly articulated by the late Kent Ericsson as also being about combating the '*institutions of the mind*' which now serve to limit the rights, freedom and equality of people with learning disabilities (Ericsson, 2005).

Plate 1: Ward blocks at St. Lawrence's Hospital, Caterham, Surrey



Plate 2: Caged walkways at St. Lawrence's Hospital, Caterham, Surrey



Plate 3: Corridor in St.Lawrence's Hospital, Caterham, Surrey.



1.2. Rationales and Influences

The work exhibited in this PhD represents selected outputs from a wider body of research and development in learning disability, framed by individual experience and politics. Despite deinstitutionalisation and the optimism of philosophies related to *An Ordinary Life*, including normalisation and social role valorisation (King's Fund, 1980; Wolfensberger, 1972, 1980 and 1984; Brown and Smith, 1992), people with learning disabilities continue to have

their sexualities regulated and ‘policed’ and experience abuse and neglect. A recent stark reminder of the latter was yet another television exposé of abuse in residential care (BBC 1, 2011 – see commentary in Section 3.1).

The defining values of national learning disability policy are expressed through the language of rights, choice and inclusion (*Valuing People* and *Valuing People Now*, Department of Health, 2001 and 2009a), although a parallel reality is that user-consumers risk becoming commodities in wider contractual relationships (Brown and Cambridge, 1995; Cambridge and Brown, 1997a). The *personalisation agenda* in social care (Department of Health, 2007), through the devices of self-directed support and personal budgets (developed from direct payments – Holman and Collins, 1997; Department of Health, 2004), introduced different patterns of risk for service users (Social Care Institute for Excellence, 2010), including new forms of financial exploitation and abuse (Manthorpe *et al*, 2009). Other policy instruments of community care, including care management and person-centred planning, similarly have the potential to control as well as empower people with learning disabilities (Cambridge, 2008a), with the exclusion of people with profound and multiple learning disabilities (PMLD) even more acute (Mencap, 2003; Mansell, 2010).

It was in this area of research and publication that my awareness of the potential for policy to become corrupted by political expediency first surfaced and my determination to inform policy by research evidence originated. I had described and modelled the micro- and macro-organisation of *Care in the Community* (in chapters 10 and 11 in Knapp *et al*, 1992, developed from an articulation in the *Care in the Community* newsletter, Knapp *et al*, 1990), to later see them, together with the respective advantages and disadvantages I had identified, presented as options in the official implementation guidance

for care management (Department of Health and Social Services Inspectorate, 1991), thus representing a totally inappropriate ‘transfer of learning’.

The period represented by the work exhibited in this submission was also characterised by major landmarks in social care policy reform and the subsequent reshaping and relabeling of the social policy landscape. Significant landmarks included de-institutionalisation and *Care in the Community* (Department of Health and Social Security, 1983), the Griffiths report on community care (Griffiths, 1988) and the 1990 *NHS and Community Care Act* (Department of Health, 1989). These heralded the development of the social care market from the mixed economies of social care characteristic of the 1980s, with new purchaser and commissioner roles for local government social services departments (Le Grand and Bartlett, 1993; Wistow *et al*, 1994; Kendall, 2003). The 1990 NHS and Community Care reforms were followed in less than a decade by increased regulation and market management through the 2000 *Care Standards Act* and the creation of minimum care standards and a national health and social care inspectorate, largely due to the failure of a distorted social care market to drive up quality through competition – the relationship between regulation and adult protection analysed in the discussion in Section 4.1.

Another policy strand influencing the earlier work exhibited in Section 2 of this submission was unfolding in health promotion and HIV prevention. The latter underwent a radical realignment in the early 1990s associated with the de-Gaying and re-Gaying of HIV and AIDS. The re-Gaying of HIV was part of an emerging *Queer* discourse and political analysis, influencing work in sexuality and learning disability (Thompson, 1994 and 1997; Cambridge, 1996a and 1997a). This provided a prequel to a developing discourse in sexuality and disability (Shakespeare *et al*, 1996; Shakespeare, 2006),

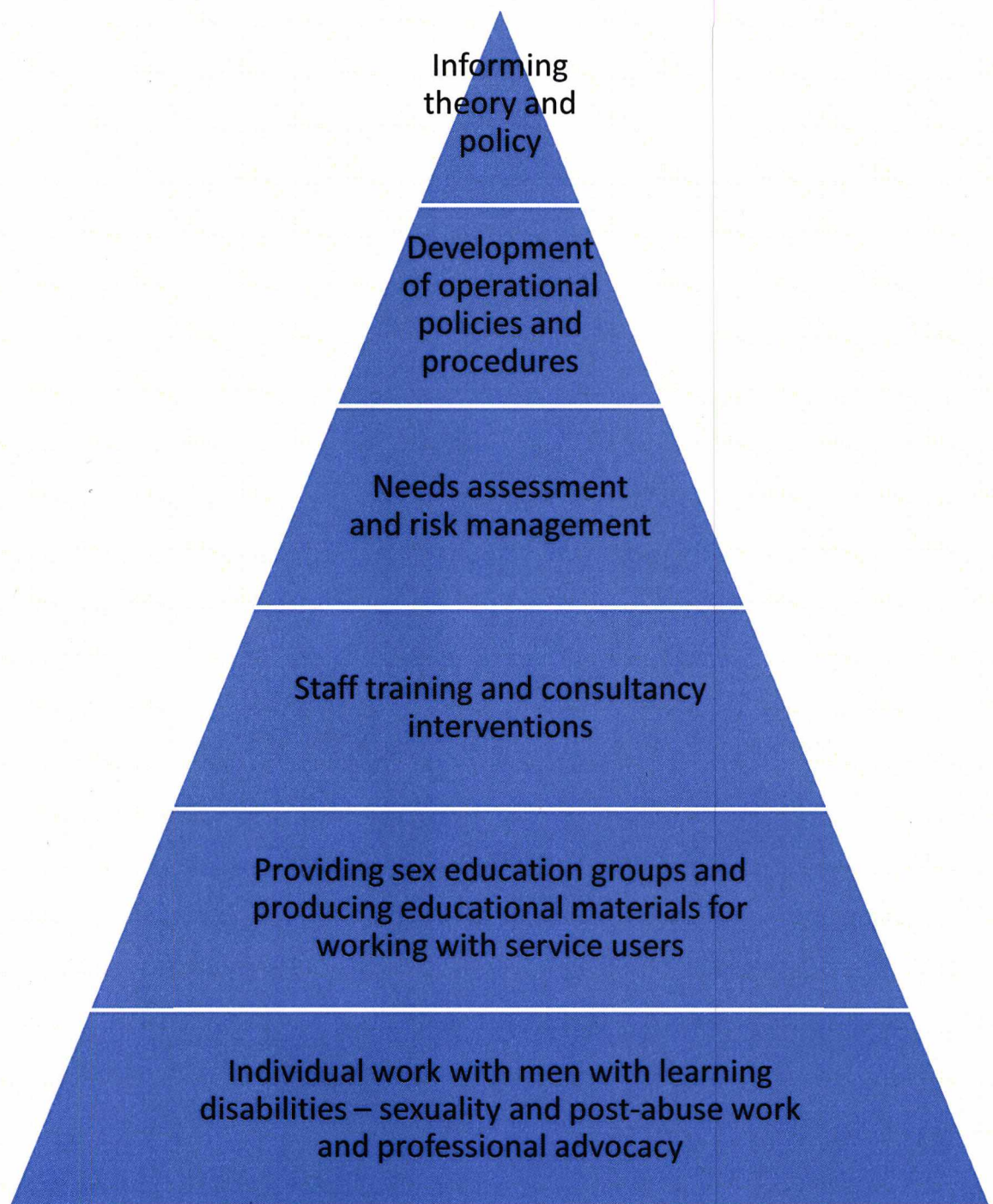
building on the foundations provided a radical discourse in disability politics (Oliver, 1990 and 1996). Radical approaches to sexual health and learning disability also paralleled a growing body of empirical evidence on the sexual abuse of people with learning disabilities (see for example Brown and Turk, 1992; Brown, Stein and Turk, 1995; McCarthy and Thompson, 1997) which served to underpin a developing feminist perspective in sexuality and learning disability (McCarthy, 1999), both informing sexuality work with people with learning disabilities more widely and contributing to the emergence and construction of a national adult protection policy (*No Secrets*, Department of Health, 2000). The exhibits in this submission consequently represent components of these connected strands of argument and thinking, with the various inter-relationships explored in greater detail in Sections 2 and 3.

A combination of *on the edge* themes such as homosexuality and abuse make for a volatile political mix, particularly when combined with disability - each are in their own ways socially and intellectually marginalised from the mainstream, are associated with stigma and subject to stereotypical interpretation. This PhD submission also therefore represents an account of how such issues were dealt with at a personal as well as intellectual level. As such it represents a personal perspective framed by gender, sexual identity, experience of disability within the family and work on de-institutionalisation and a personal response to the challenges this volatile mix presented.

The academic and professional papers exhibited in this submission and the accompanying commentaries (Sections 2 and 3) represent a body of empirical data and thinking which reflects the influences of these factors my work. My research on HIV and the sexuality of men with learning disabilities, intimate and personal care and people with PMLD and adult abuse and protection, opened different shutters on aspects of social exclusion and provided

opportunities to view and critically analyse the experiences of people with learning disabilities and related service and support responses, facilitating the identification of applied learning. This work can also be conceptually organised in relation to the link between evidence, practice and theory as reflected in the structure and thematic headings employed in Sections 2 and 3 and the hierarchy of work related activities and outputs exhibited and referenced (Figure 1).

Figure 1: Hierarchy of work related activities



1.3. Methods and Approach

Aims and related streams of work

Three inter-related aims and values have informed the development of my work in sexuality and adult protection in learning disability:

- To collect evidence on and deepen understanding of, the lives and experiences of people with learning disabilities in relation to sexuality and abuse and to interpret this in the context of anti-oppressive values
- To apply learning to inform practice and policy in sexuality and adult protection and develop service and support competence through the dissemination of evidence on best practice
- To promote the rights and protect the vulnerabilities of people with learning disabilities in relation to sexuality and adult protection through research, service development and individual work

My research has consequently been applied in nature and utilised applied learning to inform the production of various outputs including staff training and educational resources. Recommendations from my work have ranged from the effective support of people with learning disabilities to resource development and local and national policy. I also consider it critically important to develop a connection between research and evaluation in social care and related theory:

- Empirical evidence on the sexuality of men with learning disabilities has contributed, through critical analysis and argument, to the development of *Queer* and feminist theory in the field by making visible hidden experiences.

- Data on staff attitudes and the use of policies and guidelines on intimate and personal care and people with PMLD has challenged assumptions about the role of gender and sexuality in the conduct and definition of such interactions.
- Findings on the abuse of people with learning disabilities has provided a backcloth for examining assumptions about the capacity and capability of adult protection systems and the information which underpins decision-making in management and practice.

These connections and relationships are also explored in the exhibits and related commentaries in Sections 2 and 3 of this submission. My first jobs in local government were as an in-house researcher in social services, necessarily requiring the construction of evidence to inform management decision-making. My first academic appointment at the PSSRU at the University of Kent explicitly involved the monitoring and evaluation of the national *Care in the Community* initiative with the expectation that this would inform policy and policy implementation more widely (Renshaw *et al*, 1988; Knapp *et al*, 1992; Cambridge *et al*, 1994). The service development and consultancy work I undertook at the Tizard Centre was grounded in similar principles of promoting evidence based practice and the rights of people with learning disabilities, with my more recent experience as a member of the social work team at the University of Kent at Medway underlining the importance of applied research for informing teaching and placement support to social work students.

In relation to the submission of this PhD in social work, it is interesting to observe that the majority of my peer reviewed academic publications have been in social work journals, including the *British Journal of Social Work*, the

European Journal of Social Work, the *Journal of Social Work* and *Social Work Education*. For example evidence based and theoretical critiques of care management developed from the *Care in the Community* evaluations and follow-ups (Cambridge, 1992, 1999a, 2008a; Cambridge *et al*, 2006a; Xie *et al*, 2008) and cross national comparisons from a European research project on anti-discrimination and learning disability (Cambridge and Ernst, 2006). In Sections 2 and 3 below I also exhibit papers in the *British Journal of Social Work*, *Social Work Education* and the *Journal of Social Work*. This does not represent a conscious strategy to target a social work audience or produce social work relevant publications, rather, the relevance of much of my research to social work, together with its applied focus and my current academic position in the social work team at the University of Kent at Medway have subsequently combined to frame my choice to submit my PhD in this subject area.

Figure 2 maps the relationships between the different strands of my work and the body of work exhibited in this submission, namely sexuality and adult protection (Sections 2 and 3 respectively). These two primary strands of work have been connected in complex ways over time, with different elements cross-fertilising and combining to provide a coherent and unified body of research and argument. My personal account (see 1.1 above) is indicative of these inter-connections and although it is not possible to disentangle these chronologically, the primary and related themes can be mapped onto a basic time-frame (Table 1).

Figure 2: Streams of work and related themes



Table 1: Interconnection between work elements over time

| | Nature of work | Time period | Outputs | Connections |
|---|--|---------------------------|--|---|
| 1 | Care in the Community evaluation and long-term outcomes and cost research | Late 1980s to early 2000s | Reports to the Department of Health, books and academic papers | Provided evidence of institutional abuse and the neglect of sexuality and lead to an interest in the relationship between policy and practice and macro- and micro-organisation |
| 2 | HIV learning sets for learning disability service providers | Early 1990s | Workshops for staff and managers | Informed and influenced development of work on HIV and the sexuality of men with learning disabilities |
| 3 | Research on men with learning disabilities who have sex with men | Mid 1990s | Men's groups, liaison with health promotion agencies, academic and professional papers, conference presentations and workshops and a staff training and safer sex educational resource | Extended into an interest in sexuality and sexual abuse and learning disability and adult protection and learning disability more widely |
| 4 | Inquiry into abuse of people with learning disability and challenging behaviour in a residential service | Late 1990s | Report to the commissioner, academic and professional papers, book chapters and conference presentations | Identified the characteristics of an abusive culture and its relationship with care interactions, power dynamics and organisational characteristics in services |
| 5 | Consultancy on the development and implementation of sexuality policy | Mid 2000s | Reports, academic papers and book chapters and training interventions | Enabled operational links to be constructed between theory, evidence, policy and practice in sexuality and learning disability |
| 6 | Research on intimate and personal care and people with PMLD | Late 1990s early 2000s | Book, academic and professional papers, conference presentations and workshops and a management and | Highlighted the complex relationship of personal care with the sexuality of staff and service users and the risks of abuse and neglect associated with the |

| | | | | |
|----|---|--------------------|---|---|
| | | | practice resource on providing intimate and personal care for people with PMLD | provision of intimate and personal care |
| 7 | Research for Kent Social Services on the specialist adult protection co-ordinator role | Early to mid 2000s | Report and academic and professional papers | Developed understanding of the link between the organisational characteristics of services, resources and implementation of policy |
| 8 | Development of adult protection training for Kent and Medway adult protection committee | 2000s | The development of training interventions and dissemination of learning through academic papers and a special issue of the <i>Journal of Adult Protection</i> | Deepened understanding of the implementation of adult protection policy through training and the application of evidence based learning |
| 9 | Individual psych-educational work with men with learning disabilities | From mid 2000s | Professional papers and international conference presentation | Required the application of HIV and offending risk management, support for sexual fetish and post-abuse work with men with learning disability |
| 10 | Research on adult protection referrals in Kent and Medway | Late 2000s | Report and academic and professional papers | Provided evidence on the relationship between adult protection policy and practice and on patterns of risk in learning disability and other adult abuse and the opportunity to focus on the sexual abuse of people with learning disabilities |

Organisation of material

The exhibited material in Sections 2 and 3 is each organised into three sub-sections which functionally differentiate the various outputs, as signalled in section 1.2. Accompanying commentaries on each set of exhibited material is tailored to and ranges across each section and sub-section, conceptually linking the various exhibits and related discussion. . For example, with its focus on the sexuality of men with learning disability, Section 2.1 includes

early work which mapped needs and aimed to increase the visibility of the sexuality and sexual experiences of men with learning disabilities. The work included in Section 2.2, represents the broader theoretical location of this evidence and its application to practice, while Section 2.3 shifts in emphasis to service management and policy context.

Similarly, Section 3, with its focus on adult abuse and adult protection and learning disability, moves from formative learning developed from inquiry and research (Section 3.1), to relating how this evidence informed the implementation and review of policy (Section 3.2) and the promotion of evidence based management and practice (Section 3.3).

A concluding account, reflecting on the work submitted and the personal and broader learning, together with references for the whole submission, differentiating exhibited material and cross referencing it to Sections 2 and 3, is provided in Section 4 which is also organised into three sub-sections.

Research methods

No single methodological paradigm informed the research exhibited in this submission. I do not hold a reductionist view about research methodologies or the advantages and disadvantages of quantitative or qualitative approaches. My experience as a researcher in local government social services departments and later at the PSSRU led me to appreciate that the research in my first posts (London Borough of Havering and Somerset County Council) was driven by management information demands and consequently had little attachment to theory. However, it provided a springboard for my preference for a mixed-methods approach (de Vaus, 1991; Yates, 2004; Creswell, 2006), utilising methods most suited to the aims of the study and most effectively

answering the evaluation questions - mirroring a utilisation focused model of evaluation (Patton, 1997; Owen, 1999).

At the PSSRU I was influenced by the *production of welfare* research paradigm (Davies and Knapp, 1981; Davies and Challis, 1986; Davies *et al*, 1990) which examined the relationships between needs, resources and outcomes. Although a primarily quantitative research model, depending on controlled experimental designs and statistical controls, it drew on a variety of methods for collecting data, including interviews with service users. Largely however, it placed social care production in an economic as opposed to a social context, with considerations such as service user rights and questions relating to sexuality and the experience of abuse remaining largely invisible.

My research in the early to mid 1990s on men with learning disabilities who have sex with men (**Ref. 2.1.a.**) took me in a new direction as it included both qualitative and quantitative methods, such as individual accounts and aggregate profiles of experience, with data collected through interviews and service records. Where possible, data were also aggregated and analysed using SPSS in order to generate simple frequency counts across variables and cross-tabulations to explore the relationships between different variables. A similar mixed methods approach was employed in research conducted with Steven Carnaby on intimate and personal care for people with PMLD in the early 2000s (**Ref. 3.1.c.**), with methods including interviews with staff, documentary analysis and service and user case studies.

Both these pieces of research, with their applied focus on service users and service support, led to the development of staff training and service user educational resources, designed to address deficits in knowledge and educational skills - characteristics similar to action research (Stringer, 1999;

Hart and Bond, 1995). In contrast, the research conducted with Julie Beadle-Brown, Jim Mansell and Alisoun Milne on adult protection referrals (**Refs. 3.3.c., 3.3.d., 3.3.e. and 3.3.f.**) was primarily quantitative as a consequence of the available data, so was interpreted with the aid of cross-tabulations, frequencies and statistical tests of significance. It was also restricted in its coverage and depth, bringing limitations discussed in more detail in the commentary in Section 3.3. Such a quantitative approach contrasts starkly with other data evidenced in this submission, such as that collected through a structured inquiry process (**Refs. 3.1.a. and 3.1.b.**) which was obtained through interviews, documentary analysis and observation and collated thematically and chronologically. This was also an essentially phenomenological study, pertaining to a particular time, place and set of circumstances. It consequently shared limitations with other inquiries, depending heavily on subjective interpretation and the identification and further exploration of themes (Strauss and Corbin, 1998; Silverman, 2004), limitations which are discussed in more detail in the commentary in Section 3.1. Similarly, the evaluation conducted with Tessa Parkes on the specialist adult protection co-ordinator role, collected data through interviews with key players and was consequently derived from individual attitudes and experience (**Ref. 3.2.d.**).

Authorship

Some of the research and development projects I have been involved in, including their published outputs, have been collaborative in nature. The most obvious example is the *Care in the Community* work at the PSSRU which, due to its scale, involved a team of researchers and indeed a wider team of project co-ordinators. However, I was able to develop a lead and co-ordinating role for the subsequent *Five Years On* and *Twelve Years On* follow up studies.

In my work on intimate and personal care for people with PMLD, development and products were shared equally with Stephen Carnaby, the co-researcher / co-author, with the first author indicating a lead role for drafting that particular paper or chapter. For this stream of work however, ideas, involvement, interpretation and writing was effectively shared 50:50, including those exhibited in this submission (**Refs. 2.3.e., 3.1.e., 3.1.f., 3.2.a. and 3.2.a.**), as well as those referenced (Cambridge and Carnaby, 2000b).

A similar pattern appertains to my work with Tessa Parkes relating to adult protection training for Kent and later Somerset Social Services and research on the specialist adult protection co-ordinator role for Kent. However, I took lead authorship for publications, including those exhibited in this submission (**Refs. 3.2.b. and 3.2.c.**), reflecting a majority responsibility of at least 80% for the drafting and submission of the work. For the adult protection co-ordinator research, data collection was shared 50:50, although I led the writing of the report and the research paper exhibited in this submission (**Ref. 3.2.c.**) with 70% responsibility.

The paper on working effectively with the police in criminal investigations, stemming from my adult protection training in Somerset (**Ref. 3.2.d.**) was atypical. Although I drafted the paper and took responsibility for submission (at least 90% responsibility), the material included in the discussion was derived from co-training with detective sergeant Lindsay Shearlock from Yeovil Vulnerable Victims Unit. Consequently I decided to give her first authorship to acknowledge the valuable input she had provided to the training (a half day session in a two day programme).

Co-researching and co-writing bring particular strengths. For example, in the work with Steven Carnaby on intimate and personal care for people with PMLD, Steve brought insights from a clinical psychology perspective and I brought experience designing and conducting research in learning disability. In the work developing adult protection training and the research on the specialist adult protection co-ordinator role conducted with Tessa Parkes, Tessa brought her experience of research and practice in mental health and I brought my experience of learning disability and service organisation. Similar advantages are evident in research projects involving a wider team, such as the research on adult protection referrals in Kent and Medway.

Although I led the research proposal on the latter to the Nuffield Foundation, the evaluation and writing was shared across team members who adopted lead roles for particular aspects of the work. For example, I led the research papers on sexual abuse referrals for people with learning disabilities (**Ref. 3.3.d.**), adult protection processes and outcomes (**Ref. 3.3.e.**) and an overview of patterns of risk for managers and practitioners (**Ref. 3.3.f.**) as exhibited in this submission (at least 80% responsibility for each). Julie Beadle-Brown led the paper on learning disability referrals (**Ref. 3.3.c.**), Jim Mansell the prevalence paper (Mansell *et al*, 2009) and Alisoun Milne the paper on referrals of older people (Milne *et al*, in submission).

The majority of my work in sexuality and learning disability was developed on my own, including the published outputs exhibited in this submission (**Refs. 2.1.a., 2.1.b., 2.1.c., 2.2.a., 2.2.b., 2.2.c., 2.2.d., 2.2.e., 2.2.f., and 2.3.a.**). I worked collaboratively with Michelle McCarthy on service development involving sexuality training for staff, user sex education groups and policy development which led to joint publications with responsibility shared 50:50 (**Refs. 2.1.e. and 2.3.c.**). This was similar to my collaboration

with Brian Mellan who worked in sex education for people with learning disabilities (**Ref. 2.1.d.**), although I led the writing of this discussion and conceptual paper (at least 80% responsibility). Responsibility was shared 50:50 for the edited volume chapter with Hilary Brown (**Ref. 2.3.b.**) and split three ways for the paper with Stephen Carnaby and Michelle McCarthy (**Ref. 2.3.d.**), although I led the drafting and submission of this paper.

**Section 2: Sexuality and Learning Disability with a focus on
Men with Learning Disabilities**

Commentary and Exhibited Material (Appendix 1)

Commentary

2.1. Mapping Needs and Developing Theory

2.2. Using Evidence to Inform Practice

2.3. Strengthening Service Management and Policy

This section represents the first main body of work exhibited in this submission and although there is a focus on the sexuality of men with learning disabilities, the discussion contextualises this in sexuality and learning disability more widely. The exhibits offered centre on peer reviewed academic journal papers but include some peer reviewed professional papers and book chapters, reflecting the applied nature of the work. Related written outputs, including educational and training resources, are also referenced in the supporting discussion where relevant to informing the application of learning from the main body of work exhibited.

2.1. Mapping Needs and Developing Theory

It was at the height of the social, political and medical maelstrom of the early 1990s relating to the emerging HIV epidemic and HIV prevention, treatment and sexual health education, that the work represented by the first exhibits in this submission originated and are conceptually and politically located. This work is also at the fulcrum between *empowerment* and *protection*, the summary themes represented in the two strands of this submission. However, as argued in Section 4, they do not represent opposing strands of work or conflicting practice orientations. This account is not therefore about balancing the rights and responsibilities of individuals, services or staff. Rather, it is about recognising that there are two sets of demands and responsibilities on researchers and practitioners in learning disability, namely to promote and support the sexual rights of people with learning disabilities and to protect people with learning disabilities from abuse and exploitation, including sexual abuse. These are not mutually exclusive or contradictory aims, as for example, the provision of good sex education can help people

make more informed choices about sex and give them the language, negotiating skills and assertiveness to avoid or escape from abuse and to report it, for example using social stories, role play and peer education.

Work on HIV and AIDS, especially in the context of the disadvantage disability and learning disability brings, in many ways represents a microcosm for promoting empowerment and protecting vulnerabilities. For example, the first exhibit in this section (**Ref. 2.1.a.** Cambridge, 1996a), reports service responses to HIV risk, including testing for HIV, which has the potential to disregard the rights of service users (see fuller discussion in Section 2.2) or restrict the freedom of people with learning disabilities to lead aspects of their lives outside the control of service, which bring deprivation of liberty concerns.

The first three exhibits in this submission are products of research and development work undertaken in the mid 1990s in political territory which was at the heart of the maelstrom outlined above. It was also consequently at the forefront of our developing knowledge of HIV risk and risk management at the time. The over-arching aim was to articulate an evidence based critique of HIV and learning disability and a proposition for the positive support of men with learning disabilities who have sex with men (see personal account and rationale in Sections 1.2 and 1.3). At this time, homosexuality between men was the main focus of attention and anxiety in relation the emerging HIV epidemic in the West and was also consequently the main focus of concern for health promotion and HIV prevention. The first exhibit in this submission is a paper in the *Journal of Intellectual Disability Research*, which reported the findings of needs assessment

research funded in 1993 by SELHPA on HIV and men with learning disabilities who had sex with men (**Ref. 2.1.a.** Cambridge, 1996a).

Prior to the research which informed the first three exhibits, I was leading the design and delivery of a series of HIV learning sets for staff working in services for people with learning disabilities in the south-east of England, working closely with James Nichol of (the then) SELHPA. This served to highlight the needs of men with learning disabilities who had sex with men and people with learning disabilities and HIV more widely (Dixon, 1991; McCarthy and Thompson, 1994; McCarthy, 1994; Thompson, 1994). It was noticeable that empirical data outside sex education was largely absent, apart from work undertaken in the US (Kastner *et al*, 1989 and 1992; Marchetti *et al*, 1990). This was also the time HIV and AIDS was being re-Gayed, in recognition that the epidemic in the UK was still largely affecting men who had sex with men and Gay men, reflected in research outside learning disability which was developing in response to this reality (Davies *et al*, 1992; Taylor-Laybourne and Aggleton, 1992; King *et al*, 1992; Hickson *et al* 1992; Hunt *et al*, 1993; Deverell and Rooney, 1994).

The paper reporting the findings of the initial needs assessment and mapping research (**Ref. 2.1.a.** Cambridge, 1996a) included an examination of service responses to HIV risk and identified a range of support challenges for learning disability services. Most importantly, it made visible the stark reality that many men with learning disabilities were having unsafe sex with men without learning disabilities and also unsafe sex with women and men with learning disabilities within their services. Explicit quotes from staff were used as a device to highlight the reality of the sexual experiences of men with learning disabilities. These included unprotected (insertive and

receptive) anal sex, drawing attention to the severity of the HIV infection risks identified. My aim was to remove any ambiguity or uncertainty about the seriousness of the support challenges facing learning disability services, subsequently explored in more detail in a specialist learning disability professional journal paper (**Ref. 2.1.b.** Cambridge, 1996b) which also provided pointers for assessing HIV risk for staff supporting people with learning disabilities. A key objective of both papers was therefore to increase the visibility of homosexuality in learning disability by making the needs of men with learning disabilities who had sex with men apparent in the academic and practice literature. This initial work also informed the planning of a co-edited volume on HIV and learning disability (Cambridge and Brown, 1997b), which included contributions from a range of specialist perspectives, some of which were represented in the networking developed during the design and delivery of the HIV learning sets described above.

The issues raised in the needs assessment research demanded a more explicit political analysis and formulation and the discourse in a paper published in *Disability and Society*, entitled *How far to Gay?*, examined experience in HIV and learning disability in the context of the wider politics of HIV and AIDS (**Ref. 2.1.c.** Cambridge, 1997a). It explored the conceptual links between what is now called *Queer* theory and evidence about homosexuality and men with learning disabilities. One of the observations made in this paper was the relative invisibility of homosexuality in sex educational materials for people with learning disabilities, despite evidence that it was a relatively common behaviour (**Ref. 2.1.a.** Cambridge, 1996a; Thompson, 1994) and the almost complete absence of educational materials and images which addressed high HIV risk behaviours in relation to sex between men. For example, I identified the tendency for educators to use of androgynous images, the

reluctance to use unambiguous images of penetrative anal sex and the avoidance of explicit imagery surrounding the use of condoms, all serious concerns for the provision of effective sex and safer-sex education for men with learning disabilities who have sex with men (issues addressed in more detail in Section 2.3 in relation to the development of sex education and staff training resources in HIV and learning disability and sexuality and learning disability more widely). Of particular note for example, was the policing of homosexuality inside some learning disability services or the total denial of it as a support issue, both raising identity and wider political questions about the availability of homosexual or Gay space (Leap, 1999) for men with learning disabilities.

My work on HIV and learning disability necessarily led to a focus on the sexuality of men with learning disabilities more widely and the apparent lack of awareness of their sexualities outside the work of specialist practitioners and sex educators such as David Thompson (1994, 1995, 1997 and 2001). In response I led the production of a co-authored conceptual paper with Bryan Mellan, published in *Disability and Society* (Ref. 2.1.d. Cambridge and Mellan, 2000). Argument in this paper drew on a combination of empirical research evidence and anecdotal practice evidence from sex education on the sexuality of men with learning disabilities, with the aim to develop an agenda for working on sexuality with men with learning disabilities. In the process, the established and predominantly pathological attitudes about the sexuality of men with learning disabilities (by association with issues such as HIV risk and sexual abuse perpetrated by men with learning disabilities) were opened to scrutiny and exposed to challenge.

A reconstructive discourse included a host of neglected and marginalised issues for men with learning disabilities, such as men as victims of sexual abuse, the use of pornography, cross-dressing, selling sex and stylised sex were opened to scrutiny. This was followed up by editorials in the *Tizard Learning Disability Review* (Cambridge, 2001a and 2006a) referencing issues such as the use of sex workers by men with learning disabilities and more recently in relation to individual work supporting the sexual fetish of men with learning disabilities (see discussion in Section 2.2). In a similar vein, I also sought to commission pieces for the journal which reported on marginalised issues such as trans-sexuality (Wilson, 2006) and new initiatives such as dating projects for people with learning disabilities (Jenner and Gale, 2006a and b).

The connection between the two main strands of this submission, namely promoting rights and protecting vulnerabilities, is particularly evident in certain areas of work with people with learning disabilities, such as intimate and personal care for people with PMLD (discussed and unpacked in more detail at various places in Section 3). However, there is also a connection between the provision of intimate and personal care and sexuality and the final exhibit in this section, an edited volume chapter (**Ref. 2.1.e.** McCarthy and Cambridge, 2006), sought make this explicit. Considerations included for example, the right of people with PMLD to sexual self-stimulation and masturbation. There was also discussion on how to respond in enabling ways to situations where people with PMLD might be unable to distinguish between touch associated with caring and touch experienced as sexual.

2.2. Using Evidence to Inform Practice

The emphasis of the exhibits in this section of the submission is on informing practice. There is consequently a bias towards the practice rather than academic literature, although exhibits include papers published in the *British Journal of Learning Disabilities*, an international academic journal paper and two chapters in edited volumes. The majority of the work exhibited in this section represents the applied learning from the body of work on sexuality exhibited in Section 2.1, drawing on evidence from research and service development to inform practice. Section 2.3 extends the applied focus to service management and policy, also additionally referencing the staff training and sex educational resources developed from this work.

The first exhibited paper in this section (**Ref. 2.2.a.** Cambridge, 1994) was written to help disseminate the learning for practice developed from experience facilitating the HIV learning sets and conducting the original needs assessment and mapping research discussed in Section 2.1. The issues covered in this paper stemmed from and were informed by these activities, grounded through the use of a case study focus on HIV testing. I felt it critically important to identify and disseminate a practice agenda in relation to HIV and learning disability at a time HIV and AIDS was being re-Gayed and in response to the evidence on HIV risk for men with learning disabilities who had sex with men, identified by the research profiled in Section 2.1. This paper paralleled and re-enforced similar observations about HIV risk management being made at the time by sex educators working with people with learning disabilities (McCarthy and Thompson, 1994; Thompson, 1994), including considerations relating to sexual identity. Following the original needs assessment mapping research, I established a workshop for men with learning disabilities who had

sex with men, working with the South-east London branch of *People First*, a self-advocacy group for people with learning disabilities. Discussion centred on the men's experience of sex and their sexual identity, an issue highlighted as important by David Thompson's work which had identified a reluctance on the part of men with learning disabilities who had sex with men to identify as Gay – clearly an important consideration for informing the images and messages in safer-sex education for this group of men.

The edited volume chapter (**Ref. 2.2.b.** Cambridge, 1997b), developed this learning in the context of the politicisation of HIV and AIDS and considerations of service user vulnerability through discussion of the nature and methods of educational resources for men with learning disabilities, including a detailed construction of the advantages and disadvantages of HIV testing at this time. It also reviewed organisational considerations including case management and market management, both of which were still relatively new concepts and devices in social care. The opportunity was also taken to disseminate the findings and learning from the study and the British context of HIV and AIDS to an international audience in a paper in *Health Promotion International* (**Ref. 2.2.c.** Cambridge, 1998a), influenced by an awareness that national HIV epidemics were at this time being experienced elsewhere in Europe, Australasia and North America, where HIV risk was similarly centred on men who had sex with men. I consequently focused on the particular issues relating to the sexual experiences and identity of men with learning disabilities in the context of providing culturally and intellectually appropriate safer-sex education and HIV prevention information, including the representation of homosexuality in educational images. This was driven by both a moral and political imperative to inform and improve risk management and HIV

prevention for men with learning disabilities who had sex with men outside the national scene.

The next exhibit in this section (**Ref. 2.2.d.** Cambridge, 2001b) jumps to a global HIV epidemic, where HIV risk was more diverse, being associated with different risk groups, behaviours and places. Although the paper deepens the focus on men with learning disabilities who have sex with men, it also explicitly cuts through considerations of individual rights and service responsibilities for protection, drawing on experience from individual work with men with learning disabilities for a service provider in east Kent - hence its publication in the *Journal of Adult Protection*. An argument was developed from reflective analysis of case evidence and experience to offer guidelines for HIV testing and people with learning disabilities. A man with learning disabilities had been tested for HIV without his consent and allegedly without the knowledge of his service '*in his best interests*'. Moreover, confidential information on his HIV status had been shared between agencies and workers. My interpretation of these events in developing guidelines and my work with the man, his parents and the staff, were also informed by a recent study visit to Australia and New Zealand, where the case experience of Christopher Truscott, a man with learning disabilities and HIV living in Christchurch, had been made public. I consequently discussed the learning from the mismanagement of the New Zealand man's HIV risk and the public disclosure of his HIV status, drawing parallels with the case learning stemming from my involvement with the man in the UK.

The paper also included a brief discussion of a common situation faced by social workers and support staff, developed using a case profile of a man with

learning disabilities who experienced physical restraint to prevent him going out on his own because of concerns that he was exposing himself to undue HIV risk through sex with men. My individual work with him indicated that he held a positive Gay identity and self-image, although he rarely practiced safer-sex, so the emphasis of my work was to empower him to make safer decisions about the sex he had without restricting his liberty. Safety in this context also included advice and information about avoiding arrest by the police and homophobic assault. A seminar group was also established for his support staff where they were able to express their concerns and explore the advantages and disadvantages of a range of different responses. The overarching aim of the paper was therefore to demonstrate that there are ways to assess and manage perceived and actual HIV risk, including HIV testing and safer-sex education, which respect the rights of people with learning disabilities to make informed and sometimes risky choices as well as meeting service responsibilities for protection.

The emphasis on non-aversive risk management also helped frame observations in an edited volume chapter (**Ref. 2.2.e.** Cambridge, 2007a) targeted on staff and managers working in learning disability services. Drawing on experience from my work in both HIV and learning disability and intimate and personal care for people with PMLD, I unpacked and illustrated the process of risk assessment and risk management, utilising case studies to identify the different levels at which decisions on risk might be required and offer a model for a rights based approach to managing risk in services for people with learning disabilities.

I articulated more explicit rights based arguments for an academic and research audience in papers delivered at the 13th World Congress of the *International*

Association for the Scientific Study of Intellectual Disability in Cape Town in 2008 (Cambridge, 2008b and c) and unusually for a PhD submission, I have chosen to exhibit a power-point presentation delivered at this conference which modelled an ethical response to the sexual fetish of a man with learning disabilities (**Ref. 2.2.f.** Cambridge, 2008d) – also articulated in a paper in a professional journal (Cambridge, in press). This is because it generated a huge amount of interest at the conference and represents an important piece of reflection (see Section 4.2).

The paper explored the issues surfacing from individual psycho-educational work with a man with autism who had a sexual fetish for nappies and baby paraphernalia, work which was undertaken in parallel with mediated dialogue with his manager and key worker in his support service. It can be seen that I developed a professional advocacy role and utilised a rights based approach in this work (Henderson and Pochin, 2001), providing a written agreement for the man to express his sexuality safely and responsibly and to take back control of his fetish from others. The management conflict came from his perceived sexual risk to children and his subsequent supervision, although with no history of sexual offending, consideration of his right to liberty was also required (see reflective discussion in Section 4.3).

The promotion of user rights was also the driving force behind the second edited volume chapter exhibited in this section (**Ref. 2.2.g.** Cambridge, 2010) which marshalled evidence and provided advice to staff supporting people with learning disabilities on how to respond to masturbation in constructive and enabling ways. Common concerns expressed by staff about masturbation were unpacked in the context of the social and physical environments encountered in services for people with learning disabilities, such as lack of privacy. An

agenda was also provided for staff working in situations where masturbation was being experienced as a problem, with a series of case studies used to illustrate commonly experienced problems and explore solutions which respected the rights of service users to appropriate sexual expression, including for example, the use of pornography.

2.3. Strengthening Service Management and Policy

The final section in this part of the submission references and discusses exhibited evidence and material related to the application of my work in sexuality and learning disability to service management and operational policy. The raft of written outputs discussed below combine empirical evidence from research with experience from staff training, service development consultancy and group sex education with men with learning disabilities. The objective is to inform policy in sexuality and learning disability and hence strengthen management and wider staff competence in supporting sexuality *per se*. They also respond to management issues which have a sexuality dimension, such as supporting challenging behaviour and the provision of intimate and personal care. Thus, the exhibits in this section range across HIV policy, sexuality policy, managing and responding to sexually challenging behaviours such as inappropriate masturbation and responding to sexuality in intimate and personal care.

Ref. 2.3.a. (Cambridge, 1997c), published in the *Journal of Applied Research in Intellectual Disabilities*, examined HIV risk and the conflicts that present for policy development in learning disability. The aim of the paper was to unpack the task of HIV policy development for managers in learning disability

services, highlighting considerations relating to the targeting of HIV prevention resources, visibility and recognition of risk, management of apparent conflicts between the rights of service users and the responsibilities of staff and legal and moral considerations. Four relatively detailed case studies, drawn from research and practice, were used to develop user-centred argument and observation. These were counter-balanced with conceptual models relating to the disclosure and recognition of risk and conflict management. Guiding principles were also offered for policy development, with pointers for co-ordinating the connection between policy and practice. In parallel to and complementary with this strand of work, I was working on a co-edited volume on HIV and learning disability (Cambridge and Brown, 1997b – see fuller contextualisation in Section 2.1) which included a chapter on HIV policy development (**Ref. 2.3.b.** Brown and Cambridge, 1997) which focused on coherent and effective decision-making and identified the strengths and weaknesses of such policies. It articulated the reasons some policies fail and the importance of values and rights based principles for informing policy development and implementation.

The story and learning from a service development consultancy for a large learning disability provider service in Kent, based on a series of interventions including staff training, sex education groups for women and men with learning disabilities and consultation with parents for informing the development of a sexuality policy, was distilled in an academic paper in *Health and Social Care in the Community* (**Ref. 2.3.c.** Cambridge and McCarthy, 1997). This journal was targeted to disseminate experience and learning to as wide a possible audience in health and social care (as the NHS through local health trusts retained considerable responsibility for residential and other support services for people with learning disabilities). The paper essentially

outlined a model process for evidence and needs based policy development but also identified the key issues likely to inform policy, leading to other externally facing activities including training for Leicester Council and the London Borough of Hackney social services departments. Due to the wide interest this paper generated, a *model* sexuality policy was subsequently developed and made available on request - an innovative product at a time many learning disability provider services were struggling to develop such policies. Notably, the policy included rights perspectives, such as the right of service users to sex education and consenting sex. This strategy worked, as I continued to receive requests for advice in this area, referring to the paper. Moreover, experience of using people with learning disabilities as consultants during this project lead to a later initiative involving service users in focus groups to help define best value in services for people with learning disabilities (Cambridge and McCarthy, 2001).

The exhibits discussed so far as well as the two referenced below in this section have an emphasis on service user rights and person-centred approaches in common. Current national learning disability policy, as outlined in Section 1.2 (Department of Health, 2001 and 2009a), includes the explicit aim to increase service user choice and improve the social inclusion of people with learning disabilities. It is consequently at this point that I briefly reference and discuss the sex educational materials developed from my work in sexuality and learning disability. *HIV, Sex and Learning Disability* (Cambridge, 1997d) was produced using a Department of Health Shared Training Grant (1995) and included staff training materials developed and refined from those used in the HIV learning sets and new sets of sex education materials, mostly in the form of line drawings, developed from the evidence on HIV risk and sexual

behaviours surfacing from the initial needs assessment mapping research (see Section 2.1).

This resource was radical and challenging for its time, portraying high HIV risk behaviours such as insertive and receptive anal sex between men through line drawings. Social stories and scenarios relating to casual sex and sex in public places (cottaging in public toilets and cruising in other public sex environments) and the use of condoms were also portrayed. Such a radical, open and unambiguous approach to safer sex education in learning disability drew on emerging evidence on effective safer-sex education developed by Gay men, with the application of learning extended to discussion in professional journal papers (Cambridge, 1999b). Other educational resources produced included booklets with pictures and advice in plain English for use by service users, staff and parents, covering HIV and AIDS (Cambridge, 1996c, d and e) and the sexual rights of people with learning disabilities (Cambridge, 1996f; McCarthy and Cambridge, 1996).

The focus now turns to supporting sexuality in challenging behaviour (**Ref. 2.3.d.** Cambridge et al, 2003) and policy development in intimate and personal care (**Ref. 2.3.e.** Cambridge, 2006b). The first exhibit (**Ref. 2.3.d.** Cambridge *et al*, 2003) charts the complex territory surrounding challenging sexual behaviours and navigates some of the conceptual and practical barriers to responding in considered and person-centred ways, based on the needs and experiences of the person. For example, challenging behaviours are often functionally linked to difficulties associated with expressive communication or the experience of discomfort or pain, so the paper includes possible medical or physical explanations for someone experienced as masturbating too much or unsatisfactorily, as well as individual, social and environmental explanations.

Similarly, the paper provides a model process for analysing and interpreting the antecedents and consequences of a wider repertoire of challenging sexual behaviours, linking such factors to policy and practice guidance. **Ref. 2.3.e.** (Cambridge, 2006b) unpacks a host of considerations for managing the policy landscape of intimate and personal care for people with PMLD. For example, it constructs a systemic model for considering the operation of intimate and personal care policy and examines the defining topographical features of the landscape in this area of management and practice, including abuse and neglect, consent to touch, gender, staff sexuality and anti-oppressive practice (see Section 3.1 for a fuller contextualised discussion). The extension of sexuality into other policy and practice realms such as challenging behavior and intimate and personal care, as well as adult protection and abuse (see Section 3), underlines why sexuality work in learning disability should be a mainstream consideration and not partitioned off from other areas of practice.

APPENDIX 1: Exhibited Material for Section 2

Ref. 2.1.a.

Cambridge, P. (1996a) 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.

Men with learning disabilities who have sex with men in public places: mapping the needs of services and users in South East London

P. Cambridge

Tizard Centre, University of Kent at Canterbury, England

Abstract

This survey investigated the prevalence of men with learning disabilities who have sex with men in public places in three south east London boroughs. The work was administered through contact with providers of services for people with learning disabilities and was commissioned by the local health authority. It represents the first example of needs assessment work on this theme. Service responses to risk assessment and risk management in relation to HIV and the sexual behaviour of male service users were explored. The survey identified 13 services where this was a management or practice issue, and 16 and 18 men for whom this behaviour definitely or possibly applied. This paper reports the findings of the survey and identifies issues relevant to commissioning and providing services for people with learning disabilities.

Introduction

Outline

The project was based on a needs assessment exercise for men with learning disabilities who have

sex with men in public places and was supported by South East London Health Authority (SELHA) from HIV/AIDS prevention resources. There was case evidence from learning disability and health promotion that some men with learning disabilities were at high risk of HIV infection, and/or of sexual and emotional exploitation.

The aim of the project was to map service responses to known or suspected user behaviours in Lambeth, Lewisham and Southwark. This included assessing service competence in risk assessment and risk management, and exploring the appropriateness of interventions and resources.

Therefore, the work was interest to:

- (1) men with learning disabilities who have sex with men;
- (2) men who have sex with men in public places;
- (3) service providers in learning disability and HIV;
- (4) HIV prevention and health promotion;
- (5) outreach projects for men who have sex with men; and
- (6) commissioners of health and social care services.

Background

A needs assessment exercise in Camberwell (Taylor-Laybourn & Aggleton 1992) identified deficits in health promotion and HIV prevention for

Correspondence: Paul Cambridge, Tizard Centre, University of Kent at Canterbury, Canterbury, Kent CT2 7LZ, England.

men with learning disabilities who have sex with men.

'Subsequent to the implementation of the Community Care Act, increasing numbers of men with learning disabilities are living in the community, in some cases with only limited knowledge of safer sex.'

'... Respondents with specialist knowledge in this area expressed concern about the frequency with which they believed unsafe sex took place.'

The South East Thames Regional Health Authority sexual health strategy (*Health of the Nation SETRHA*, 1993) targeted gay men and other men who have sex with men and young people (both within and outside educational care or employment settings). Therefore, the target group for the project included both groups, making the work relevant to wider regional HIV strategy as well as the local situation.

The survey was the first to investigate the incidence of men with learning disabilities who have sex with men in public places. Previous surveys of the sexual behaviour of people with learning disabilities (Brown & Turk 1992) indicate the importance of having appropriate language to describe sexual behaviours. Therefore, the survey included descriptions of the behaviours of interest, using unambiguous language.

The growing literature on sexual abuse and people with learning disabilities (Brown & Craft 1989) has paved the way for increased awareness of the sexuality of people with learning disabilities. However, descriptions of men with learning disabilities who have sex with men in public places are scarce in the learning disability literature, although there are references (MacLeod, 1992; McCarthy & Thompson 1993) and the presence of men with learning disabilities in such situations is given some attention in HIV prevention materials (Jones 1993).

Lessons from the developing awareness of sexual abuse and the scant attention to sex in public places in the literature, suggest that services will seriously under-report this behaviour. Staff need to recognize such behaviour in the first place, and are less inclined to report behaviour they do not like or value, as shown by early studies of the sexual behaviour of people with learning disabilities

(Mulhern 1975). Therefore, the high incidence of men with learning disabilities who have sex with men in public places reported by a specialist local service is understandable (Morris 1993).

Cottaging and cruising

Some men have sex with men in public places. 'Cottaging' is when men go to public toilets to have sex or to meet men to have sex with. Cottaging is gay slang for this activity because some public toilets look like cottages. Men who cottage do so to have quick, easy, anonymous and uncomplicated sex. Other public places such as parks, commons or secluded urban areas are also used, and are known, as cruising areas. Particular cottages or cruising areas become well known, and are popular venues to meet and have sex. The police sometimes arrest or take the names of men they think are soliciting for sex.

Sex usually takes place at the location, there is often little or nothing said between the men, and payment is rarely made for sex. The sex commonly includes mutual masturbation or oral sex. Anal sex happens less frequently because it is difficult to hide and is known to be a high-HIV-risk activity. Sometimes, there is a lack of reciprocity in the sexual encounter, often based on perceived attractiveness, image or identity.

There is evidence from outreach projects (Jones 1993) that men with learning disabilities also cottage and are disproportionately involved in higher-risk sexual behaviours. There is also evidence (McCarthy & Thompson 1992) that they are at disproportionate risk of exploitation and abuse because of an imbalance of power. Social isolation makes cottaging an especially attractive but risky activity for men with learning disabilities. They are likely to be at higher risk of HIV infection as well as other sexually transmitted diseases because they may not know about or understand safer sex, or have ready access to condoms; they also may be more compliant or acquiescent.

Services are often unaware that male users are cottaging. Sometimes this is because they respect personal privacy, but more usually they fail to recognize indicators that such sex might be taking place. If they find out, they may not have the

competence to respond as complex legal, moral, medical and professional issues compete to act as a disincentive to believing and reporting (Morris 1994). Although someone with a learning disability may not understand ordinary safer sex information, experience suggests that individual educational responses are effective in helping people make more informed choices in relation to HIV and sexual behaviour (McCarthy & Thompson 1992).

Method

The operation of the project involved four stages, although this paper concentrates on reporting and discussing stage 1, which was the responsibility of the author:

- (1) a questionnaire survey to local services to map the issue and identify support needed;
- (2) an interest group from the contacts made through the survey;
- (3) support and information for local staff through a training day;
- (4) dissemination through a conference, and publication of a report and summary findings.

It was hoped that the project would lead to further work focused on the needs of this group of men, and the development of special services, educational materials and service competence in this area.

Coverage

The survey aimed to cover all residential, day support, peripatetic and specialist services for people with learning disabilities in Lewisham, Lambeth and Southwark. Intensive liaison was undertaken over the telephone to maximize coverage with the main service providers. Most services were briefed about the survey. In addition, two major local providers, Southwark Consortium and Southside Partnership, liaised with the residential service components of their service. Some gaps in coverage in public-sector-led services were plugged by a second round of questionnaires. The survey was conducted in early 1993.

Questionnaire package

The survey package comprised a covering letter, information sheets about the project and research topic, and two questionnaires. Questionnaire 1 covered the service and questionnaire 2 individual service users for whom this behaviour definitely or possibly applied. Simple instructions for completing and returning the questionnaires, and an explanation of procedures for safeguarding confidentiality were included (copies of the information sheets and research instruments are available from the author on request).

Responses

The problems associated with recognition and under-reporting have been identified (Turk & Brown 1993) and a similar model is helpful for this survey. Like sexual abuse, a major barrier is recognition, but unlike sexual abuse, cottaging is not of general management or practice concern, and is not a widely acknowledged activity within learning disability. A predominantly heterosexual social environment in community services creates barriers to externalizing cottaging as a practice issue. It is probable that reporting is limited compared with sexual abuse because the issue tends to come to the attention of staff and managers as a result of a crisis (Cambridge 1994).

The services contacted included residential, day support, employment, counselling, peripatetic resources, and a number of specialist sexuality and HIV services possibly providing support to people with learning disabilities. A total of 115 service contacts were made and 26 service questionnaires (questionnaire 1) were returned (a response rate of 23%). A total of 34 user questionnaires (questionnaire 2) were returned by the 26 services participating in the study.

The potential problem of double-counting people supported by more than one service was addressed by screening questionnaires for similar patterns of behaviour and profile characteristics. The relatively low response rate means that the survey findings need to be interpreted with caution, although it has to be acknowledged that cottaging is unlikely to be an issue for services supporting less able men who do not have independent access to the community.

A small number of services also reacted negatively to the challenging nature of the subject. Moreover, experience in other prevalence surveys suggests the results are likely to be a considerable underestimate (Brown *et al.* 1995).

Analysis

Both questionnaires were analysed using a statistical analysis package (SPSS, 1990). All user-level information on the data base was anonymized using identification codes provided by the services themselves. Service identification codes were also held separately.

The analysis involved a process of coding, data entry and simple statistical examinations such as frequency counts, percentages and averages. The aim was to provide counts of each of the answers given to particular questions. This was generally a yes/no answer, although there were some multiple-answer questions. Open-ended responses were examined and post-coded into naturally occurring categories. The number of questionnaires returned and the nature of the information provided meant that complex statistical procedures were inappropriate.

Results

Services (questionnaire 1)

Service functions

Table 1 summarizes the functions of the 26 services responding. The majority (15) were residential or had residential components. Of the 10 services indicating other functions, most provided forms of outreach or sessional support (three) or therapeutic resources (seven). None of these functions are

Table 1 Service functions

| | Number | Percentage |
|----------------------|--------|------------|
| Day services | 8 | 31 |
| Residential services | 15 | 58 |
| Peripatetic services | 2 | 8 |
| Education services | 6 | 23 |
| Other | 10 | 39 |

mutually exclusive, with some services responding that they performed more than one function.

Behaviours of users

Services were asked if they worked with any men with learning disabilities who displayed a range of behaviours which could be indicators that they were having sex with other men or sex in public places, or were subject to sexual exploitation or abuse. The indicators in Table 2 comprises the checklist.

These indicators in Table 2 give an impression of the frequency of different behaviours which definitely or possibly relate to sex with men, which is of value for risk assessment and ascertaining the rights of individuals and the responsibilities of services. These should be used in combination, not individually, although some are clearly stronger indicators than others. For instance, an unexplained sexually transmitted disease is evidence that sex, probably unsafe sex, has taken place. However, being picked up by the police for cottaging also reflects the way gay space is policed by society and is not necessarily a definite indicator, so the indicators have to be interpreted carefully and in combination (the training and advocacy components of the

Table 2 Behaviours of users

| | Number | Percentage |
|---|--------|------------|
| Has sex with other men with learning disabilities | 12 | 46 |
| Cottages or has sex with men in similar places | 8 | 31 |
| Has been picked up by the police for cottaging | 7 | 27 |
| Has talked about sex with men or sex in public toilets | 12 | 46 |
| Has been seen hanging around public toilets or similar places | 9 | 35 |
| Has had an unexplained sexually transmitted disease | 3 | 12 |
| Shows signs that they might be having sex with other men, e.g. soiled underwear | 6 | 23 |
| You know little about how he spends his time | 20 | 77 |
| Has contacts with men who don't have learning disabilities | 12 | 50 |
| Has unexplained presents, money or cigarettes | 6 | 25 |

project were designed to follow up and tackle these considerations).

Knowledge about and proximity to places where sex takes place outside services has affected user behaviour in a significant proportion of services. The last group of indicators are signs that sexual activity of a potentially exploitative or abusive kind may be taking place, but these need to be interpreted as part of a considered risk assessment exercise.

When asked directly whether any service users were men with learning disabilities who cottaged or had sex with men in public places, five services indicated definitely and eight services possibly yes. On the basis of these answers, services were then asked to complete a separate questionnaire for each user for whom this behaviour applied. Information about individual service users in this group is provided in the section 4 on 'users' below.

Service responses

Services were asked whether they had discussed the possibility of men with learning disabilities having sex with men. Over half (15) responded that they had discussed this possibility in relation to sex between men with learning disabilities, 11 in relation to men with learning disabilities having sex with other men and 11 in relation to men with learning disabilities having sex in public places (categories not mutually exclusive). Nine services (over one-third of respondents) said that they had not discussed the possibility of men with learning disabilities having sex with men. Services which had discussed the possibility were asked to describe their discussions. These included the following:

'The issue was discussed because a client is keen to use local public toilets regularly.'

'It is being discussed because of long absences and reported sightings near a cottage in a local park.'

'One of the men our team supports has recently started to explore his sexuality. We've tried to get him into a sexuality class but it's totally oversubscribed, so we're trying to set up a group within our own service.'

'Discussions around formulating a sexuality policy.'

'In the context of groups for parents of young people with special needs.'

'Around the rights of gay men and the risks of unsafe sex.'

'Discussed in sex education and with individuals, the latter being in a reactive rather than proactive way.'

'We discuss whether there is an element of abuse to consider in some sex relationships between men and whether a particular client might be cottaging.'

The rationales for discussion ranged from inclusion in general staff training or meetings (10 services) to responding to identified client behaviour (four services). One service discussed this in the context of the parents' group. It is evident that those services which had raised or discussed the issue were at a marked advantage when the issue surfaced as a result of identified user behaviour. They had time to think about the issue in a considered way, take management or policy guidance, and codify appropriate responses into staff culture.

Services were also asked whether they did any work with users on personal relationships, sexuality and sexual health: 77% (20) indicated that they did such work. Of these, 15 indicated that this included work on sexual relationships between men. This group was asked to describe their work. Responses included groupwork (four), individual advice and sessions (seven), and using various sex educational resources (although the evaluation could not assess the quality or appropriateness of group or individual work).

One of the services responding was a specialist service working with men through group therapy, individual counselling and outreach for men not in receipt of other services. Their responses are illustrated as follows:

'We are using the *My Choice-My Own Choice* video. The reference to gay sex is limited, but it at least puts the issue on the agenda (SELHPS 1992).'

'We talk about gay relationships with residents in an open way but not in specific detail.'

'This is in the context of supporting and reassuring the client around his choice of sexuality and attempting to educate him around the use of condoms, not in the context of service-wide issues such as policy or procedures.'

'In relation to working with individuals over consent and safety.'

It is evident from the above that the specialist service had the skills and competence to work in

valued and constructive ways with users about their sexuality, reducing the risks of HIV and exploitation in particular. A case can be made for the use of such specialist resources outside mainstream competence in this area (Cain 1992).

Users (questionnaire 2)

Thirteen out of the 26 services responding reported that they supported men who cottaged or had sex with men in public places. For the other 13 services, this was not perceived to apply. An introductory question was asked to cross check the responses with the information given in questionnaire 1. There was a rough balance between men who were said definitely to cottage (16) and men who were said possibly to cottage (18).

Cottaging

Services were asked to describe cottaging behaviour. Descriptions ranged from open discussions with users who told staff about their cottaging (three), where it was known users cottaged (four), to being seen around public toilets (seven), charging for sex (one), or less-specific responses such as spending long periods outside the service in places such as parks (five) or simply away (three); for instance:

'He has access to the rent scene and uses arcades in the West End.'

'He has a gay identity and is on the gay scene.'

'He has disclosed having sex with strangers and for payment.'

'He visits the local cottage up to seven times a week and has regular unprotected anal intercourse.'

The above selection of responses are representative of a group of men receiving specialist support for their sexuality. It can be seen that other services responded in similar ways:

'He cottages in public toilets, and Hampstead Heath, Crystal Palace and other parks.'

'He is very sexually active and knows men who cottage.'

'The client has asked people he likes to accompany him to local toilets.'

'He will return home late after visits to a local park and will not talk about what he has been doing.'

'He has been picked up by the police in the park for hanging around public toilets and has been seen talking to young boys.'

'The client meets men in public toilets and goes back to their homes with them.'

Some of the above responses suggest naivety not usually associated with gay-identified and politicized men. Outreach work (Jones 1993) indicates that men who cottage are not necessarily gay-identified. This is also usually the case for men with learning disabilities who have sex with men (Thompson D. 1994). Helping someone adopt a gay identity is not necessarily an answer. The positive aspects of gay lifestyles are largely unattainable for men with learning disabilities (Dowsett & Davies 1992), and attempts to gain access to gay culture may prove disempowering or result in rejection by a disabilist gay elite (Connell *et al.* 1991).

Profiles

The ages of the men in the sample ranged between 17 and 60 years, the median being 30. Thirteen men were aged between 17 and 22. The average age of the men in the sample was 27. Most of the men were in their teens or twenties.

The majority of the men in the sample had good (eight) or very good (19) verbal communication skills (24 and 56%, respectively). Nearly one-third (11) lived in their family home, and over one-third (14) in staffed or unstaffed housing. Two men lived in hospital and two in hostel accommodation. The majority of men in the sample received adult education and/or day support services (10 and 14, respectively).

Sexuality and sexual behaviour

Services were asked about the aspects of each man's sexuality or sexual behaviour which caused concern or challenged the service. This was an open-ended question, and responses ranged from histories of abuse or abusing (two), and approaching staff for sex or inappropriate sexual behaviour towards staff (two) to specific mention of unsafe sex (two).

They were also asked whether the men had sex with other men or women with learning disabilities. Table 3 reports the responses. Nearly 90% of men (30) definitely or possibly had sex with other men with learning disabilities (14 and 16, respectively),

Table 3 Sex with other men or women with learning disabilities

| | Number | Percentage |
|----------------|--------|------------|
| Men | | |
| Definitely | 14 | 41 |
| Possibly | 16 | 47 |
| Definitely not | 3 | 9 |
| No response | 1 | 3 |
| Women | | |
| Definitely | 7 | 21 |
| Possibly | 13 | 38 |
| Definitely not | 7 | 21 |
| No response | 7 | 21 |

while a sizeable proportion definitely or possibly had sex with women with learning disabilities, as the following two responses illustrate:

'He has a steady girlfriend and several other women friends who he may also be having sex with.'

'He is very sexual with people he finds attractive and is known to have sex in the day centre toilets.'

This evidence, as well as that from direct safer-sex education work with users (McCarthy & Thompson 1994), raises difficult-to-answer questions about service responsibilities for protecting the sexual health of users as well as their rights to sexual activity.

Services were also asked whether the police had ever picked him up or become involved. Around half of the men in the sample (15) had been picked up by the police for sexually related behaviours; for example:

'He was cautioned and interviewed about alleged sexual abuse of children and an alleged rape of a woman.'

'Repeatedly picked up by police at a mainline British Rail station.'

A large majority of the men in the sample (30) had talked about their sexual behaviour or their sexual behaviour had been discussed with them. Three men were reported to block any discussion, which is not surprising given that men with learning disabilities tend to hold negative attitudes about sex with men (Thompson D. 1994). Seventeen men had discussed things with a keyworker or member of staff, and six had received counselling, including:

'Group discussion and counselling.'

'Through a men's group.'

'Within a sex-education perspective.'

The above responses came from a specialist service. Other services reported less structured discussions; for example:

'I have talked with him, but he became very embarrassed and uncommunicative.'

'A male member of staff has spoken with him about this matter.'

'He has had little real support to enable him to come to terms with his sexuality positively and few positive role models. His family make it difficult for him to talk about his sexuality.'

'He admits to taking money for sex, but says it is with one partner and not in public.'

Overall, the responses suggest associations of secrecy or guilt common to men who are not open about their sexuality or who have been sexually abused (Charleson & Corbett 1994), and characteristic of times when homosexual behaviour between men was totally criminalized (Weeks 1983). These associations are readily perpetuated in institutionalized settings, and it is probable that some of these men have been penalized in the past for expressing their sexuality, suggesting that help for developing assertiveness and positive self-image is required.

HIV risk

When asked whether the user was having sex which put him at risk of HIV infection, responses reflected high levels of uncertainty. Over three-quarters of the sample (26) were reported as possibly having sex which put them at risk of HIV. Four men were said to be definitely having unsafe sex and four men definitely not having unsafe sex (the research was unable to validate this assessment, such as whether the potential for acquiescence in the non-use of condoms was considered). However, it is evident from the responses below that many providers do not hold a refined understanding of safer sex and risk (Cambridge 1994):

'Advised to use condoms and given a supply but he does not like using them. He gives inconsistent replies when asked if he uses them.'

'He appears not to understand the concept of safer sex.'

'It is unclear if he practises safer sex.'

'His sexual liaisons appear to be exploitative, without the use of condoms.'

'The staff team can only speculate at this moment in time. If he is cottaging, then we don't know if he is practising safer sex.'

Five users were said not to like using condoms and one man had a partner who did not use condoms. For six men, little detail was known about the risks attached to their sexual behaviours. Two men were said to know about safer sex.

Exploitation and abuse

Services were also asked whether the man had been sexually exploited or abused. Around one-third of the men in the sample (11) were reported definitively to have been sexually abused. Fifteen were reported possibly to have been sexually abused; for instance:

'There is evidence that sexual abuse was taking place at a home where he was living when he was younger.'

'He was sexually abused by his father and father's male friend, and was possibly sexually exploited by other men when living in a hostel.'

'He has disclosed physical and sexual abuse by his mother.'

'The ongoing relationship in the cottage appears to be exploitative.'

'He is wandering into situations which he cannot control, with encounters controlled by others.'

'A member of staff in a service was alleged to have abused him and several other users, but the case was thrown out of court.'

'He has had sex for money in the past and we think this may be continuing.'

The above figures and comments on the prevalence of abuse could not be validated, nor was abuse clearly defined. However, these and the responses above are not totally surprising given the findings of studies on the incidence of sexual abuse and learning disability outside a specifically same-sex context (Turk & Brown 1993), and the findings of specialist services who work with men with learning disabilities (Morris 1993). It is also

Table 4 Service responses

| | Number | Percentage |
|----------------------------------|--------|------------|
| Keeping at home | 4 | 12 |
| Supervision when out | 3 | 9 |
| Assertiveness work | 14 | 41 |
| Check for STD | — | — |
| Counselling for HIV | 8 | 24 |
| HIV antibody test | 1 | 3 |
| Referral to psychologist | 2 | 6 |
| Referral to general practitioner | — | — |
| Other referral | 3 | 9 |
| Other response | 22 | |

important not to perceive of abuse as symptomatic of homosexual behaviour rather than of an imbalance of power.

Responses to individual needs

For each of the men in the sample, services were asked how they had responded to his sexuality and sexual behaviour. Table 4 lists the number of men for who each response applied. Multiple responses were given in many cases, indicating that a mix of work and support was often provided.

It has to be acknowledged that this information gives little detail about the quality of response or resources for which referrals were made. Important issues emerge, however. Keeping someone at home or supervision when out may be an attractive immediate response, but the longer-term appropriateness of such aversive options should be challenged. The high frequency of non-averse responses such as assertiveness work suggests that most services are attempting to respond in positive and valued ways.

Keyworking, care management and individual service planning offer formal mechanisms to respond to sexuality, sexual health, personal relationships and social opportunities in a holistic way, but the development of the social care market and diverse organizational arrangements (Cambridge 1992; Cambridge *et al* 1994), risk creating disincentives for best practice and inequities in individual planning and service receipt.

Counselling for HIV needs to be intensive and take account of cognitive ability. It is important that the service agenda does not override individual interests or rights, such as confidentiality and that

informed consent for HIV antibody testing is sought and provided. Services sometimes believe that pushing someone to have an HIV antibody test is the only route open to them without thinking through the consequences of a positive or negative test result for the user or the service, such as who needs to know.

Help needed

Services were asked whether there was any support which they would find helpful in their work with the user. Just over half the sample (16) identified skills or resource deficits in their work with individuals, including advocacy (one), counselling for abuse (three), sex education and sexuality counselling (three), specific sex educational resources (two), and specialist support groups (one); for instance:

'I think his day centre would value constructive support in enabling him to develop positive role models, how to work with his family and how to help him express his sexuality more positively.'

'Ability to help maintain regular contact with his own outreach worker and a gay man's group for people with learning disabilities.'

Other responses referenced help and counselling around past abuse or attraction to children, problems securing mainstream resources such as counselling and psychology, and the need for one to one support on an intensive or regular basis from outside the service, such as counselling or therapy, not uncommon to the needs of young men coming out in family situations (Sanderson 1991).

Discussion

Although the findings are not directly transferable to other services or localities, it would be foolish to assume that this is not an issue to a greater or lesser degree elsewhere. Some of the findings and recommendations are of general relevance:

- Purchasing and commissioning in learning disability should be informed by an awareness of HIV prevention and sexual health, including the special and ordinary needs of men with learning disabilities who have sex with men.
- Service provision in learning disability should be more responsive to the needs of users around HIV prevention and sexual health, including the

needs of men with learning disabilities who have sex with men.

- Specialist HIV/AIDS services should develop the competence to respond to the special needs of people with learning disabilities, particularly in relation to counselling and informed consent for HIV antibody testing.
- Learning disability and HIV resources should be targeted to provide specialist service interventions around safer-sex, including peer education, counselling and group therapy. Special safer-sex educational resources are needed for men with learning disabilities who have sex with men, such as videos and one-to-one materials.
- Policy guidance on service responsibilities for supporting users at risk of HIV, and guidelines for practice and staff training are needed. These should include men with disabilities who have sex with men and their sexual partners.

The role users are playing in HIV prevention, sexual health and peer education has been little explored. An important lesson from the gay community is that self-help and self-organization is an essential response to the group and individual demands imposed by AIDS. Bridges need to be built between gay organizations fighting AIDS and self advocacy groups in learning disability.

Although the gender power dynamic often present in sexual abuse or sexual relationships between men and women with learning disabilities (McCarthy 1993) is absent in sexual encounters or relationships between men with learning disabilities and other men, there remain questions of role, status and power to be further explored: for instance, the adoption of roles and differentiation of fantasy and reality in rough or sadomasochistic sex (Thompson B. 1994), which people with learning disabilities might encounter; or the more subversive expression of power through economic, social and intellectual dimensions. An understanding of such dynamics is critical for ascertaining informed consent for certain types of sex, or the potential for exploitation and abuse in sexual or emotional relationships or encounters.

Assessment also needs to be grounded in an interpretative understanding of the environmental and social conditions, and individual psychological and sexual motivations behind cottaging and related activities, including anticipated outcomes, and the

acts and events leading to them. Services will need to develop their skills in exploring such links in order to assess the risks of abuse and exploitation as well as informed consent for safer or unsafe sex. This necessitates an understanding of how sex is linked with HIV and AIDS, illness, and death. The evidence from HIV prevention work in the gay community (Rooney 1992) and from safer sex work with men with learning disabilities (McCarthy & Thompson 1993) is that these are difficult concepts for individuals to associate with their own behaviours and translate to individual safer-sex strategies or repertoires.

Conclusions

The training day found that outreach work in other parts of the country and specialist local resources considered that this was an essential area for further HIV prevention work. Men with learning disabilities who cottage are at particular risk of exploitation and HIV infection, as demonstrated by the survey.

The survey found that this was a current area of concern in services in the SELHA area, but only important for the minority of services working with more able men. Most services were unable to work proactively. There were a significant number of services which knew that the men they supported were cottaging and having unsafe sex, some also with other men and women inside the service. In relation to the services responding, the survey found that:

- (1) nearly half supported men who had sex with other men with learning disabilities;
- (2) around one-third responded to key indicators that this was an issue, with one in five supporting men who definitely cottaged; and
- (3) the issue was not usually discussed in detail unless it was in relation to identified client behaviour, suggesting most services do not have the skills to respond proactively.

In relation to the men in the sample the survey found that:

- (4) around half definitely cottaged or had sex with men in public places, with behaviours ranging from the use of the gay scene to sex for payment and regular, frequent cottaging;
- (5) this issue was predominantly associated with

relatively young men and men who had relatively good communication skills;

- (6) two in five men definitely had sex with other men with learning disabilities, and one in five with women with learning disabilities;
- (7) over three-quarters of the men were possibly having sex which put them at risk of HIV infection; and
- (8) there was a high reported historical prevalence of sexual abuse or abusing, with about one-third of the men reported to have been definitely sexually abused and around a half to have been possibly sexually abused.

It is reasonable to conclude that a relatively high proportion of the men in the sample are at risk of HIV infection, and that support services need additional direct help in the areas of staff training and indirect help to access appropriate resources for therapeutic and educational work.

Acknowledgements

The project was built upon the work of the few individuals and organizations to have addressed this issue locally, namely: Paul Cambridge, Tizard Centre; David Thompson, Sex Education Team, Harperbury Hospital; James Nichol, Health First; Simon Davies, Southside Partnership; and Steve Morris and Al Corbett, Respond.

I would like to thank David Thompson for his help with the design of the questionnaire and his suggestions for this paper, and June Stein for her help with the analysis. However, the interpretations are my own, and not necessarily those of the Advisory Group, the Tizard Centre or SELHA.

References

- Brown H. & Craft A. (eds) (1989) *Thinking the Unthinkable*. FPA, London.
- Brown H., Stein J. & Turk V. (1995) Report of a second two-year incidence survey on the reported sexual abuse of adults with learning disabilities. *Mental Handicap Research* 8, 3-24.
- Brown H. & Turk V. (1992) Defining sexual abuse as it affects adults with learning disabilities. *Mental Handicap* 20, 44-54.
- Cain H. (1992) Open for learning. *Community Care* 9 July, 14-16.

- Cambridge P. (1992) Case management in community services: organisational responses. *British Journal of Social Work* 22, 495-517.
- Cambridge P. (1994) A practice and policy agenda for HIV and learning difficulties. *British Journal of Learning Disabilities* 22, 134-9.
- Cambridge P., Hayes L. & Knapp M. (1994) *Care in the Community Five Years On: Life in the Community for People with Learning Disabilities*. Arena, Aldershot.
- Charleson N. & Corbett A. (1994) A birthday to remember. In: *Treating Survivors of Satanist Abuse* (ed. V. Sinason), pp. 164-68. Routledge, London.
- Connell R., Dowsett G., Rodden P. & Davies M. (1991) Social class, gay men and AIDS prevention. *Australian Journal of Public Health* 15, 178-89.
- Dowsett G. & Davies M. (1992) *Transgression and Intervention: Homosexually Active Men and Beats*. National Centre for HIV Social Research, Macquarie University Unit, Sydney.
- Jones J. (1993) *Men with Learning Difficulties and Cottageing*. Saturday Seminars, NWTRHA, London.
- MacLeod J. (1992) More than one barrier—HIV and AIDS and men with intellectual disabilities who have sex with men. An educational needs assessment. Victoria AIDS Council, Melbourne.
- McCarthy M. (1993) The sexual experiences of women with learning disabilities in long-stay hospitals. *Sexuality and Disability* 11, 227-86.
- McCarthy M. & Thompson D. (1992) *Sex and the 3R's: Rights, Responsibilities and Risks, A Sex Education Package for Working with People with Learning Difficulties*. Pavilion, Brighton.
- McCarthy M. & Thompson D. (1993) *HIV and people with learning difficulties*. AIDS Dialogue, HEA.
- McCarthy M. & Thompson D. (1994) *Sex and Staff Training: A Training Manual for Staff Working with People with Learning Difficulties*. Pavilion, Brighton.
- Morris S. (1993) Protect and Survive. *Community Care* 30, 12-13.
- Morris S. (1994) You will only hear half of it and you won't believe it. In: *Treating Survivors of Satanist Abuse* (ed. V. Sinason), pp. 159-63. Routledge, London.
- Mulhern T. (1975) Survey of reported sexual behaviour and policies characterising residential families for retarded citizens. *American Journal of Mental Deficiency* 79, 670-3.
- Rooney M. (1992) Risks worth taking. Conference report, SWTRHA, London.
- Sanderson T. (1991) *A Stranger in the Family*. Other Way, London.
- South East London Health Promotion Service (1992) *My Choice—My Own Choice* SELHPS, Pavilion, Brighton.
- South East Thames Regional Health Authority (1993) *The Health of the Nation in South East Thames: Regional HIV Prevention and Sexual Health Strategy*. Directorate of Public Health, Bexhill-on-Sea.
- SPSS (1990) *SPSS/PC+40 Base Manual*. SPSS Inc., Chicago, IL.
- Taylor-Laybourn A. & Aggleton P. (1992) *HIV Health Promotion Needs Assessment for Men who have Sex with Men in Camberwell: Final Report*. Kings HIV and GUM and Goldsmith's College, King's Health Care, University of London.
- Thompson B. (1994) *Sadomasochism*. Cassell, London.
- Thompson D. (1994) Sexual experience and sexual identity for men with learning disabilities who have sex with men. *Changes* 12, 254-63.
- Turk V. & Brown H. (1993) The sexual abuse of adults with learning disabilities: results of a two year incidence survey. *Mental Handicap Research* 6, 193-216.
- Weeks J. (1983) *Coming Out: Homosexual Politics in Britain from the Nineteenth Century to the Present*. Quartet, London.

Received 23 September 1994; revised 27 February 1995

Ref. 2.1.b.

Cambridge, P. (1996b) Assessing and meeting needs in HIV and learning disability, *British Journal of Learning Disabilities*, 24 (4), 52-57.

Assessing and Meeting Needs in HIV and Learning Disability

Paul Cambridge is Lecturer/Service Department Consultant in Learning Disability at the Tizard Centre, University of Kent at Canterbury.

The aim of this paper is to identify progress and explore issues in relation to HIV prevention and safer sex education for people with learning disabilities. A number of practical, conceptual and political questions surface in relation to assessing and meeting needs in HIV and learning disability. These raise dilemmas for those involved in commissioning services, developing safer sex educational resources or providing safer sex education. The imperative in HIV prevention is to target messages on people who are most at risk of HIV infection, namely men who have sex with men. This paper argues that effective HIV prevention must be relevant to people's lives and behaviours; it has to involve empowerment and therefore sexual and service politics. As a consequence lessons from safer sex and sexual health work by gay men could be used to inform HIV prevention work in learning disability. The paper identifies and outlines these areas and the range of services and interventions available for taking work forward. The ideas and arguments presented have been developed from needs assessment work, reviewing educational resources in staff training and work developing a sex education and staff training resource on HIV and learning disability.

Introduction

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

The de-gaying of AIDS by HIV prevention campaigns in the 1980s aimed at heterosexuals and the subsequent re-gaying of AIDS in the 1980s, in recognition of where the need for HIV prevention and AIDS services is located, has had consequences for the ways HIV risk is perceived, the work of health and social care services for people with HIV or AIDS, the work of health promotion departments and the content and style of safer sex education campaigns. The re-gaying of AIDS has made this

work much more relevant but, also, more political as it is now part and parcel of gay politics and sexual politics more widely. By contrast, we have not seen a similar shift in sex and safer sex education in learning disability, despite evidence that risk lies mainly with men with learning disabilities who have sex with men.

No commissioner or provider of services for people with learning disabilities is immune from the issue. The evidence from sex education (McCarthy & Thompson, 1994), peer education (People First, 1994), counselling and therapeutic services (Morris, 1993), sexual health outreach (Jones, 1993; Cambridge, 1995) and research (Cambridge, in press) clearly indicates the level and location of HIV risk and the need to develop appropriate service interventions and responses effectively targeted on men with learning disabilities who have sex with men.

People with a learning disability who are sexually active, are at risk in a number of different ways: the person who cannot communicate verbally and who is sexually abused; the woman with learning disabilities who sometimes has sex for money or cigarettes; the young person with learning disabilities developing their first sexual feelings or relying on intimate care; and the man with learning disabilities who frequently has unsafe sex with anonymous partners in public toilets.

Men who have sex with men

The disproportional impact of HIV and AIDS on gay and bisexual men is evident from UK statistics from voluntary named testing about known HIV infection and reported AIDS cases:

'By the end of 1993, there had been a cumulative total of 13,015 men with HIV-1 infection acquired via sex with other men, 62% of total infections reported since 1984 ... By the end of 1993 AIDS cases amongst gay and bisexual men comprised 78% of all the adult AIDS cases reported since the start of the epidemic, and 70% of adult cases reported from January to December 1993' (Rooney, 1994).

In recognition of the significance of AIDS for gay men, South East London Health Authority funded research and training on the subject of men with learning disabilities who have sex with men in public places, putting the question firmly on the commissioning agenda (Cambridge, 1994). The needs assessment component of the project indicated that a number of men with learning disabilities in SE London were at high risk of HIV infection (Cambridge, in press), supporting similar evidence from sex education (Thompson, 1994) and needs assessment in mainstream sexual health (Taylor-Laybourn & Aggleton, 1992).

- There was a significant number of men with learning disabilities reported to be possibly or definitely having sex in public toilets (the total in Lewisham, Lambeth and Southwark was 34 men). This is likely to be an under-estimate considering the problems associated with the recognition and reporting of similar issues such as sexual abuse (Brown *et al.*, 1995) and the fact that many men in this situation hide their behaviour because they think it is wrong or contradicts their social or sexual identity (Thompson, 1994).
- Men with learning disabilities who have sex with men in public toilets are at an especially high risk of HIV. Rarely are they in a position to insist on or practise safer sex; they have different sexual partners and are usually penetrated anally or orally by men from a high risk group *'he visits the local cottage up to seven times a week and has regular unprotected anal intercourse'*. A few men in the sample had developed sophisticated cottaging repertoires.
- The median age of the men in the sample was 30 and 80% had good communication skills. They were, therefore, a relatively young and able group of men, although they were supported by a wide range of residential services, including hospitals, hostels, group homes and unstaffed housing.
- Over 40% of the men in the sample definitely had sex with other men with learning disabilities and over 21% definitely had sex with women with learning disabilities. This raises critical questions for managing risk in services *'he has a steady girlfriend and several other women friends who he may also be having sex with'*.
- Risk assessment and risk management skills were poorly developed, although this, in part, reflected the skills of men in hiding their behaviours and reluctance to talk with staff about what they did. Most providers did not hold a refined understanding of HIV, safer sex or the competence to provide educational inputs *'he was advised to use condoms and given a supply but does not like using them and gives inconsistent replies'*.

Users as commodities

Before services can respond it is necessary to acknowledge how disempowered users are in making choices about their lives, including sexual choices. What has happened increasingly over the last five years, with the introduction of the social care market, is that the people

who use learning disability services have, at best, been exchanged and, at worst, traded as commodities (Brown & Cambridge, 1995). Their behaviours, skills, abilities and needs, including their needs for visible things like housing, or challenging behaviour and less visible things like friendships, personal relationships and sexual expression, have been priced and marketed. Yet it is unusual, even with the trend to individual service specifications, to find sexuality and HIV referenced in contracts. Most people are still unable to choose where they live, who they live with or which agency supports them, let alone who they have sex with, what type of sex they have and whether they have safer sex.

The needs gap could be closed by specifying radical models of intervention and support for sexuality, sexual health and learning disability, but radicalism depends on the individual attitudes and behaviours of people who work and live within the learning disability community. Examples of radical and innovative approaches include: the empowerment of women at risk of sexual exploitation or HIV; sex education within a feminist discourse; sexual health outreach; support for the whole person; the provision of safe space outside services; and advocacy and peer education. Such models depend on a political radicalism and activism which may not be well understood by commissioners.

Assessing and recognising need

'Resources and education campaigns have been remorselessly targeted at those at least risk of contracting HIV, as if the priority of preventing an epidemic among heterosexuals had been established at the expense of halting the epidemics that are actually raging throughout the developed world' (Watney, 1993).

This has also been the case in learning disability. Resources available for sex education have been predominantly heterosexual in content and largely avoided HIV. Mirroring the de-gayng of AIDS, they missed addressing the needs of those most at risk of HIV infection, namely men with learning disabilities who have sex with men (Craft, 1991; Dixon, 1991). While more recent resources make limited reference to HIV, safer sex and homosexuality between men (McCarthy & Thompson, 1992; SELHPS, 1992) or with pictures which neutralise gender by using androgynous images (LSS, 1992), there continues to be a barrier to the equal and equivalent treatment of homosexuality in image or representation, despite increasing reference to men who have sex with men (WLHPA, 1995; FPANSW, 1993). Using puppets, one video resource (WLHPA, 1995), depicts the anus on the men who have sex with men as a stitched seam with shadow penetration, while, in the heterosexual sequence, there is an explicit representation of a vagina and penetration. Critical safer sex messages, such as how to use a condom properly during anal sex and after ejaculation are consequently blurred for the highest HIV risk group.

We need to use explicit and accurate images of men having sex with men in safer sex education materials and any debate about the level of explicitness of such materials is less relevant considering the imperative of HIV prevention. The use of erotic and sexually explicit images in safer sex education materials targeted at gay

men is based upon the view that they will reinforce a positive self-image and a positive image of (safer) sexual activity (Deverell & Rooney, 1994). They may not produce the same response for men with a heterosexual identity. Many men with learning disabilities who have sex with men have negative self-images concerning their sexual behaviour. Unless this disincentive to practising safer sex is removed, it seems likely that people will react adversely to the implied morality of the educator or the sex education materials.

This is not to say that all images of men having sex with men should be positive. It is important to acknowledge that sexual exploitation and abuse exists in a homosexual as well as heterosexual context. We also know from research into the patterns and occurrence of sexual abuse that most abusers are men who abuse men as well as women with learning disabilities and that a high proportion of the men who abuse also have learning disabilities (Brown *et al.*, 1995).

Language and communication

Similar constraints to the use of visual images also apply to our use of language to create barriers to effective communication. The social suppression of sexual diversity, resulting in the denial of sexual realities has led to a reluctance to use explicit language in sex and safer sex educational materials. This stopped when gay men started producing materials and information relevant to the lives and needs of gay men. This emphasised the importance of the language used by gay men and suggested other lessons, potentially transferable to work in learning disability (Box 1). A classic example of woolly language in safer sex messages is 'avoid the exchange of body fluids'. This can be simplified to 'don't fuck' or 'suck off', but can be made less prohibitive and more enabling by adding 'without a condom'. Some language used in resources designed for work with people with learning disabilities has been similarly ambiguous or simply missing, although good resources should encourage the educator to use people's own words. An example of the latter is the video on safer sex acted by people with learning disabilities (SELHPS, 1992).

The complexity of need

The complexities surrounding the transmission of HIV and treatment of AIDS have always been simplified, to a greater or lesser extent, in health promotion and HIV prevention work, including safer sex work with people with learning disabilities. For instance, risk is presented as high, medium or low, and key messages about the number of sexual partners and using protection for penetrative sex are presented outside other factors which help assess risk, such as how condoms are used or the presence of other infections. This has also been the case in safer sex education in learning disability. There are sound arguments for not distinguishing between HIV and AIDS (McCarthy & Thompson, 1994), but many people with learning disabilities, who are sexually active, are also relatively able. Distinguishing between HIV and AIDS could help them appreciate the importance of continuing to practice safer sex in view of the long timescales and uncertainties involved in HIV infection and the development of AIDS.

The central question is how best to meet the needs of people with learning disabilities for information on HIV, AIDS and safer sex without excluding them from sexual opportunities or exposing them to avoidable risk. The differences between HIV and AIDS are very real in relation to lifestyle (such as hospitalisation, medication and social care). Sex education should aim to differentiate HIV and AIDS because of the different consequences.

A challenging example is HIV testing. It is arguably impossible to give informed consent for HIV antibody test (from anyone, with or without a learning disability) without understanding the differences between being HIV negative or positive (which is what the test indicates) and having an AIDS related illness. Ten key questions and answers (with some more complex secondary questions in brackets) help illustrate this argument and provide a useful reference when assessing informed consent for an HIV test for a person with learning disabilities (Box 2). There are also compelling arguments that such assessments should come from outside

Box 1. Lessons from gay men's safer sex education experience

- Don't pathologise individuals or their behaviours
- Never impose a moral framework and work to individuals' own assumptions and agenda
- Don't marginalise HIV as an issue in services or general day-to-day work
- Recognise the reality of risk groups and risk behaviours and develop risk assessment skills
- Respond with practical support to reduce or replace risk behaviours, rather than trying to limit sexual expression
- Reflect the realities of sexual experience through language and image
- Encourage positive images about self and sexual preference (identity for gay men or behaviour for men who have sex with men)
- Promote assertiveness and negotiation for safer sex within and outside relationships
- Use HIV testing only as part of an individual strategy to manage HIV risk
- Provide a safe and confidential environment for this work

services and that weight should be given to the very real drawbacks involved in HIV testing (Tatchell, 1994).

Responding to need

These considerations informed a set of booklets on HIV and AIDS for people with learning disabilities and their staff and carers, which the author was asked to revise (Cambridge, 1995). The original booklets did not differentiate HIV and AIDS and made no reference to same sex relationships or sex outside relationships. This needed to be addressed by including homosexual sex as a valid sexuality and casual sex as a reality, rather than portraying heterosexual monogamous relationship as ideal. This is also more in line with the experiences of people with learning disabilities.

The booklet on HIV and AIDS produced through self advocacy and peer education in learning disability (People First, 1994) also makes a connection between HIV and AIDS, but in abstract and complicated ways. Resources need the capacity to address this difference simply. More attention also needs to be paid to the potential risks of HIV infection through oral sex. Men with learning disabilities are as likely to be in a passive position in relation to oral sex with men as they are with anal sex (Thompson, 1994). The, albeit, low risk of contracting HIV from oral sex, lies in possible transmission through semen and pre cum. Some sex educators choose to prioritise safer sex messages on high risk activities, arguing that it is unreasonable to expect people with learning disabilities to use condoms for oral sex when this has not been taken up by the general population (McCarthy & Thompson, 1994). An Australian video

resource adopts a different approach, depicting all sex between two people with a condom, thus offering an unambiguous message (FPANSW, 1993).

The use of words like 'fuck', 'suck' and 'spunk', were preferred because most people know what they mean. More medical terms like 'intercourse', 'semen', 'oral sex' and 'anus' are often used by practitioners in positions of authority over people with learning disabilities. 'Fuck' is certainly a word more able and sexually active people with learning disabilities are likely to know or encounter and is less ambiguous than 'doing it' or 'getting on top'. People need to be empowered through language, not just to communicate more precisely about consenting sex, but also about safer sex.

Meeting need

Most people with learning disabilities do not have their sexual, emotional and sexual health needs adequately assessed and identified. The reasons are their lack of meaningful involvement in case reviews and planning meetings and lack of power in asserting their needs and wants. Commissioners are usually responsible for the core tasks of care management, including assessment and individual service planning, and are therefore in a position to ensure sexuality and sexual health are properly represented. Box 3 identifies ten key areas for integrating work on sexuality and HIV into individual programme and service planning systems.

Even with a multi-agency approach to sexual health in learning disabilities, barriers exist between mainstream sexual health services (GUM and HIV testing and counselling), GP purchased services and specialist ser-

Box 2. Questions to help assess informed consent for an HIV test

What is a blood test/HIV test?

(how is it taken and how long will you have to wait for the result?)

Do you know what it shows/tells and does not show/tell you?

(do you know it will not tell you if and when you might get AIDS, get ill or die or whether or not you will get HIV or AIDS in the future?)

Do you want an HIV test?

(why/what reasons?)

Do you think you have HIV?

(how could you have got it and why?)

How do people get HIV?

(and what can people do so they don't get HIV?)

How will you feel if you are HIV positive?

(what will you do (feel like doing/not doing) if you are HIV positive/negative?)

How will you feel about having sex and safer sex, relationships and friendships

(now and in the future?)

What happens to someone with HIV?

(do you know what AIDS is, how long it may take to get AIDS and what happens to people who have AIDS?)

Who would you tell and why?

(what do you think they would say/do/think and would they tell other people?)

What help and support do you think you would need?

(in thinking/worrying/coping with HIV/AIDS?)

Box 3. Areas for integrating work on sexuality and HIV into individual plans

negotiating skills

(negotiating use of condoms and consent to sex and risk)

expressive and receptive communication skills

(understanding requests and saying or signing 'yes' or 'no' to sex, safer sex and condom use)

assertiveness skills

(confidence when to say 'yes' and reject unwanted or unsafe situations)

life skills

(access to condoms and sexual opportunities, including knowledge about HIV and safer sex)

social skills

(ability to utilise sexual and social opportunities to affect constructive experiences and learning opportunities)

adaptive behaviour skills

(ability to use condoms properly and effectively during sexual encounters)

personal presentation skills

(self care and the ability to affect a positive personal image)

self motivation skills

(motivation to protect sexual and emotional health through a positive self-image and self-worth)

independence skills

(determining one's own wants and life goals and functional capacity to achieve them)

personal relationship skills

(capacity and robustness to make and break personal relationships and express emotions)

vices working in HIV and learning disability. A solution would be to top slice both the learning disability and HIV budgets to protect adequate resources for developing sexual health services and resources in learning disability.

Commissioners are likely to need to consider the following interventions and models in HIV and learning disability. The pattern will ultimately depend on the identification of local needs, how resources are matched to needs and service principles and philosophies.

- Specialist sex education through one-to-one work and group workshops, available free and according to need.
- Self advocacy and peer education have proved an effective model in HIV and safer sex education for young people and there are good examples of peer education in HIV and learning disability.
- Joint projects involving young gay men and men with learning disabilities who have sex with men could also be developed, including befriending and support schemes.
- Specialist counselling and therapeutic services for people with learning disabilities who are at risk of HIV, to respond to issues such as HIV antibody testing, valid consent and confidentiality.
- Sex education for young people with learning disabilities and parallel training for parents and staff in special schools.
- Training for staff and managers in learning disability services on sexuality and HIV to develop the

competence of services, not only to support the sexuality of services users, but in HIV risk assessment and risk management skills.

- Specialist training for certain staff able to develop key roles and functions within services in relation to sexuality and HIV, such as sex and safer sex education, leading risk assessment and reporting and managing sexual abuse.
- Policy development on sexuality, including HIV (and sexual abuse), designed to go hand in hand with staff training and an assessment of user needs. This is required to pick up on key practice issues and develop tailored local responses.
- Assertiveness training for users, including communication and negotiation skills. This would need to be part of wider work helping people develop a positive self image and say 'no' to abusive or unsafe sex.
- Training in learning disability for staff and managers in GUM, HIV counselling and nursing and other HIV/AIDS related services provided by the NHS and voluntary organisations.
- Staff training and sex educational resources which place a priority on risk and convey unambiguous messages about sex and safer sex in relation to the sexual realities and experiences of people with learning disabilities.

References

- Brown, H. and Cambridge, P. (1995) Contracting for change: Making contracts work for people with learning disabilities. In T. Philpot and L. Ward (eds) *Values and Visions: Changing Ideas in Services for People with Learning Difficulties* (pp. 148–63). London: Butterworth Heinemann.
- Brown, H., Stein, J. and Turk, V. (1995) The sexual abuse of adults with learning disabilities: Report of a second two year incidence survey. *Mental Handicap Research* 8(1), 3–24.
- Cambridge, P. (1994) A practice and policy agenda for HIV and learning difficulties. *British Journal of Learning Disabilities* 22, 134–9.
- (1995) *Respond Outreach Research Project: Final Report*. London: Respond.
- (1996) *What You Need to Know about HIV and AIDS*. Kidderminster: BILD.
- (in press) 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 (3).
- Craft, A. (1991) *Living Your Life: A Sex Education and Personal Development Programme for Students with Severe Learning Difficulties*. Wisbech: Learning Development Aids.
- Deverell, K. and Rooney, M. (1994) Using sexually explicit materials for safer sex work with gay men, HIV project, North Thames Regional Health Authority, London.
- Dixon, H. (1991) *AIDS and People with Learning Difficulties*. Kidderminster: BIMH.
- FPANSW (1993) *Feeling Sexy, Feeling Safe* (video). Family Planning Association of New South Wales.
- Jones, J. (1993) Men with learning difficulties and cottaging. Saturday seminars, North West Thames Regional Health Authority.
- King, E. (1993) *Safety in Numbers*. London: Cassell.
- LSS (1994) *Take Care of Yourself: Safer Sex and People with Learning Disabilities*. London: Lewisham Social Services.
- McCarthy, M. and Thompson, D. (1992) *Sex and the 3 Rs: Rights, Responsibilities and Risks*. Brighton: Pavilion Publishing.
- (1994) HIV/AIDS and safer sex work with people with learning disabilities. In A. Craft (ed.) *Practice Issues in Sexuality and Learning Disabilities* (pp. 186–201). London: Routledge.
- Morris, S. (1993) Protect and survive. *Community Care*, 30 December, 12–13.
- People First (1994) *Everything You Ever Wanted to Know About Safer Sex but Nobody Bothered to Tell You*. London: People First.
- Rooney, M. (1994) Information file, HIV project, North Thames Regional Health Authority, London.
- SELHPS (1992) *My Choice, My Own Choice* (video). South East London Health Promotion Service. Brighton: Pavilion Publishing.
- Tatchell, P. (1994) *Safer Sexy*. London: Freedom Editions.
- Taylor-Laybourn, A. and Aggleton, P. (1992) *HIV Health Promotion Needs Assessment for Men who have Sex with Men in Camberwell: Final Report*. London: King's Healthcare.
- Thompson, D. (1994) Sexual experience and sexual identity for men with learning disabilities who have sex with men. *Changes* 12(4), 254–63.
- Turk, V. and Brown, H. (1993) The sexual abuse of adults with learning disabilities: Results of a two year incidence survey. *Mental Handicap Research* 6(3), 193–216.
- Vatney, E. (1993) Powers of observation: AIDS and the writing of history. In *Practices of Freedom*. London: Rivers Oram.
- VLHPA (1994) *Piece by Piece* (video). London: West London Health Promotion Agency.

Disability Newsletters

Healthworks

FOR FURTHER INFORMATION
ABOUT HEALTHWORKS MEDICAL
INFORMATION SERVICES & PRODUCTS LOOK AT OUR
INTERNET SITE AT:

<http://www.healthworks.co.uk>

Assistive Technology Monitor

Keeps readers up-to-date with the latest developments in assistive technology worldwide. Covers such topics as : *Augmentative communication, Environmental Controls, software, Touch Keys, Touch Screens, Alternate keyboards, Speech Synthesizers, Interface Devices, Voice Recognition, Optical Recognition, Screen Readers, Switches, Switch Software, Book Reviews, Business News and details of assistive technology events worldwide.*

It is packed with information for anyone who needs to be aware of what is currently happening in this exciting field.

Assistive Technology Monitor

Published 6 times a year.

e-mail version : £95.00 (anywhere in the world)

UK & Europe £175.00 print version.

Rest Of the World £195.00 / \$285.00 print version.

Disabilities Informer

Enables care professionals to easily locate the latest information available on disabilities around the world. Covers both traditional print-based : *newsletters, magazines, journals, reports, brochures, books, manuals and directories* as well as new electronic media : *Internet & commercial Online Services, CD Roms, electronic books, on-disk publications, video and audio tapes, audiotext and faxback services.*

An essential resource guide for care professionals and others involved in the provision of information, services and products for people with disabilities.

Disabilities Informer

Published 6 times a year.

e-mail version : £65.00 (anywhere in the world)

UK & Europe £95.00 print version.

Rest Of the World £125.00 / \$190.00 print version.

To order either of these publications please send your order to the address below, stating which format you require. Please make cheques payable to 'Healthworks Limited' or call the credit card line : 0113 243 9899 (24 hours)
**Healthworks Limited, 30-38 Dock Street,
Leeds LS10 1JF, England**

Ref. 2.1.c.

Cambridge, P. (1997a) How far to Gay? the politics of HIV in learning disability, *Disability and Society*, 12 (3), 427-453.



How Far to Gay? The Politics of HIV in Learning Disability

PAUL CAMBRIDGE

Learning Disability and Service Development Consultant, Tizard Centre, University of Kent, Canterbury, Kent CT2 7LZ, UK

ABSTRACT *This paper examines work in sexual health and HIV prevention in services for people with learning disabilities from a political stance associated with the re-homosexualisation of AIDS in Britain. Arguments are made for the re-homosexualisation of AIDS in services for people with learning disabilities, based on evidence of where HIV risk lies in relation to men with learning disabilities who have sex with men. This provides an opportunity to critically review approaches and responses to HIV risk assessment and risk management in services for people with learning disabilities, with reference to the assumptions which underpin practice and issues of sexual identity. The case is made for a more radical sexual politics in learning disability to help combat HIV and to provide more realistic approaches to service commissioning and safer sex education. Pointers for service development and key areas where the re-homosexualisation of AIDS can inform practice and resource development are also provided.*

Introduction

With the benefit of hindsight... one can only conclude that the de-homosexualisation of AIDS has led directly to the marginalisation of gay men's unparalleled experience and contributions to fighting the epidemic, and has ultimately exacerbated the harmful effects of the epidemic on those who are most at risk. (King, 1993, p. 170)

The *de-gaying* of AIDS by Government public health campaigns, health promotion departments, and some gay-led voluntary providers of safer sex education and services to people with HIV or AIDS, had health and political consequences for gay men (BBC, 1995). As a response to the homophobia associated with early years of the AIDS epidemic in Britain, the *de-gaying* of AIDS ultimately led to the mis-targeting of HIV prevention activities away from men who have sex with men, who were and are at most risk of HIV infection, to the heterosexual population, who were at relatively low risk (King, 1993). Organisations like the Terence Higgins Trust, which had gay origins were caught in a cleft stick. They heavily depended on public funding for their service providing activities. Funds were easier to secure if need was presented as general rather than gay-specific.

Gay Politics and AIDS

The subsequent *re-gaying* of AIDS in the 1990s resulted from a reappraisal of gay politics, underpinned by a more radical '*Queer*' identity, and direct action to fight homophobia and AIDS. Campaigning organisations like Gay Men Fighting AIDS and Big Up (for black gay men) helped refocus HIV prevention priorities, and work for and by gay men, backed up on a political front by activists and alliances with groups like OUTRAGE, ACT UP and The Sisters of Perpetual Indulgence (gay men who dress up as nuns to expose hypocrisy and homophobia, and to promote safer sex). This approach avoided collusion with the central political establishment, but successfully impacted on health promotion activities and sexual health outreach by health authorities. What started a gay and lesbian political reappraisal of AIDS is beginning to inform policy and practice in learning disability services, such as in safer sex education and counselling services.

The disproportional impact of AIDS on gay men is evident from UK statistics from voluntary named testing for known HIV infection and reported AIDS cases. Rooney (1994) reported the longer term evidence, stressing that 62% of total HIV infections reported since 1984 were accounted for by sex between men, and that AIDS cases amongst gay and bisexual men comprised 78% of adult AIDS cases reported since the start of the epidemic, and 70% of adult cases reported from January to December 1993. The latest figures from the Communicable Diseases Surveillance Centre [obtainable from the HEAs National HIV Prevention Information Service (NHPIS), 1996], indicates that by the end of March 1996, there were 12 565 reported AIDS cases, with transmission attributed to sex between men for 9079 (72%), between men and women for 1720 (14%) and injecting drug use for 755 (6%). The respective numbers for reported HIV infection out of a total of 26 641 were 16 303 (61%), 4963 (19%) and 2877 (11%) for each group, respectively.

Yet aggregate statistics mask the diversity of sexual behaviours found in any community of interest or identity, be it lesbian, bisexual, gay or people with learning disabilities. It is necessary to unravel this diversity to appreciate the complexities of HIV prevention work. While gay men and other men who have sex with men are a high risk HIV group, there is also evidence to suggest diversity of sexual behaviour, lifestyles and responses to HIV risk within this population. More importantly, while there is a raft of evidence about responses to HIV risk within different populations. Some suggest that safer sex interventions work in reducing HIV infection (Berkelman *et al.*, 1989) and others that an increase in knowledge about safer sex is not necessarily associated with the practice of safer sex (Davies *et al.*, 1993).

Project SIGMA (Social-sexual Investigation of Gay Men and AIDS, Davies *et al.*, 1993) tracked a cohort of more than 1000 gay and bisexual men over a 4-year period examining behavioural changes in response to HIV and AIDS. It demonstrated a wide variety of sexual and social behaviour patterns related to HIV risk, with some evidence of unsafe sexual behaviour as part of rational and formulated responses to managing HIV risk within certain parameters, and some evidence of relapse into more general unsafe sexual practices (Davies *et al.*, 1993). Related

studies illustrate that status in relationships, self esteem, sexual identity and demographic factors such as age contribute to the motivation and sustainability of safer sexual practices (Davies *et al.*, 1992; Hickson *et al.*, 1992; Hunt *et al.*, 1993). Previous research into homosexual behaviour also suggests a variety in relationships, numbers of sexual partners and sexual identities (Kinsey *et al.*, 1948), so differing responses to HIV risk should be assumed. Needs assessment work, HIV prevention campaigns and direct safer sex education should therefore recognise and respond to this diversity, including work in learning disability.

The case for the better targeting of HIV prevention activities and resources is powerfully articulated by King (1993) who observed just 3 years ago that of the 15 or more posts in HIV or AIDS that the Health Education Authority had established, only one was specifically for men who have sex with men, with evidence of budget cuts in HEA funding for campaigns targeting gay men, representing under 20% of the overall AIDS budget (Pink Paper, 1992). The mis-targeting of HIV prevention initiatives by organisations working in the field is echoed by others involved in monitoring HIV prevention activities. Reporting on a national survey of HIV prevention work, King *et al.* (1992) conclude:

It is dismaying that two thirds of the agencies surveyed reported that they were not engaged in any kind of HIV prevention work targeting gay or bisexual men. . . . It is alarming that fewer than 3.5% of the agencies surveyed reported a level of HIV prevention activity targeting gay or bisexual men that could be ascribed as substantial. (King *et al.*, 1992, p. 23)

Recognising HIV Risk in Learning Disability

Competence in HIV risk assessment is similarly required in services for people with learning disabilities to ascertain the nature and location of risk, and to respond with effectively targeted HIV prevention. Informed risk-taking is complex to assess, but a useful parallel is provided by informed consent for sex. Using Brown & Turk's model (1992), sex is abusive if

- the person withholds their consent;
- the person is unable to give their consent; or
- some other barrier to consent is present.

A barrier to consent might include pressures or bribes, or not appreciating the consequences of saying yes to sex. In relation to HIV risk and safer sex, the person would need to know about HIV and AIDS, the health implications and social consequences of unsafe sex, how HIV is transmitted and what happens to someone infected with HIV. Such basic knowledge is a prerequisite to assessing informed consent for sex and safer sex.

The issue becomes more complex when legal factors are considered. In addition to the laws regarding sex and consent which apply to everyone, there are laws about sex and people with learning disabilities (see Gunn, 1996, Sexual Offences Acts,

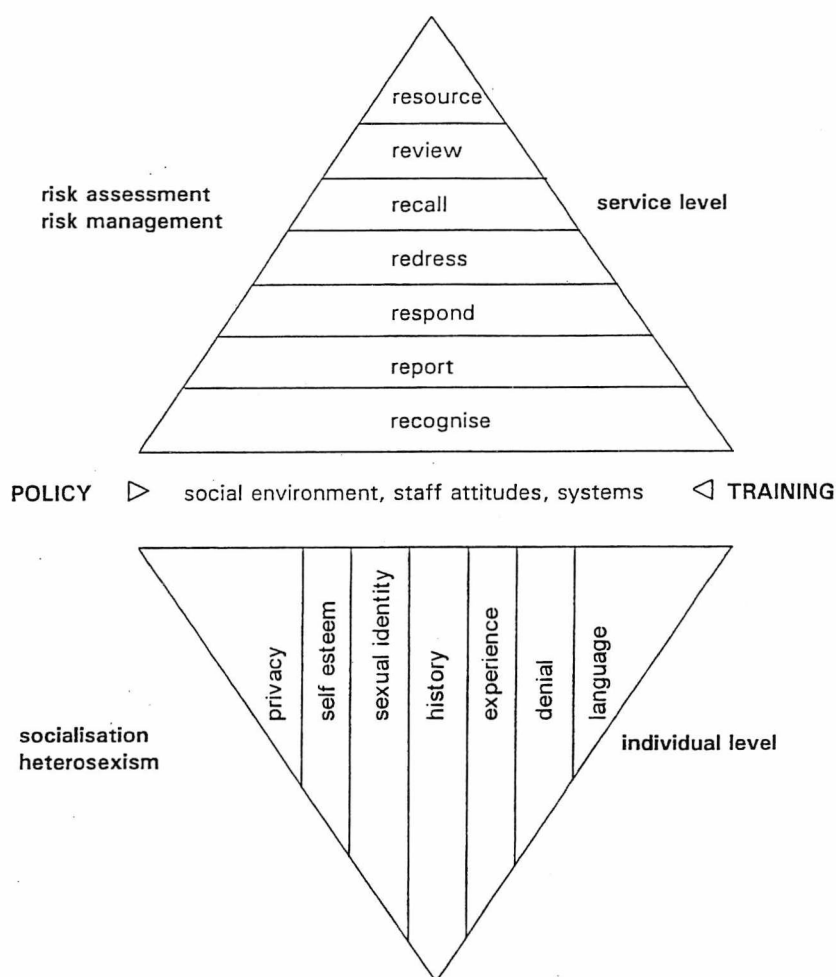


FIG. 1. Disincentives to disclosure, recognition and response in HIV and learning disability (developed from Turk & Brown, 1993).

1956 and 1967), and laws about HIV testing and liability for HIV infection which can be interpreted in the context of learning disability (see Gunn, 1997). What these mean in relation to HIV and learning disability is that services and individuals have various responsibilities when HIV status is known or suspected, and that risk assessment and risk management for HIV are essential activities for best practice.

Recognition of HIV risk in learning disability services remains low compared to sexual abuse and a range of factors contribute to this relative invisibility (Fig. 1). No person with a learning disability who is sexually active or who engages in interactions with other people is free from HIV risk, rather the nature and level of risk will vary. The young person with learning disabilities developing their first sexual feelings or relying on intimate care; the person who cannot communicate verbally and who is sexually abused; the woman with learning disabilities who

sometimes has sex for money or cigarettes; the man with learning disabilities who frequently has unsafe sex with anonymous partners in public toilets.

Men with learning disabilities who have sex with men are less likely to have their needs recognised because of social and practice disincentives. Although anal sex is no longer illegal, the law discriminates against homosexuality in a number of areas (such as the age of consent for sex which is 18 as opposed to 16 for heterosexual sex) and Section 28 of the 1988 Local Government Act, which attempted to outlaw the representation of homosexuality in certain educational contexts. Such inequalities affect attitudes and responses in services for people with learning disabilities (Cambridge & McCarthy, 1997).

This is partly explained by an approach to sexuality which is fundamentally pathological because it sees sexuality as a problem to be managed and focuses on protection, such as in sexual abuse. Homosexuality has similarly presented in relation to challenging or offending behaviour (see Brown & Thompson, 1997) and HIV has helped to reinforce the perception of homosexuality as pathological.

The fight against AIDS is also a fight for individual and collective rights, including the rights of people with learning disabilities. These include the right to protect yourself from HIV, the right to live a full life with HIV, freedom from persecution and discrimination on the basis of your sexuality or HIV status, right to sexual expression and relationships, and to safety from abuse and exploitation (Cambridge, 1996a; McCarthy & Cambridge, 1997). These are difficult rights to extend to people with learning disabilities because they largely depend on formal carers and services to safeguard rights, and being dependent on other people makes it difficult for someone to recognise and demand their rights or to be self-determining (Jenkinson, 1993). Although there are important ways disability politics can learn from gay politics (Corbett, 1994), there is also evidence of a lack of consensus in the ways to best relate gay experience to work in learning disability (as recent debates illustrate, see Thompson, 1995).

Until power is shared and resources more equitably allocated, best management and practice in services can help safeguard rights, respect and dignity, and empower people to make more informed choices about their sexual health and sexual lives (see Davies, 1997 for an example). The development of HIV policies in services for people with learning disabilities can also provide a valued framework for action to address some of the disincentives to best practice (Cambridge, 1997b; Brown & Cambridge, 1997), helping combat resource led decision-making and defensive management practice.

Re-examining Social Constructs

Despite their powerful influence on services for people with learning disabilities, philosophies such as normalisation and social role valorisation (Wolfensberger, 1980, 1984) and their translation to principles for practice, including *An Ordinary Life* (King's Fund, 1980) and the *Five Accomplishments* (O'Brien, 1987), struggle with their interpretation of sexuality and minority sexualities are conspicuous by their absence. They are primarily heterosexist philosophies and their failure to

reference socially marginalised behaviours or interests make the construction of equivalent responses within services difficult for practitioners seeking to support peoples' sexuality on a day-to-day basis in practical ways. Post-normalisation critiques are needed to help navigate heterosexism and arrive at interventions and support grounded in the realities of diversity, individuality and practicality. Adopting a feminist discourse on power and people with learning disabilities, Brown & Smith (1992) observe:

The difficulties of implementing high quality services for them [people with learning 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 & Smith, 1992, p. 149)

Most men with learning disabilities who have sex with men do not have a gay identity (Thompson, 1994b), and remain isolated compared with the political and social and sexual identities lesbians, bisexuals and gay men have constructed through self-organisation (such as Pride) and publishing (such as Pink Pages). There are important differences between homosexual behaviour, homosexual identities and homosexual lifestyles, and many analyses have failed to distinguish between them (Richardson, 1981). 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), forcing the shift from defensive to offensive politics which is continuing in relation to the fight against AIDS.

... the AIDS crisis mobilised the gay and lesbian community by concentrating its focus on a single threat and involving many people who had not been politically active before. (Cruikshank, 1992, p. 182)

The social and political construct of lesbian, gay or bisexual identity is therefore largely associated with lifestyle choices and opportunities falling outside the boundaries of normalisation, and the ordinary behaviours and interventions provided by services for people with learning disabilities. The predominantly heterosexist stance of normalisation and existing support arrangements work against the facilitation of gay identity, as illustrated for example in the reactionary attitudes of residential staff towards mandatory HIV testing of people with learning disabilities (Murray *et al.*, 1995). 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 learning disabilities which do not fall under the general umbrella of heterosexual and which cannot be properly defined as lesbian, gay or bisexual because they do not have the self-recognition or lifestyle attributes constructed by lesbians, bisexuals or gay men.

The work of Davies and colleagues in Project SIGMA (Davies *et al.*, 1993), demonstrates how safer sex is integrated into gay culture and codified in gay

behaviour. Some of the names of the Sisters of Perpetual Indulgence demonstrate this, such as Sister Latex of the Immaculate Protection and Sister Voluptua of the Absolute Condomania. As Davies *et al.* (1993) have commented on the trend to normalise HIV and safer sex:

... incorporating safer sex within existing and other concerns, treating it as inescapable but as only one facet of gay experience, is an important one. Many gay men have devoted our professional lives to HIV and its effects. Sometimes it is easy to forget that for many other men HIV is less central to their existence, less important in their views of the world. (Davies *et al.*, 1993, p. 174)

The marginalisation of sexual identity is mirrored in the construction of a learning disabled identity by people with learning disabilities which has largely by-passed issues of sexual identity. Although there are examples of self advocacy and peer education in HIV and learning disability (Lawnmowers, 1994; People First, 1994; Barber & Redfern, 1996), more action is needed to make a major impact in services. In parallel, many gay men have used their experiences of HIV and AIDS to help direct and inform work in learning disability, with sex and safer sex education, counselling and other projects led or facilitated by gay men (see Thompson, 1994b, for an example). Despite this helping make sexuality in learning disability more visible, building on the innovative work of Craft and colleagues (Dixon, 1988; Craft, 1991), the issues associated with the development of gay and lesbian identities by people with learning disabilities are only beginning to be explored (Davidson-Paine & Corbett, 1995).

Assessing HIV Need in Learning Disability

Health and social service commissioners, care managers and other purchasers of services for people with learning disabilities need to engage the issues of HIV, as there is accumulating evidence that people with learning disabilities are exposed to HIV risk, and that some groups of people with learning disabilities are at high risk of HIV infection. This explodes the myth that people supported by services are protected from HIV or that segregation or institutionalisation are the same as isolation or insulation in relation to HIV. Although little is known about the epidemiology of HIV infection in people with learning disabilities (Simonds & Rogers, 1992), there is evidence that people with learning disabilities have become infected with HIV (Kastner *et al.*, 1989, 1992; Marchetti *et al.*, 1990). There is also powerful indirect evidence of HIV risk in the population of people with learning disabilities: from sex education (McCarthy, 1994; McCarthy & Thompson, 1994; Thompson, 1994b); peer education (Lawnmowers, 1994; People First, 1994); counselling and therapeutic services (Morris, 1993, 1997); mainstream sexual health outreach (Jones, 1993) and outreach for women with learning disabilities (Cambridge, 1996b). These diverse perspectives confirm risk groups and behaviour within learning disability, and point to the imperative to develop appropriate interventions and responses. Moreover, localised but strong evidence exists on the prevalence of

high risk sexual behaviour in the population of men with learning disabilities supported by residential and day support services (Cambridge, 1996c).

In response to the re-homosexualisation of AIDS and visible local needs in learning disability, South East London Health Authority funded research and staff training on men with learning disabilities who cottaged (have sex with men in public places). This put HIV firmly on the learning disability agenda and ring-fenced health promotion resources for work in learning disability (Cambridge *et al.*, 1994). The needs assessment component of the project indicated that a number of men with learning disabilities in SE London were at high risk of HIV, and that safer sex education and management competence needed to be developed in this area of work (Cambridge, 1994, 1996c). The findings alerted commissioners to the risks of not providing preventive interventions for a high HIV risk group, although evidence from needs assessment in mainstream sexual health locally (Taylor-Laybourn & Aggleton, 1992) had suggested that younger men with learning disabilities could be at high risk of HIV.

There are a number of explanations for the vulnerability of men with learning disabilities to HIV risk from unsafe sex in public places. They include both individual and environmental factors (Fig. 1) some of which are within the power of services to influence, but the quality of intervention depends on how accurately need is assessed.

The research was particularly challenging as it was the first example of needs assessment work in HIV and learning disability, and had the task of crossing market and agency divides, and the findings highlighted important considerations for commissioners (and providers) on the service and support needs of men with learning disabilities who have sex in public toilets—known as cottaging (Cambridge, 1996c). The survey identified 13 services where this was recognised as a management and practice issue from the 26 services responding in the survey Boroughs of Lambeth, Lewisham and Southwark. The key findings are summarised below:

- There was a significant prevalence of 34 men with learning disabilities known and reported to be possibly or definitely cottaging (16 and 18 men, respectively). This is likely to be an under-estimate considering the problems associated with the recognition and reporting of similar issues such as sexual abuse (Brown *et al.*, 1995, Fig. 1). Many men in this situation hide their behaviour, thinking it is wrong because they have been socialised as heterosexual (Thompson, 1994b; Cambridge, 1996c).
- Men with learning disabilities who have sex with men in public toilets are at an especially high risk of HIV. Rarely are they in a position to insist on or practice safer sex, they have different sexual partners and are more likely to be penetrated anally or orally by men from a high HIV risk group (see Thompson, 1994). Services were asked to describe the behaviour they considered carried a high HIV risk. Descriptions ranged from open discussions with users who told staff about their cottaging (3), where it was known users cottaged (4), to being seen around public toilets (7), charging for sex (1), or

less specific responses such as spending long periods outside the service in places such as parks (5) or simply away (3), for instance:

He has disclosed having sex with strangers and for payment.

He visits the local cottage up to seven times a week and has regular unprotected anal intercourse.

He cottages in public toilets, Hampstead Heath, Crystal Palace and other parks.

He is very sexually active and knows men who cottage.

The client has asked people he likes to accompany him to local toilets.

He will return home late after visits to a local park and will not talk about what he has been doing.

He has been picked up by the police in the park for hanging around public toilets.

The client meets men in public toilets and goes back to their homes with them.

- The survey asked services to respond to a range of indicators of behaviour, which taken in combination might suggest the men in the sample were cottaging or having sex with men. These are ranked by frequency of response in Fig. 2. Some indicators, such as having an unexplained sexually transmitted disease, are clearly more directly indicative of high HIV risk sexual behaviours. The frequency of responses provide a useful picture for helping risk assessment.
- The median age of the men in the sample was 30 and 80% had good communication skills. They were therefore a relatively young and able group of men, although they were supported by a wide range of residential services, including hospitals, hostels, group homes and unstaffed housing.
- Over 40% (14) of the men in the sample definitely had sex with other men with learning disabilities and over 21% (7) definitely had sex with women with learning disabilities (Fig. 3). The numbers of men for whom staff were uncertain on this question was even higher, pointing to poor risk assessment and risk management skills.

he has a steady girlfriend and several other women friends who he may also be having sex with.

- Services have the difficult task of safeguarding the freedom, privacy and rights of service users, and managing their responsibilities for protecting people from an unacceptable risk of HIV (McCarthy & Thompson, 1992), but this is different from holding poor knowledge of needs as a number of the responses indicate:

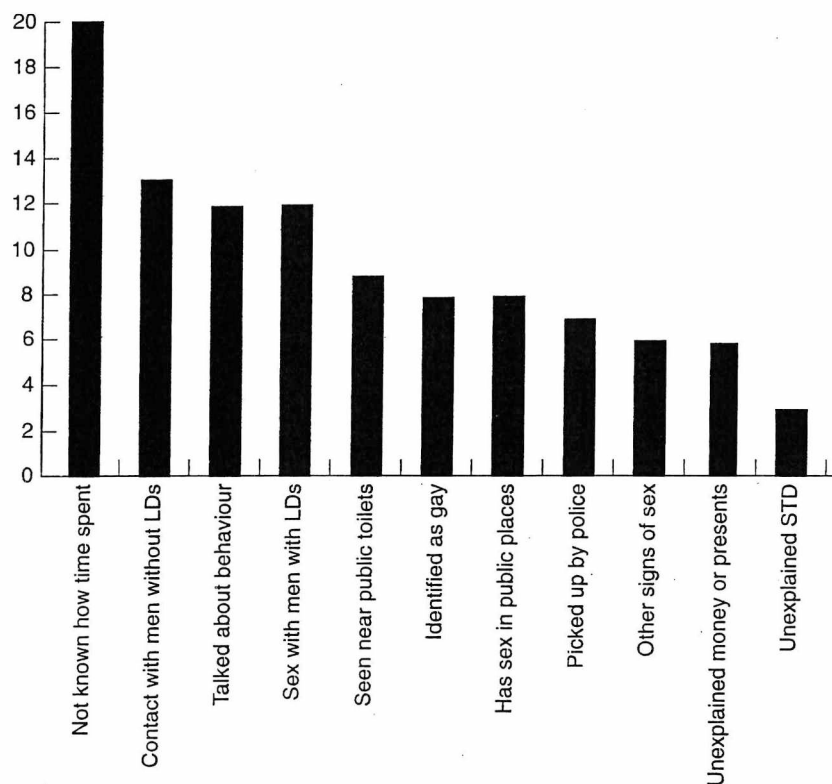


FIG. 2. Indications of behaviour. Number of services = 26. Number of responses = 104.

Advised to use condoms and given a supply but he does not like using them. He gives inconsistent replies when asked if he uses them.

He appears not to understand the concept of safer sex.

It is unclear if he practices safer sex.

His sexual liaisons appear to be exploitative, without the use of condoms.

The staff team can only speculate at this moment in time. If he is cottaging, then we don't know if he is practising safer sex.

- For each of the men in the sample, services were asked how they had responded to his sexuality and sexual behaviour—service and risk management responses varied (Fig. 4). Multiple responses were given in many cases, indicating that a mix of work and support was often provided. Although it has to be acknowledged that this information gives little detail about the quality of response or the resources for which referrals were made, important issues emerge. Keeping someone at home or supervision when out

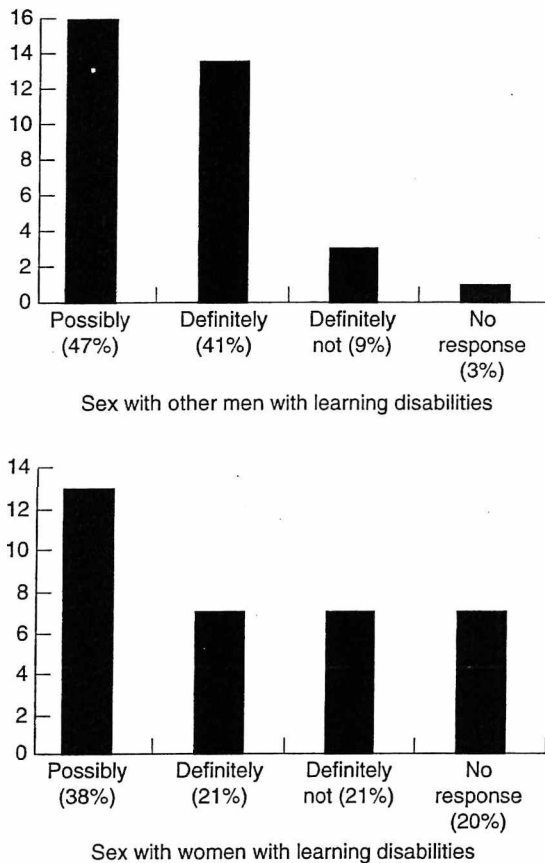


FIG. 3. Complexity of HIV risk in services. Number of cases = 34. Number on which percentage is based = 34.

may be an attractive immediate response but the longer-term appropriateness of such aversive options should be challenged. Similarly, the consequences for the individual and wider implications of HIV testing would suggest extreme caution with such a response (see section below). The high frequency of non-averse responses such as assertiveness work, suggest most services are attempting to respond in positive and valued ways to the problems associated with acquiescence in sexual encounters, including poor negotiating skills for safer sex.

This is an area of need where joint commissioning offers considerable potential, but only if need is recognised and responded to in appropriate ways. There is currently an implementation gap in commissioning and providing HIV competence in learning disability services and competence at working with people with learning disabilities in HIV and AIDS services. Some specialist services bridge the gap (Barber & Redfern, 1997; Morris, 1997), but most people with learning disabilities fall through

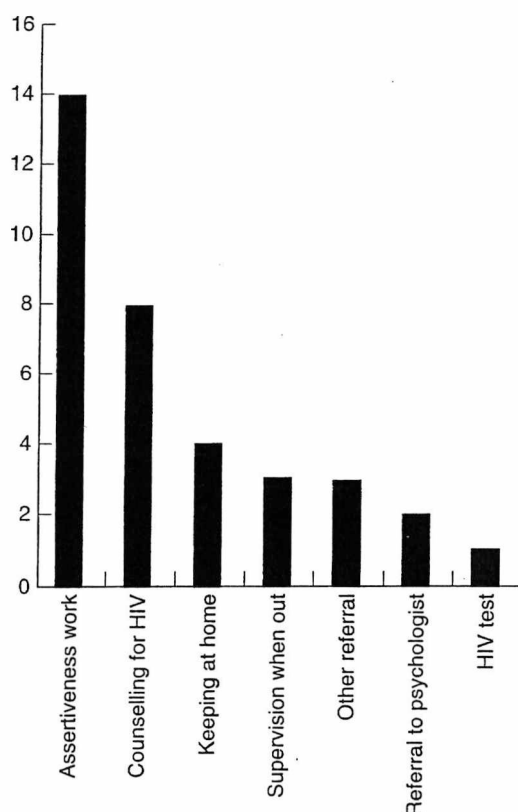


FIG. 4. Services responses to HIV. Number of services = 26. Number of responses = 35.

on issues such as managing informed consent for sex, assertiveness for using condoms (McCarthy, 1994) are valid consent for HIV testing (Murray *et al.*, 1995).

Managing and Challenging the Market

Commissioning can be used to specify radical service models within a coherent philosophy and strategy, and devolved purchasing by care managers can access specialist sexuality and HIV services, and co-ordinate these with residential and day support services. Moreover, assessment is the key task of the care management process (Challis & Davies, 1986). Some models of care management or contracting put the person at the centre of decision making through individualised service specification (Cambridge, 1992; Brown & Cambridge, 1995), although even at the individual level, decision-making by people with learning disabilities is difficult to facilitate or sustain in services (Jenkinson, 1993).

In relation to disincentives to change or divest power Ward (1990) has remarked:

It is unlikely that contracts will change or eradicate... historical prob-

lems... Instead it might be better to see them as a new language to describe old problems. (Ward, 1990, p. 18)

This observation is reinforced by Churchill (1992) by reference to the status of the service user in the market:

bi-lateral contracts will become the norm and... any element of consumer influence must be grafted on to a supplier/purchaser relationship which essentially excludes the person receiving the service. (Churchill, 1992, p. 78)

There are clear structural reasons why needs are not recognised or those which are recognised can be left for another contract or another day. The needs and resources most important to commissioners and providers receive priority, such as housing and staff support, and it is easier to specify these than peoples' sexual health needs. Moreover, commissioners of service for people with learning disabilities do not live in a different moral or social world and their behaviour may reflect homophobia or ignorance of HIV or AIDS held more widely in society, although the local political environment is significant, as the SE London work illustrates.

Users of services for people with learning disabilities cannot be compared with consumers in most other markets and are more akin to *customers* travelling with a warrant on a partly privatised railway system. They have at best been exchanged between agencies and at worse traded as commodities. Their behaviours, skills, abilities and needs, including needs for visible things like housing and challenging behaviour, and less visible things like friendships, personal relationships and sexuality have been priced and marketed. Accountability has become blurred by the contract, because those who provide services are further away from those who fund them. Lines of political accountability have been broken and lines of management accountability fractured.

It is unusual, even with the trend to individual service specifications (Brown & Cambridge, 1995) to find sexuality and HIV referenced in contracts. Most people are still unable to choose where they live, who they live with or which agency supports them, let alone who they have sex with, what type of sex they have and whether they have safer sex. Best practice and provision requires a competence which is difficult to specify through the contract, as it depends on individual values and commitment. It is not just the difficulty of putting best practice into words or assessing performance in meaningful ways, but also of resolving contentious issues through the contract, such as responsibility for managing HIV risk and paying for educational and health interventions.

The needs gap could be narrowed by specifying radical models of intervention and support for sexuality and sexual health, such as the empowerment of women at risk of sexual exploitation or HIV, sex education within a feminist discourse, sexual health outreach, support for the whole person, the provision of safe space outside services, and advocacy and peer education. Such approaches are based on an assertiveness and activism likely to frighten commissioners, a state symptomatic of structural and social inequalities where people with learning disabilities remain

socially, politically and economically marginalised—reflected in their sexual exploitation and abuse (Turk & Brown, 1993; Brown *et al.*, 1995).

Providing lies at the other side of the market divide. The competence of providers to recognise need, take risks supporting sexual expression and protect people from sexual abuse, and HIV is as critical as competence in commissioning. Only a small minority of providers have taken the lead in this area (see Davies, 1997) or have developed sexuality policies so are in a position to lobby commissioners in an informed way for more resources in sexuality and HIV (Cambridge & McCarthy, 1997; Cambridge, 1996b).

A Capable Market in HIV and Learning Disability?

There is a scarcity of specialist counselling, sex education, and therapeutic services in sexuality and HIV for people with learning disabilities. A few specialist services working in sexuality, HIV and learning disability (and often also in sexual abuse) have emerged. They demonstrate the *ad hoc* fashion in which competent and dedicated services have developed.

Respond in London (Morris, 1997) grew from the work of committed individuals who saw that an important need for counselling and therapeutic interventions within a safe space remained unmet. It has to charge for its services on a commercial basis, although local commissioners have funded some limited projects, such as sexual health outreach (see Cambridge, 1996c). Individuals are funded by their commissioners. The Sex Education Team (originally at NW Herts Health Promotion Unit but now Horizon NHS—learning disability—Trust) also developed from practice competence in sex education (McCarthy & 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, other than for consultancy. The Tizard Centre at the University of Kent undertakes policy development and staff training, and some individual work with service users, but has to charge consultancy rates. The current dispersal and location of specialist expertise and financial disincentives to access it suggests inequities, and that a better balance should be struck between individual contracts and longer term development and pump-priming funding.

Commissioners and contract managers have a duty to give preference to those arrangements which generate the most productive outcomes in the lives of the people who use services. There is little objective evidence from evaluation or review of such associations in sexuality and sexual health, and time is scarce for developing radical models in sexual health and learning disability. Pilot or demonstration services, properly evaluated are needed to inform development priorities based on evidence of effectiveness and only a few such examples exist (see Cambridge & Brown, 1997, for an overview).

An evaluation of the outcomes and cost-effectiveness of the interventions described at the end of this paper would require elaborate longitudinal experimental designs and control groups. The exclusion or delay of potentially life saving inter-

ventions to people at risk of HIV infection would be immoral. As Davies *et al.* (1993) have commented:

HIV prevention programs are bedeviled 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)

The task of commissioners is to respond to HIV risk in learning disability by commissioning services targeted on need, despite the probability of reactionary political pressures to the contrary. An equivalent task faces those charged with responsibility for developing effective HIV prevention resources for use with people with learning disabilities.

Matching Resources to Needs

Resources and education campaigns have been remorselessly targeted at those at least risk of contracting HIV, as if the priority of preventing an epidemic among heterosexuals had been established at the expense of halting the epidemics that are actually raging throughout the developed world. (Watney, 1993, quoted in King, 1993, p. 69)

Until very recently, resources available for sex education and learning disability were predominantly heterosexual and avoided HIV. Mirroring the *de-gaying* of AIDS in the late 1980s, they missed the needs of those most at risk of HIV, namely men with learning disabilities who have sex with men (Craft, 1991; Dixon, 1991). While more recent resources make limited reference to HIV, safer sex and homosexuality between men (McCarthy & Thompson, 1992; SELHPS, 1992) or with pictures which neutralise gender by using androgynous images (LSS, 1992), there continues to be a barrier to the equal and equivalent representation of homosexuality. Using video resources to illustrate this point, the anus on the puppets of two men who have sex together in one safer sex video sequence is a stitched seam with shadow penetration, while there is an explicit representation of a vagina and penetration in the heterosexual sequence (WLHPA, 1994). Critical safer sex messages, such as how to use a condom properly during anal sex, after ejaculation and when withdrawing the penis are consequently blurred for the highest risk group. Although using actors and consequently more explicit in its representation of bodies and sexual acts, an Australian video resource (FPANSW, 1993) which includes sequences of penetrative vaginal sex and anal sex between two men, similarly avoids close ups of anal sex, while giving more visual details of vaginal sex.

There are three possible explanations for this apparent reluctance to show explicit images of men having sex with men. Commissioners or producers are homophobic, viewing homosexual sex as lower emotional or physical value than heterosexual sex, afraid of the law as it relates to the portrayal of homosexuality or anal sex or concerned that explicit representation of homosexuality will deter

potential funders, purchasers or users of such resources. In other words, political or commercial concerns come before the imperative to provide well targeted, clear and unapologetic safer sex messages. Recent video and printed safer sex educational materials produced for and by gay men (Tatchell, 1994; THT, 1994) illustrate that explicit photographic images of men having sex with men, including penetrative anal sex, erect penises and semen can be represented in a safer sex educational context.

... 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 & Rooney, 1994, p. 7.)

The effective use of erotic images in the context of safer sex education for gay men raises interesting questions for HIV prevention in learning disability. This is at first sight a different debate from the level of explicitness. While eroticism is arguably a rational strategy for gay men's sexual health promotion, safer sex education in learning disability works to different demands. Using eroticism as a vehicle to deliver a safer sex message could generate problems for sex education, as the message could be misread or the educator could find the material offensive. However, images need to be accurate and culturally appropriate, reflecting the reality of the sexual experiences of men with learning disabilities, but what is culturally appropriate to gay men may not be to other men who have sex with men, including men with learning disabilities.

Despite these considerations, positive images of homosexuality and safer sex are lacking for men with learning disabilities, an important consideration for reducing guilt, denial and negative self-image, and therefore combating disincentives to practice safer sex. The line between eroticism and positive self-image is a fine one to draw, but is a line worth exploring for both practical and political reasons in safer sex education for men with learning disabilities who have sex with men. This is not to say that all images of men having sex with men need to be positive. It is important to acknowledge exploitation and abuse in a homosexual, as well as heterosexual context. Most sexual abusers are men who abuse men, as well as women with learning disabilities and a high proportion of the men who abuse other people with learning disabilities are themselves service users (Brown *et al.*, 1995). This reality, however unpleasant, also needs to be represented.

A creative and innovative resources for work in learning disability (a comment also echoed by staff in staff training exercises) was produced in the Netherlands for sex education with young people with learning disabilities (Marneth, 1994), using effective combinations of photographs, line drawings and overlays. These include pictures of both negative and positive personal and social contexts to sex, different sexual behaviour patterns, erect penises, semen, condoms on penises, semen in condoms, and other considerations essential for explaining consent, safer sex and HIV risk.

Equivalent constraints to the use of images also apply to the use of language,

creating additional barriers to effective communication. The reluctance to use explicit language in safer sex education stopped when gay men started producing materials and information relevant to the lives and needs of gay men. A classic example of woolly language in safer sex messages is 'avoid the exchange of body fluids', which really means 'don't fuck or suck off without a condom'. Some language used in resources designed for work with people with learning disabilities has been similarly ambiguous, although good resources should encourage the educator to use peoples' own words. An example of the latter is the video on safer sex acted by people with learning disabilities (SELHPS, 1992).

It would be a missed opportunity if the experience of gay men in promoting safer sex is not transferred to work in learning disability. A number of potential lessons are evident. The most important is not to pathologise homosexuality or individual sexual behaviour. Rather, the reality of risk should be reflected in targeted sex education outside an irrelevant moral framework. Practical support to practice safer sex is also needed, including access to condoms and help to develop the assertiveness needed to negotiate safer sex. HIV testing should only be considered as part of an individual strategy to manage risk, with an appreciation of the different consequences of the result. This is best undertaken in a safe and confidential environment, as informed consent is difficult to assess and services have a number of moral and legal requirements to adhere to (see Cambridge, 1996a; Gunn, 1997).

The Complexity of HIV and Responses to Need

The complexities surrounding the transmission of HIV and treatment of AIDS have always been simplified to some extent in health promotion and HIV prevention work, including safer sex work with people with learning disabilities. HIV risk behaviour patterns are presented as high or medium or low and key messages about reducing the number of sexual partners or using protection for penetrative sex are presented outside co-factors which help assess risk, such as how condoms are used or the presence of other infections. This has also been the case in safer sex education in learning disability. There are sound arguments for not distinguishing between HIV and AIDS or concentrating on high risk behaviours (McCarthy & Thompson, 1994), but many people with learning disabilities who are sexually active and at risk of HIV are relatively able and might benefit from a more refined understanding of HIV.

The central question is how best to meet the needs of people with learning disabilities to information on HIV, AIDS and safer sex without excluding people from sexual opportunities or exposing people to avoidable risk. The differences between HIV and AIDS are also very real in terms of lifestyle implications (such as hospitalisation, medication and social care), and the uncertainty in time between HIV infection and the development of AIDS. The simplified link between sex and AIDS (and illness and death) might be conceptually appropriate for some people with learning disabilities, but is also potentially misleading if people are unable to appreciate uncertainty and long timescales.

A very challenging example is HIV testing. Arguments could be constructed that informed consent for HIV antibody testing (from anyone, with or without a learning disability) requires a basic understanding of HIV infection and the differences between being HIV antibody negative or positive (which is what the test indicates) and having an AIDS related illness. A person with a learning disability would need to understand this difference and its implications for future lifestyle or behaviour before consent was informed. They would also need to understand what a blood test entails and the concept of confidentiality. An understanding of the advantages and disadvantages of having an HIV test (Tatchell, 1994) might also prove relevant to exploring informed consent to HIV testing in learning disability. The advantages include benefits from medical monitoring if positive, reduction in anxiety if negative, and empowerment to make informed choices and priority to lead safer sexual lives. The disadvantages include uncertainty about AIDS and potential depression, rejection and discrimination if positive. The potential disadvantages suggest a strong case for policies and guidelines in services for people with learning disabilities to make HIV testing almost impossible, as Cambridge (1996b) has argued. This is particularly important considering the positive attitudes of a high proportion of residential staff to mandatory HIV testing reported in a recent study by Murray and colleagues (Murray *et al.*, 1995).

Direct Ways to Responding to HIV

The above considerations were used to help inform work in learning disability. When recently revising a set of booklets on HIV and AIDS for people with learning disabilities and their staff and carers (Cambridge, 1996d), it was evident that the original materials made no reference to same sex relationships or sex outside relationships, with a heterosexual monogamous relationship portrayed as the ideal model. This did not reflect reality in the sexual lives and experiences of people with learning disabilities, and the deficit was addressed by representing homosexuality, as well as heterosexuality, and sex outside relationships, as well as within relationships, better reflecting the diversity of sexual experience.

The differences between HIV and AIDS were also explained in the user booklet. The booklet on HIV and AIDS produced through self advocacy and peer education in learning disability (People First, 1994) also makes these connections as does an information booklet produced by users (Lawnmowers, 1994). People with learning disabilities constantly receive direct and indirect messages and information about both HIV and AIDS, and this ideally needs to be matched to safer sex inputs related to their understanding and risk. Simply linking unsafe sex with AIDS and death is neither helpful nor relevant to the sexual lives of many people with learning disabilities.

More careful attention also needs to be paid to the potential risks of HIV infection through oral sex in education and training resources in learning disability. Men with learning disabilities are as likely to be in a passive position in relation to oral sex with men as they are known to be in relation to anal sex (see Thompson, 1994b for an explanation of the latter). If there is a low risk of HIV from oral sex

then it lies in possible transmission through semen and pre cum. Until evidence about the risk of oral transmission to the person sucking is clearer, then educational resources should have the capacity to address this question and give men and women the information they need to better protect themselves or take more informed risks. In contrast to many British resources, the producers of the Australian video (FPANSW, 1993) only show oral sex with a condom. As the producers argue, this at least provides a consistent message that condoms should be used when having sex. Oral sex may lead to penetrative sex and the risk of the entire sexual encounter needs to be considered even if unprotected oral sex is very low risk. Neither approach addresses the potential for informed choice or risk-taking however, although such an ideal would be difficult to achieve for people who usually do not enjoy informed choices about the sex they have or who they have it with.

The decision was also made to use words like 'fuck', 'suck', 'lick', 'spunk' and 'cock' in the user booklet because most people know what they mean. Men with learning disabilities in a sex education group knew these words, and used them to describe sexual behaviours and body parts. More medical terms like 'intercourse', 'semen', 'oral sex' and 'anus' are usually associated with practitioners in positions of authority over people with learning disabilities. The Australian video is a good example of this, with people with learning disabilities using their own words and an educator imposing more comfortable words. Words like 'fuck' are certainly words more able and sexually active people with learning disabilities are likely to use or encounter and should be helped to learn and are less ambiguous than 'doing it', 'getting on top' or 'intercourse'. People need to be empowered through language, to communicate more precisely about consent, body parts, behaviour patterns and safer sex.

When working on a Department of Health-funded HIV risk management resource for men with learning disabilities who have sex with men (Cambridge, 1997), 10 guiding principles were developed with an Advisory Group to inform the development of the sex education materials.

1. Present sexuality as positive except in abusive or exploitative situations.
2. Show safer sex as empowering.
3. Represent the reality of sexual experience of men who have sex with men, including men with learning disabilities.
4. Provide explicit images of sex and safer sex and unambiguous language to describe them.
5. Include diversity in ethnicity and disability.
6. Have the capacity to differentiate between HIV and AIDS.
7. Represent visible aspects of learning disability.
8. Minimise irrelevant details and focus on event and place.
9. Depict contemporary appearances, but also diversity in style.
10. Include event sequences, consequences and outcomes.

This resource also has the task of addressing a range of possible situations, including cottaging, casual sex, and sex with both men and women. In addition to portraying mutual and enjoyable safer sex, it also needs to include abusive and exploitative sex,

prostitution and stylised sexual behaviour (Thompson, 1994a) all of which have the potential to impact in on men with learning disabilities.

Most men with learning disabilities who have sex with men are not in the more fortunate position of gay identified men who can more easily tap into self-help groups, informal support networks or dedicated HIV or AIDS services. Service commissioners in HIV and in learning disability have a responsibility to plug that gap, as have gay men themselves.

Organisational Responses to HIV

In theory, commissioners should undertake needs assessment in HIV and learning disability, design an appropriate array of services to meet identified needs, commission services through contract specification and review their effectiveness through monitoring quality and outcomes (Knapp & Wistow, 1992). In practice there are problems in relation to commissioning services and developing mainstream competence in specialist learning disability services (HMSO, 1992), let alone sexual health in learning disability.

Most people with learning disabilities do not have their sexual, emotional or sexual health needs adequately assessed and identified. The reasons are their lack of meaningful involvement in case reviews and planning meetings, and lack of power in asserting or communicating their needs and wants, as well as asexual service models (Brown & Cambridge, 1996). Commissioners are usually responsible for the core tasks of care management (Challis & Davies, 1986), including assessment and individual service planning, or should at least have such information at hand (Knapp & Cambridge, 1997). They should therefore be able to ensure sexuality and sexual health are properly represented in service configurations.

This can be achieved at the systems level by integrating work on sexuality and HIV into individual programme and service planning systems. For instance:

- negotiating skills (negotiating use of condoms and consent to sex);
- expressive and receptive communication skills (understanding requests and saying or signing yes and no);
- assertiveness skills (confidence when to say yes and reject unwanted or unsafe sex);
- life skills (access to condoms and sexual opportunities, including knowledge about HIV and safer sex);
- social skills (ability to utilise sexual and social opportunities to affect constructive experiences and learning opportunities);
- adaptive behaviour skills (ability to use condoms properly and effectively during sexual encounters);
- personal presentation skills (self-care and ability to affect positive personal image);
- self-motivation skills (motivation to protect sexual and emotional health through a positive self-image and self-worth);

- independence skills (determining own wants and life goals and functional capacity to achieve them);
- personal relationship skills (capacity and robustness to make and break personal relationships and express emotions).

Service Priorities

Even with a multi-agency approach to sexual health in learning disability there remain barriers between mainstream sexual health services (GUM and HIV testing, and counselling), GP purchased services and specialist services working in HIV and learning disability. A solution would be to top slice both the learning disability and HIV budgets to protect adequate resources for sexual health in learning disability. This would encourage commissioners to adopt a longer term perspective than the usual planning and commissioning cycle, and invest in service development and pump priming resources to get new specialist services off the ground, and staff training to increase mainstream competence in HIV and sexuality. Policy development will similarly be needed and this will have to involve providers and users themselves if policy guidelines are to be effective for management and practice decision-making (see Cambridge, 1997b; Cambridge & McCarthy, 1997).

Wider disincentives to good joint commissioning also remain to be overcome. In addition to adopting a short-term perspective, agencies tend to minimise the cost or impact to their own budgets. With budgets declining in real terms, as well as in relation to needs, the decision not to provide sex education and safer sex education and counselling in HIV for people with learning disabilities may be easier to make when another agency such as the NHS will have to pick up the tab for the longer-term health care consequences of doing nothing.

Commissioners are likely to need to consider the following interventions and models in HIV and learning disability. The pattern of services will ultimately depend on a combination of competence in needs assessment and service specification, attitude to investing in HIV prevention and the value attached to particular service models.

- Sex and safer sex education is an immediate practical response. This should ideally combine specialist sex education in one to one and group settings (McCarthy, 1997; Thompson, 1997).
- Self-advocacy and peer education have proved an effective model in HIV and safer sex education for young people, and there are examples of peer education in HIV and learning disability (Barber & Redfern, 1997).
- Joint projects involving young gay men and men with learning disabilities who have sex with men could also be developed. There are a few successful examples of befriending and support schemes.
- Specialist counselling and therapeutic services for people with learning disabilities who are at risk of HIV, to cope with issues such as HIV antibody testing, valid consent and confidentiality (Morris, 1997).

- Sex education for young people with learning disabilities, and parallel training for parents and staff in special schools (Stewart, 1997).
- Training for staff and managers in learning disability services on sexuality and HIV will be needed to develop the competence of services, not only to support the sexuality of service users, but to develop appropriate risk assessment and risk management responses (Davies, 1997).
- Specialist training for certain staff to develop key roles and functions within services in relation to sexuality and HIV, such as sex and safer sex education, leading risk assessment, and reporting and managing sexual abuse.
- Policy development on sexuality, including HIV (and sexual abuse), to go hand-in-hand with staff training and an assessment of user needs. This is necessary to pick up on key practice issues and develop tailored local responses (Brown & Cambridge, 1997).
- Assertiveness training for users, including communication and negotiation skills. This would need to be part of wider work helping people develop positive self-images and say no to abusive or unsafe sex.
- Training in learning disability for staff and managers in GUM, HIV counselling and nursing, and other HIV/AIDS provided by the NHS and voluntary organisations.
- Staff training and sex educational resources which place a priority on risk, and convey unambiguous messages about sex and safer sex in relation to the sexual realities and experiences of people with learning disabilities.

A single development priority for commissioners in HIV and learning disability is a dedicated sex education and counselling service, open to referrals from all individuals, agencies and sectors locally, and provided free and according to need (HIV and emotional risk), and linked into self-advocacy. Such a resource would benefit from links with other services such as counselling for sexual abuse and GUM services.

The priority for pro-active providers is to develop in-house competence in management and practice through policy development and training, and to build safeguards to user involvement such as advocacy and user workshops for sex education and safer sex. Both commissioners and providers should share the front loaded costs in terms of consultancy and staff time needed to develop the policies, guidelines and training required to support management and practice.

In relation to the development of specialist resources on sex and safer sex education, commissioners and purchasers need to ensure resources are well targeted on need and achieve their identified aims. Videos and photographs designed for group and individual work which address sexual behaviour and protection in a clarity and accuracy which reflects the real sexual, social and emotional experiences of people with learning disabilities are currently lacking. This includes men with learning disabilities who have sex with men, women with learning disabilities and men with learning disabilities who sexually abuse (Brown & Thompson, 1997).

Conclusions

A local strategic commitment is needed by commissioners to combat HIV in learning disability. This will require clarity in community care planning, service specification and inter-agency co-ordination, including collaboration with providers to develop policy and a facilitative function for health promotion, with the integration of social care, health care and education inputs (see Nichol, 1997, for an example). This framework should be grounded in a philosophy of empowerment, and a culture of delegated responsibility in order to generate innovative, radical and effective service interventions.

The success of such a strategy will depend on the wider visibility of homosexuality in services for people with learning disabilities and homosexuality being placed at the centre of safer sex educational resources and HIV prevention campaigns. More work is needed to make sexuality, in all its forms, a valid and valued issue in services for people with learning disabilities, and there are similarly issues of gender, race and culture which sex education and HIV prevention services should also have the capacity to address, and which are compounded by wider social and economic inequalities, including prejudice in relation to HIV.

Arguments for the re-homosexualisation of AIDS in services for people with learning disabilities can be developed on a number of fronts. Recognition by commissioners of the reality of HIV risk and need in services for people with learning disabilities in relation to men with learning disabilities who have sex with men is an essential first step to release resources which can be properly targeted on HIV need. Increased visibility for homosexuality in sex and safer sex educational resources for people with learning disabilities is necessary to realistically address the sexual health needs of people with learning disabilities. More widely, the inclusion of men with learning disabilities who have sex with men in befriending, counselling and sexual health services run by gay men would also help break down barriers surrounding questions of identity and self-esteem, as would peer education services by men with learning disabilities who have sex with men.

REFERENCES

- BARBER, F. & REDFERN, P. (1997) Safer sex training for peer educators, in: P. CAMBRIDGE & H. BROWN (Eds) *HIV and Learning Disability* (Kidderminster, British Institute of Learning Disabilities).
- BBC (1995) *End of Innocence*, BBC2, 5 December 1995.
- BERKELMAN, R., THOMAS, P., KERNDT, P., RUTHERFORD, G. & STEHR-GREEN, J. (1989) *Are AIDS cases among homosexual males levelling?* Paper presented at the 5th International Conference on AIDS, Montreal.
- BROWN, H. & CAMBRIDGE, P. (1995) Contracting for change: making contracts work for people with learning disabilities, in: T. PHILPOT & L. WARD (Eds) *Values and Visions: changing ideas in services for people with learning difficulties* (London, Butterworth Heineman).
- BROWN, H. & CAMBRIDGE, P. (1997) Policies and their contribution to coherent decisionmaking, in: P. CAMBRIDGE & H. BROWN (Eds) *HIV and Learning Disability* (Kidderminster, British Institute of Learning Disability).
- BROWN, H. & SMITH, H. (1992) Assertion, not assimilation, in: H. BROWN & H. SMITH (Eds) *Normalisation: a reader for the nineties* (London, Routledge).

- BROWN, H., STEIN, J. & TURK, V. (1995) The sexual abuse of adults with learning disabilities: report of a second two year incidence survey, *Mental Handicap Research*, 8, pp. 1-22.
- BROWN, H. & THOMPSON, D. (1997) A minefield in a vacuum: the ethics of working with men with learning disabilities who have unacceptable or abusive sexual behaviours, *Disability & Society*, in press.
- BROWN, H. & TURK, V. (1992) Defining sexual abuse as it affects adults with learning disabilities, *Mental Handicap*, 20, pp. 44-54.
- CAMBRIDGE, P. (1992) Case management in community services: organisational responses, *British Journal of Social Work*, 22, pp. 495-517.
- CAMBRIDGE, P. (1994) A practice and policy agenda for HIV and learning difficulties, *British Journal of Learning Disabilities*, 22(4), pp. 134-139.
- CAMBRIDGE, P. (1996a) *The Sexuality and Sexual Rights of People with Learning Disabilities: considerations for staff and carers* (Kidderminster, British Institute of Learning Disabilities).
- CAMBRIDGE, P. (1996b) *Evaluating Sexual Health Outreach for Women with Learning Disabilities*, Bulletin No. 15, National Association for the Protection from Sexual Abuse of Adults and Children with Learning Disabilities (Nottingham, NAPSAC/University of Nottingham).
- CAMBRIDGE, P. (1996c) 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, pp. 241-251.
- CAMBRIDGE, P. (1996d) *HIV and AIDS and People with Learning Disabilities: What You Need to Know about HIV and AIDS/Guidelines for Staff and Carers* (Kidderminster, British Institute of Learning Disabilities).
- CAMBRIDGE, P. (1997a) *HIV, Sex and Learning Disability* (Brighton, Pavilion) (In press).
- CAMBRIDGE, P. (1997b) At whose risk? Priorities and conflicts for policy development in HIV and learning disability, *Journal of Applied Research in Intellectual Disabilities*, in press.
- CAMBRIDGE, P. & BROWN, H. (1997) *HIV and Learning Disability* (Kidderminster, British Institute of Learning Disabilities).
- CAMBRIDGE, P. & MCCARTHY, M. (1997) Developing and implementing sexuality policy for a learning disability provider service, *Health and Social Care in the Community*, 5(3), in press.
- CAMBRIDGE, P., DAVIES, S., NICHOL, J., THOMPSON, D., MORRIS, S. & CORBETT, A. (1994) *Men with Learning Disabilities who have Sex with Men in Public Places* (Canterbury, Tizard Centre/University of Kent).
- CHALLIS, D. & DAVIES, B. (1986) *Case Management in Community Care* (Aldershot, Gower).
- CHURCHILL, J. (1992) Contracts or partnerships, in: T. THOMSON & P. MATHIAS (Eds) *Standards and Mental Handicap* (Balliere, Tindall).
- CORBETT, J. (1994) A proud label: exploring the relationship between disability politics and gay pride, *Disability & Society*, 9, pp. 343-357.
- CRAFT, A. (1991) *Living Your Life: a sex education and personal development programme for students with severe learning difficulties* (Wisbech, Learning Development Aids).
- CRUIKSHANK, M. (1992) *The Gay and Lesbian Liberation Movement* (London, Routledge).
- DAVIDSON-PAINE, C. & CORBETT, J. (1995) A double coming out: gay men with learning disabilities, *British Journal of Learning Disabilities*, 23(4), pp. 147-151.
- DAVIES, P., WEATHERBURN, P., HUNT, A., HICKSON, F., MCMANUS, T. & COXON, A. (1992) The sexual behaviour of young gay men in England and Wales, *AIDS Care*, 4, pp. 259-272.
- DAVIES, P., HICKSON, F., WEATHERBURN, P. & HUNT, A. (1993) *Sex, Gay Men and AIDS* (London, Falmer Press).
- DAVIES, S. (1997) A provider perspective, in: P. CAMBRIDGE & H. BROWN (Eds) *HIV and Learning Disability* (Kidderminster, British Institute of Learning Disabilities).
- DEVERELL, K. & ROONEY, M. (1994) *Using Sexually Explicit Materials for Safer Sex Work with Gay Men*, HIV Project (London, North Thames Regional Health Authority).
- DIXON, H. (1988) *Sexuality and Mental Handicap—Chance to Choose* (Wisbech, Learning Development Aids).
- DIXON, H. (1991) *AIDS and People with Learning Difficulties* (Kidderminster, British Institute of Mental Handicap).

- F.P.A.N.S.W. (1993) *Feeling Sexy, Feeling Safe* (Ashfield, Family Planning Association of New South Wales).
- GUNN, M. (1996) *Sex and the Law: a brief guide for staff working with people with learning difficulties* (London, Family Planning Association).
- GUNN, M. (1997) The law, HIV and people with learning disabilities, in: P. CAMBRIDGE & H. BROWN (Eds) *HIV and Learning Disability* (Kidderminster, British Institute of Learning Disabilities).
- HICKSON, F., DAVIES, P., HUNT, A., WEATHERBURN, P., MCMANUS, T. & COXON, A. (1992) Maintenance of open gay relationships: strategies for protection against HIV infection, *AIDS Care*, 4, pp. 409-419.
- HMSO (1992) *Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs* (London, HMSO).
- HUNT, A., WEATHERBURN, P., HICKSON, F., DAVIES, P., MCMANUS, T. & COXON, A. (1993) Changes in condom use by gay men, *AIDS Care*, 4, pp. 439-448.
- JENKINSON, J. (1993) Who shall decide? The relevance of theory and research to decision-making by people with an intellectual disability, *Disability, Handicap and Society*, 8, pp. 361-375.
- JONES, J. (1993) *Men with Learning Difficulties and Cottaging*, Saturday Seminars (London, North West Thames Regional Health Authority).
- KASTNER, T., HICKMAN, M. & BELLEHUMEUR, D. (1989) The provision of services to persons with mental retardation and subsequent infection with HIV, *American Journal of Public Health*, 79, pp. 1-4.
- KASTNER, T., NATHANSON, R. & MARCHETTI, A. (1992) Epidemiology of HIV infection in adults with developmental disabilities, in: A. CROCKER, H. COHEN & T. KASTNER (Eds) *HIV Infection and Developmental Disabilities* (London, Brookes).
- KING, E. (1993) *Safety in Numbers* (London, Cassell).
- KING, E., ROONEY, M. & SCOTT, P. (1992) *HIV Prevention for Gay Men: a survey of initiatives in the UK* (London, National AIDS Manual).
- KING'S FUND (1980) *An Ordinary Life: comprehensive locally-based residential services for mentally handicapped people* (London, King's Fund Centre).
- KINSEY, A., POMEROY, W. & MARTIN, C. (1948) *Sexual Behaviour in the Human Male* (Philadelphia, Saunders).
- KNAPP, M. & CAMBRIDGE, P. (1997) The cost dimension in commissioning and providing services for people with learning disabilities, in: N. BOURAS & P. DONLAN (Eds) *Commissioning and Providing Services for People with Learning Disabilities* (Brighton, Pavilion).
- KNAPP, M. & WISTOW, G. (1992) *Joint Commissioning for Community Care* (Canterbury, Personal Social Services Research Unit).
- LAWNMOWERS (1994) *The Big Sex Show* (Newcastle, Them Wives).
- L.S.S. (1992) *Take Care of Yourself: safer sex and people with learning disabilities* (London, Lewisham Social Services Department).
- McCARTHY, M. (1994) Against all odds: HIV and safer sex education for women with learning difficulties, in: L. DOYAL, J. NAIDOOI & T. WILTON (Eds) *AIDS: Setting a Feminist Agenda* (London, Taylor and Francis).
- McCARTHY, M. (1997) HIV and heterosexual sex, in: P. CAMBRIDGE & H. BROWN (Eds) *HIV and Learning Disability* (Kidderminster, British Institute of Learning Disabilities).
- McCARTHY, M. & CAMBRIDGE, P. (1996) *Your Rights about Sex: a booklet for People with Learning Disabilities* (Kidderminster, British Institute of Learning Disabilities).
- McCARTHY, M. & THOMPSON, D. (1992) *Sex and the 3 Rs: rights, responsibilities and risks* (Brighton, Pavilion Publishing).
- McCARTHY, M. & THOMPSON, D. (1994) HIV/AIDS and safer sex work with people with learning difficulties, in: A. CRAFT (Ed.) *Practice Issues in Sexuality and Learning Disabilities* (London, Routledge).
- MARCHETTI, A., NATHANSON, R., KASTNER, R. & OWENS, R. (1990) AIDS and state developmental disabilities agencies: a national survey, *American Journal of Public Health*, 80, pp. 54-56.

- MARNETH, A. (1994) *Geen Kind Meer: Seksuele voorlichting aan jongeren met een verstandelijke handicap vanaf 12 jaar* (Utrecht, Rutgers Stichting).
- MORRIS, S. (1993) Protect and survive, *Community Care*, 30 December, pp. 12–13.
- MORRIS, S. (1997) Experiences of risk: the role of therapy in sexual health, in: P. CAMBRIDGE & H. BROWN (Eds) *HIV and Learning Disability* (Kidderminster, British Institute of Learning Disabilities).
- MURRAY, J., MACDONALD, R. & MINNES, P. (1995) Staff attitudes towards individuals with learning disabilities and AIDS: the role of attitudes towards client sexuality and the issue of mandatory testing for HIV infection, *Mental Handicap Research*, 8, pp. 321–332.
- N.H.P.I.S. (1996) Health Education Authority, National HIV Prevention Information Service, 0171 388 9855.
- NICHOL, J. (1997) HIV prevention and health promotion, in: P. CAMBRIDGE & H. BROWN (Eds) *HIV and Learning Disability* (Kidderminster, British Institute of Learning Disabilities).
- O'BRIEN, J. (1987) A guide to lifestyle planning: using the activities catalogue to integrate services and natural support systems, in: B. WILLCOX & G. BELLAMY (Eds) *The Activities Catalogue: an alternative curriculum for youth and adults with severe disabilities* (Baltimore, Brookes).
- PEOPLE FIRST (1994) *Everything You Ever Wanted to Know About Safer Sex but Nobody Bothered to Tell You* (London, People First).
- PINK PAPER (1992) *AIDS Budget Slashed*, 214, March.
- RICHARDSON, D. (1981) Theoretical perspectives on homosexuality, in: J. HART & D. RICHARDSON (Eds) *The Theory and Practice of Homosexuality* (London, Routledge).
- ROONEY, M. (1994) *Information File, HIV Project* (London, North Thames Regional Health Authority).
- SEIDMAN, S. (1993) Identity and politics in a 'postmodern' gay culture: some historical and conceptual notes, in: M. WARNER (Ed.) *Fear of a Queer Planet: Queer politics and social theory* (Minneapolis, University of Minnesota).
- SIMONDS, R. & ROGERS, M. (1992) Epidemiology of HIV infection in children and other populations, in: A. CROCKER, H. COHEN & T. KASTNER (Eds) *HIV Infection and Developmental Disabilities* (London, Brookes).
- S.E.L.H.P.S. (1992) *My Choice, My Own Choice* (video), South East London Health Promotion Service (Brighton, Pavilion Publishing).
- STEWART, D. (1996) Sex education for students with severe learning disabilities, in: P. CAMBRIDGE & H. BROWN (Eds) *HIV and Learning Disability* (Kidderminster, British Institute of Learning Disabilities).
- TACHELL, P. (1994) *Safer Sexy* (London, Freedom Editions).
- TAYLOR-LAYBOURN, A. & AGGLETON, P. (1992) *HIV Health Promotion Needs Assessment for Men who have Sex with Men in Camberwell: final report* (London, King's Healthcare).
- T.H.T. (1994) *Gay Mens' Guide to Safer Sex* (video) (London, Terrence Higgins Trust).
- THOMPSON, B. (1994a) *Sadomasochism* (London, Cassell).
- THOMPSON, D. (1994b) Sexual experience and sexual identity for men with learning disabilities who have sex with men, *Changes*, 12, pp. 254–263.
- THOMPSON, D. (1995) Debate between MacManus, Bainbridge & Thompson, *Health Psychology Update*, 12, pp. 3–7.
- THOMPSON, D. (1997) Safer sex work with men with learning disabilities who have sex with men, in: P. CAMBRIDGE & H. BROWN (Eds) *HIV and Learning Disability* (Kidderminster, British Institute of Learning Disabilities).
- TURK, V. & BROWN, H. (1993) The sexual abuse of adults with learning disabilities: results of a two year incidence survey, *Mental Handicap Research*, 6, pp. 193–216.
- WARD, L. (1990) Community care: implications of changes for black communities, in: *Equality by Agreement* (London, National Council of Voluntary Organisations).
- WATNEY, E. (1993) Powers of observation: AIDS and the writing of history, in: *Practices of Freedom* (London, Rivers Oram).

- W.L.H.P.A. (1994) *Piece by Piece* (video), West London Health Promotion Agency (Brighton, Pavilion Publishing).
- WOLFENSBERGER, W. (1980) The definition of Normalisation: update, problems, disagreements and misunderstandings, in: R. FLYNN & K. NITSCH (Eds) *Normalisation, Social Integration and Community Services* (Baltimore, University Park Press).
- WOLFENSBERGER, W. (1984) A reconception of normalisation as social role valorisation, *Mental Retardation (Canadian)*, 34, pp. 22-25.

Ref. 2.1.d.

Cambridge, P. and 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.



Reconstructing the Sexuality of Men with Learning Disabilities: empirical evidence and theoretical interpretations of need

PAUL CAMBRIDGE & BRYAN MELLAN*

Tizard Centre, University of Kent at Canterbury CT2 7LZ, and *Consent, Horizon NHS Trust, Abbots Langley, Hertfordshire WD5 0HT, UK

ABSTRACT *Research and practice in sexuality and learning disability has directly and indirectly highlighted the pathological sexual behaviour of men with learning disabilities, particularly their abuse and exploitation of women with learning disabilities, and relatively high HIV risk sexual behaviour with men without learning disabilities. It is consequently argued that there has been a relative neglect of their wider sexuality and sexual needs. This paper reconstructs this wider agenda, drawing on empirical evidence and theoretical interpretations of need from research and sex education in support of the observations made. In identifying a range of key issues for sexuality work with men with learning disabilities and arguing that they require greater recognition and attention, the paper also provides directional pointers for informing such work and for responding more widely.*

Introduction

The history of sex education for people with learning disabilities is characterised by a mixture of neglect, distortion and toleration (Johnson & Kempton, 1981; Kempton, 1982: observations of Malhotra & Mellan, 1996). Although the new and important consensus which emerged with the pioneering work of Ann Craft and colleagues (Brown, 1980; Craft, 1983, 1987, 1991; Dixon, 1988) was based on the premise that people with learning disability had the right to lead sexual lives, this inevitably led to a focus on sexual abuse, particularly of women with learning disabilities (Brown *et al.*, 1995; McCarthy & Thompson, 1996, 1997), and the experiences and perceptions of women with learning disabilities themselves (McCarthy, 1993, 1994, 1998).

Although the focus on abuse has recently been extended in research to the role of men with learning disabilities as abusers (Brown & Thompson, 1997; Thompson, 1997a; Thompson & Brown, 1997; Thompson *et al.*, 1997), and reflected in national guidance (ARC/NAPSAC, 1997), the sexual needs of men with learning

disabilities have remained relatively invisible. Where they have surfaced outside abuse, this has largely been in relation to HIV and homosexuality (Thompson, 1994b, 1997b; Cambridge, 1996a, 1997a, 1999), again risking pathological views about their sexuality.

Deconstructing Challenging or Pathological Sexual Behaviour

Research on the sexual abuse of people with learning disabilities indicates that male perpetrators account for almost all recorded cases—93% (Sobsey & Varnhagen, 1989), 97% (Hard & Plumb, 1987), 100% (Dunne & Power, 1990), 100% (Buchanan & Wilkins, 1991), 97% (Brown *et al.*, 1995), and 98% male: female abuse and 93% male: male abuse (McCarthy & Thompson, 1996). A significant proportion of the men who abuse are more able men with learning disabilities, averaging at around 39–40% (Turk & Brown, 1993), 53% (Brown *et al.*, 1995), 16% (Bergh *et al.*, 1997) in the Netherlands, and 42% male: female and 21% male: male (McCarthy & Thompson, 1996).

Such a stark reality tends to deflect attention from the wider sexuality and sexual needs of men with learning disabilities, and although the needs of both men and women with learning disabilities who have been sexually abused have been specifically targeted (Brown & Stein, 1997; Stein & Brown, 1997), the focus remains on abuse. It has also recently been observed that the focus of pathology in sexuality and learning disability has narrowed to particular behaviour such as homosexuality, illustrated by the general failure to recognise and respond in targeted ways to HIV risk (Cambridge, 1997a, 1998). Men with learning disabilities are, similarly, most likely to have only received sex education within a heterosexual context, despite the reported frequency of homosexual behaviour (Thompson, 1994b; Cambridge, 1996a). Consequently, men's sexual health needs have received a low priority, illustrated by the few representations of sex between men or anal sex in educational resources (Cambridge, 1997a, b, 1998).

Critical deficits in social-sexual knowledge and skills are often immediately evident, even when working with more able men with learning disabilities, such as those with good verbal communication who are present in the community and who are, or have been, sexually active (Cambridge & McCarthy, 1997). Although they are readily able to describe the sexual things they do to women (and more reluctantly to other men) with learning disabilities and some of the sexual things which have been done to them, they are mostly unable to relate what is right or wrong about these behaviours. For example, although their knowledge superficially appears good, as they are able to describe how women become pregnant, few are able to say precisely how this happens or exactly where babies come from. There was a parallel absence of knowledge and language about negotiating sex, seeking consent, good and bad touch and mutuality and the social dimensions of gender:

When asked about the differences between men and women, one person in the men's group responded in relation to the club he used to attend '... the

men sit on that side of the room [pointing] and the women on the other'.
(Cambridge & McCarthy, 1997, p. 230.)

Gender is often crudely defined by the differences between men's and women's names, their social and economic roles, hair length and clothing.

Men's wider sexual behaviour also often generate aversive service responses. There are references of such from research on HIV risk management (Cambridge, 1996a), where services police the sexuality of men with learning disabilities who cottages (have sex with men in public toilets) by restricting their activities, limiting their opportunities to be present in the community, introducing staff chaperones or pushing for HIV testing. Medical models may also be used to define and treat the sexual behaviours of men with learning disabilities, echoing the past use of aversion therapy for homosexuality. Puri & Singh (1996) report the successful use of pharmacotherapy with pimozone on a man with learning disability who cross-dressed and El-Badri & Robertshaw (1998) the use of brain scans for temporal lobe dysrhythmia or epilepsy for two men with learning disabilities who displayed foot-fetishes, effectively ignoring the social and learned aspects of sexuality by focusing on the elimination of perceived illness.

The term 'challenging sexual behaviour' is often used to characterise the more unusual, as well as inappropriate or abusive sexual behaviour of men with learning disabilities—along a continuum in severity from homosexuality, sex in public places, inappropriate sexual touching, self-stimulation in semi-public spaces to sexual violence and rape. In service environments, the informal codes relating to particular sexual behaviour or the sexual norms within particular cultures or communities are usually absent, thus increasing the probability that some more unusual sexual behaviours will be labelled as challenging or pathological. The following examples are discussed in more detail.

Pornography

Feminist political critiques (Dworkin, 1981; Jeffreys, 1985), have influenced social attitudes about the production and use of pornography, focusing on the economic exploitation of women through the abuse of power by men. Most sexuality policies in services for people with learning disability ban or severely restrict the use of pornography (Cambridge & McCarthy, 1997). This mirrors wider political concerns, but also the reality that pornography is frequent inappropriately use by men with learning disabilities, through a lack of privacy and boundaries. However, privacy is itself difficult to define in congregate and shared service provisions, and it is also important to consider how men with learning disability obtain pornography, and interpret its many and varied images.

Experience from sex education suggests that pornographic material is often obtained through sexual encounters with men without learning disabilities, where the man with learning disability will be sexually vulnerable, and open to coercion or exploitation. Some more able men will obtain it themselves and some request it from staff. The past absence of specialist sex education materials sometimes led to the use

of pornography for explicit sex education, although this would clearly now be interpreted as abusive. This is because of the likelihood that the man with learning disabilities would experience the use of pornography for education as erotic and more directly, because specialist sex education materials are now widely available (McCarthy & Thompson, 1992), including those targeted on men with learning disabilities (Cambridge, 1997b).

There are additional risk management implications for services if men with learning disabilities use pornography. A primary consideration is the legality of the material itself. Pornography containing sexual images of children is clearly illegal. In addition, homosexual pornography is more readily interpreted by the police as obscene (the police have also seized explicit gay safer sex educational materials, considering them obscene or likely to corrupt, although there is an overriding public interest defence in relation to HIV prevention (Tatchell, 1994; Cambridge, 1997b)). As a consequence, however, different standards are often imposed on men with learning disabilities than on other men who use pornography, reinforcing a pathological view of their sexuality within services, and introducing conflicts between individual rights and service responsibilities for care and protection.

Cross-dressing

Cross-dressing is regularly reported by support staff during sexuality training and is a sexual behaviour which generates considerable professional and management concern. Yet there is often a reluctance to refer to it until prompted, or it may be obliquely referenced as the 'misuse' or 'theft' of women residents' underwear, reflecting the widespread stigma it attracts. Cross-dressing confronts conventional attitudes about sex, gender and appearance, creating confusion about heterosexuality (most men who cross dress generally identify as heterosexual, as cross-dressing is not the same as drag). Considerable confusion between cross-dressing, trans-sexuality and homosexuality therefore frequently surfaces in staff teams, and such imprecision risks re-enforcing any confusion the man himself might hold in relation to his sex, gender, sexuality or sexual identity.

Although cross-dressing occurs infrequently as a direct reason for referral to the Sex Education Team (Consent), it more often emerges during one to one sex education with men with learning disabilities. The reluctance of referring professionals to address cross-dressing reflects a wider reluctance to respond positively to men with learning disability who cross-dress or express an interest in women's clothes. Staff training workshops on the subject are frequently over-subscribed and many staff will have had direct experience of this behaviour, with a host of negative interpretations regularly surfacing. The most characteristic is that the behaviour is socially deviant or pathological, with links constructed to sexual abuse or theft and attitudes or emotions acutely associated with embarrassment and discomfort. Moreover, the man is generally portrayed as a figure of ridicule by staff and other service users, with dominant staff concerns expressed towards the victim of the theft or the female support worker who may express disgust at the behaviour.

Given the general negativity surrounding cross-dressing, it is apparent that men

with learning disabilities who cross-dress need consistent, positive and constructive advice and support to divert from stealing to more appropriately obtaining women's underwear, with legitimate access to women's clothes explored as part of individual work. There have been referrals where the initial response was to off-load work to a support group for transvestites, but unless he was able to participate in group dynamics or the group was competent at including a man with learning disability, such a referral risks his further exclusion. There have also been situations where support has been naïve in that the man has been placed at an unacceptable risk of verbal and physical abuse due to his poor skills at cross-dressing in public places.

Prostitution

Some men and women with learning disabilities regularly or occasionally sell sex, mirroring behaviour within the wider population. Similar to pornography, there are differing social and political views about prostitution, but the dominant feminist interpretation is that prostitution is potentially dangerous for the person selling sex, devalues sex and exploits women (Dworkin, 1997). As a result, there will generally be a reluctance to develop service interventions which do other than simply restrict such activities. The need for alternative support or guidance is, however, transparent: men with learning disability who sell sex, like women with learning disabilities, will be especially vulnerable to exploitation, sexual abuse, physical assault and particularly to HIV infection (as are other men who have sex with men).

Individual accounts from sex education, suggests different patterns in selling sex for men and women with learning disabilities. It is rare for men with learning disabilities to have sex with women without learning disabilities and relatively common for men and women with learning disabilities to have sex with men without learning disabilities (McCarthy, 1996; McCarthy and Thompson, 1996). This observation points to the centrality of gender in power and status in sexual relationships, including those where money or goods are exchanged for sex. For men with learning disabilities who sell sex, intellectual, rather than gender power differentials will apply and operate.

Men with learning disabilities are most likely to be offered money or inducements to have sex as a form of control in abusive or non-consenting relationships or in public sex environments, such as public toilets or parks, where there is little chance to negotiate reciprocity. It is well known from sex education that some more able men with learning disability cottage (have sex in public toilets: Thompson, 1994b; Cambridge, 1996a), or are themselves likely to gain sexual favours from women or other men with learning disability by using pressures or bribes (McCarthy, 1993, 1998).

Sexual health outreach for women with learning disabilities (Cambridge, 1996b), found women to be at greater risk of exploitation within service environments, such as day centres, which are assumed by many to be relatively safe, rather than on the street or in commons or pubs. This compares starkly with evidence about prostitution and men with learning disability from one to one education (Thompson, 1994b) and research (Cambridge, 1996a), with most such men active

in public sex environments. Men with learning disabilities who sell sex are also likely to be unwilling to readily disclose their prostitution and reluctant to change their patterns of behaviour. Prostitution brings significant rewards in terms of physical closeness and recognition as a sexual person as well as financial incentives. Interventions will therefore need to prioritise HIV risk, physical safety and the risks of arrest by the police as well as seeking to divert men to more appropriate and less dangerous forms of sexual expression.

Stylised Sex

As a typical form of stylised sex, sado-masochism is increasingly openly discussed as a valid form of sexual expression, centred on considerations of consent and safety, challenging established perceptions of violence and dangerousness (Thompson, 1994a; Butt & Hearn, 1998). Yet interpretations remain polarised, as some feminist critiques present homosexual sadomasochism as a reflection of the failure of gay liberation to address inequalities in power, class or age (Jeffreys, 1990). Attention is thus distracted from consenting sadomasochism and other acted out sexual fantasies, regardless of considerations of reciprocity, agreed rules and limits, and broader role play.

The perceived dangerousness of sadomasochism may be used as an excuse not to respond constructively through one to one education and support, although both women and men with learning disabilities who have sex with men without learning disabilities will potentially encounter stylised sexual behaviours and overt role play. Moreover, if it is not addressed, there are risks that more able men with learning disabilities will learn such behaviour from their encounters with men without learning disabilities and replicate them within services, requiring the function for the man himself to be ascertained. It is evident from one to one educational work with men with learning disabilities who cottage, that they sometimes encounter men who enjoy dominant or rough sex, including slapping, smacking or bondage in isolated or private places. Such encounters are likely to be confusing to the man with learning disability, rather than simply becoming an optional extension of his sexual repertoire.

Various factors will need to be included in any related risk assessment. People with learning disabilities have usually been socialised into acquiescence, have poor negotiating skills, lack the language needed to negotiate sex and lack assertiveness in their relationships in general. This applies to both women and men with learning disabilities who have sex with men, making it difficult for them to extricate themselves from situations they do not understand or encounters they dislike. It is also highly likely that the non-learning disabled man will assume a lack of verbal responses or body language, passivity or compliance (on the part of the man with learning disability) equates with consent, especially if his learning disability is not immediately visible.

An important consideration for support and education services, is therefore, the impact of such behaviours on the man and his interpretations of them. He may

perceive them as further punishment for his disability (Morris, 1997). There is also the possibility that he may replicate them outside an appreciation of the informal rules associated with stylised sex and without the skills to conduct them safely (Cambridge, 1996a). Indeed, using the social learning model of abuse (Sobsey, 1994), it could be hypothesised that such behaviour might be replicated in an abusive context within services by men with learning disabilities.

The criminalisation of consenting homosexual sadomasochistic sex in Britain (Spanner case, Thompson, 1994a), compared, for example, with the eroticisation of heterosexual dominatrix sex, makes it unsurprising that some support staff and sex educators have adopted wholly negative views about stylised sex, and are reluctant or unwilling to attempt constructive work with men with learning disabilities on the subject. Non-aversive support is, however, essential if the man is to understand the risks and opportunities inherent in such encounters. Failure to provide advice in relation to exercising more informed choice or appreciating the potential implications, risk placing the man and other service users at an increased risk of sexual abuse, physical injury or psychological harm.

Experience with staff training in sexuality suggests staff sometimes interpret relationships between women and men with learning disability to be an exploration of sado-masochistic sex, with the man usually exerting power over the woman. Careful consideration is required to ascertain the nature of the relationship. However, that sadomasochistic activities are complex to interpret regarding consent and a misinterpretation of a relationship in this context could result in the reinforcement of sexual abuse, particularly if the dominant partner is a more able man. Specialist sex educators should therefore be competent at risk assessment, but also be mindful of the risks inherent in aversive responses which restrict user choices. One possibility is to raise awareness on the part of the man with a learning disability about the meaning and significance of codified behaviours, although in reality the rules associated with them may prove very difficult for some men to learn, exchange or use.

Sex and Children

Individual referrals to sex education at Consent sometimes reference '*paedophile tendencies*' or less explicitly that '*the man has an unhealthy interest in children*'. Individual case studies and references by staff during sexuality training often raise similar concerns. Service considerations centre on their responsibilities for risk management, as well the potential legal consequences for the man himself. Concern has also been heightened by the current political interest in child protection, partly in response to numerous disclosures by young adults about child sex abuse and organised paedophilia in social care more widely.

Experience suggests that the reality behind this broad area of concern is variable and complex. There is case evidence of staff anxiety about men with learning disabilities who approach children in shops and who attempt to play games or interact with them in other ways. Such behaviour is alarming to parents and support staff who immediately assume a sexual motive. However, the reality that some men

with learning disabilities may simply find it easier to identify as and relate to children, rather than adults, should be acknowledged. Indeed, for much of their lives they will have been treated like children, as parents and carers sometimes find this a convenient response to protecting young adults and avoiding the provision of sex education. Thompson & Brown (1997) comment in relation to this issue:

Peculiar to men learning disabilities is the suggestion that their abuse of children derives from developmental immaturity. Firstly, playing with children facilitates opportunities for abuse and, secondly, an incomplete psychosexual development may leave children as a possible sexual object. However, it is recognised that the sexual abuse of children may, at times, result from a specifically *sexual* interest in children (Thompson & Brown, 1997, pp. 22–23).

'Dangerousness concerns' invariably surface when working with men with learning disabilities who express their sexuality in this way. However, actual cases where men with learning disabilities express a sexual interest in children (such as by approaching and fondling a young child in a supermarket), suggest his lack of knowledge and awareness about the illegality and social consequences of such behaviours, demonstrated by the fact that this often happens in very public and visible places.

In reviewing the case histories of men with learning disabilities who have sexually abused children, Murphy (1997a,b) identifies the victim and perpetrator characteristics of specific cases and risks. The latter have frequently included poor sexual knowledge, social rejection, social impairment, strict religious backgrounds, sexual abuse (as victim) and poor understanding of others feelings, suggesting root causes such as social disadvantage, isolation and exclusion—the acute political issues current in services for people with learning disabilities.

Recognising and Meeting Needs

The focus of this paper now moves to identifying the competencies required for responding to the sexuality and sexual needs of men with learning disabilities.

Assessing Legal Context to Consent

Legal considerations for assessing the consent of a person with a learning disability to sex are complex, with general laws relating to sex, such as those concerning rape, which apply to everyone and specific laws which reference learning disability (Gunn, 1996 and 1997). A person with a severe learning disability (mental defective) is deemed unable to give consent (Sexual Offences Acts, 1956 and 1967). In addition, there are discriminatory laws which reference homosexual sex, where the age of consent and the circumstances under which sex is considered private, vary compared to heterosexual sex (Cambridge, 1997b). The problem facing staff and service managers is that case evidence is minimal and legal considerations alone can provide perverse incentives for bad practice.

Laws relating to HIV and homosexuality warrant particular attention. During

training staff often assert that they are unable to work with men with learning disabilities who have sex with men through fear of breaking obscenity laws or promoting homosexuality (Section 28 of the 1988 Local Government Act—Cambridge, 1997a,b). Work with men on informed consent to sex, responding to sexual abuse or the provision of safer sex education in a homosexual context are legal and reflect best practice. In relation to homosexual safer sex education, for example, a 'public interest' defence ensures that sexually explicit educational materials will not be considered 'obscene' or 'likely to corrupt', so long as the education is in response to assessed HIV risk and user needs (see educational materials and exercises in Cambridge, 1997c).

Informed Consent. The idea of informed consent to sex has been articulated in the context of people with learning disability as a response to intelligence on sexual abuse, and the need for services and staff to understand the vulnerability of people with learning disabilities in relation to valid consent. Considerations can also be extended to assessing mutuality and exploitation in sexual and personal relationships. Informed or valid consent to sex can be assessed using the Turk & Brown (1993) model, which asserts that sex is abusive if the person:

- (1) did not consent (even if they were in an ongoing sexual relationship);
- (2) 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);
- (3) was pressured into consenting (by a figure of power or authority, be it a familial or care-giving relationship, or with force or threat, such as pressures or bribes).

This last point is critical because many people with learning disability will have been socialised into acquiescence, find it difficult to make sense of what has happened to them and do not appreciate the consequences of particular sexual behaviour or options. However, it is also relatively frequently employed to stop same sex relationships involving men with learning disabilities compared with heterosexual relationships in which consent is interpreted more liberally. Conversely, case interpretations of same sex abuse indicate how homosexuality can be explicitly blamed for the abuse, where heterosexuality is never blamed in opposite sex abuse (Cambridge & Mellan, 1998).

Murphy & Clare (1995) develop point 3 further, arguing that the constraints imposed can sometimes appear unduly restrictive and that where care staff are worried about the issue of consent, they should consider whether:

- (1) there is a power imbalance between the two people;
- (2) tangible inducements are being used by one person;
- (3) the people involved (in heterosexual relationships) know about the risks of pregnancy;
- (4) both partners know about safer sex and are able to use this knowledge;

- (5) if pregnancy is a possible outcome, the couple have been given appropriate access to genetic counselling and parenting training.

Cambridge (1997b) has also stresses the importance of knowledge about the consequences in relation to HIV regarding informed consent in sexual relationships between men with learning disabilities and other men, although Murphy (1997c) has additionally pointed out that some care staff would argue that even the above 5 points are too restrictive. Although the greatest possible care must be taken to establishing full consent, there is also the need to ensure that standards are not imposed on people with learning disabilities which are more restrictive than those operating more widely in society.

Homosexual Behaviour and Sexual Identity

Referrals to sex education at Consent indicate that around 33% of the men with learning disabilities referred to the service were known to be having sex with men. This is itself likely to be an under-estimate, given that many men who have sex with men will not readily disclose this behaviour (Thompson, 1994b) and will have successfully hidden it from staff (Cambridge 1996a). What is particularly surprising therefore, is the near invisibility of sex between men in all but the most recent specialist sex education resources for men with learning disabilities (Cambridge, 1997c).

Thompson (1994b) has indicated the importance of sexual identity when working with men with learning disability who have sex with men, observing that most will hold a heterosexual identity. This demands skills for working with men on acceptable behaviours and sensitivity to partners, with potential conflicts in the dynamics of their relationships with women, where they will almost certainly hold power, and those they have with men without learning disability, where they will almost certainly not. It may prove tempting for some services to encourage men with learning disabilities who have sex with men to adopt a gay identity, as this initially appears a rational response. It is, however, flawed, as it disregards the likely implications for the man himself, with his relatively low social and economic status, as well as his disability.

Most potential exists for lesbian and gay identified staff to provide positive role models, and one to one support and advice for some service users, but the success of such approaches critically depends on respective support from managers, codified into service culture and practice guidance. More challenging to manage, but of particular potential for increasing the man's self-esteem and assertiveness are befriending or sexual health outreach projects run by gay men and gay organisations fighting HIV and AIDS.

Sex in Public Places

Few educational resources in learning disability have attempted to address or represent the realities of sex between men in public places. This is despite a range

of evidence to suggest this is an important issue and significant behaviour—sexual health outreach (Jones, 1993), sex education (Thompson, 1994b), service provision (Davies, 1997) and research (Cambridge, 1996a). Consequently, same sex relationships and sex between men in public places are relatively difficult to introduce into group or one to one sex education. However, innovative service providers (Davies, 1997) have explored effective ways to support men with learning disabilities who cottage and manage the complex staff support and risk management considerations in formulating responses:

One day a member of staff who was off duty was taking a leisurely stroll through the local park in the early evening. She spotted Sonny standing outside a public toilet and, waiving her usual greeting to him, went over to have a quick chat. As she approached, Sonny became visibly anxious, breaking into a sweat and stumbling over his words. The member of staff got a clear impression that Sonny was trying to cover something up. She began to put two and two together and felt a great sympathy for Sonny's uneasé. She made what turned out to be a perfect judgement, setting the pattern for the organisation's response. Polite goodbyes were said and the member of staff retreated. Sonny had been shown the respect that he had a right to expect. (Davies, 1997, p. 63.)

The longer-term service response included asking a series of legal and practice questions to help formulate a risk management strategy, which included individual support and staff and management training. Dedicated resources can also help place such issues on service and educational agendas (Cambridge, 1997c).

Managing HIV Risk

The rationale for the re-gaying of HIV in learning disability has been established (Cambridge, 1997a,b), informed by the wider re-gaying of AIDS in Britain and much of North America in recognition that the de-gaying of HIV in the 1980s had disadvantaged those most at risk of infection (King, 1993). Mainstream sexual health needs assessment (Taylor-Laybourn & Aggleton, 1992) identified HIV risk to young men with learning disabilities. HIV needs assessment in south-east London (Cambridge, 1996a) targeted men with learning disabilities and identified high HIV risk sexual behaviour, along with deficits in staff training and safer sex education.

Direct sex education work (McCarthy & Thompson, 1994; Thompson, 1994b) provided evidence of HIV risk behaviour' and poor knowledge and practice of safer sex on the part of men with learning disabilities and their learning disabled women partners. Experience of specialist services working with men with learning disabilities at risk of HIV and exploitation (Morris, 1997) suggests similarly high HIV risks. Moreover, direct epidemiological evidence from the US (Kastner *et al.*, 1989, 1992; Marchetti *et al.*, 1990) points to HIV infection and AIDS in the population of people with learning disabilities. If there is a known or assessed risk of HIV, services have a legal duty of care and a responsibility to intervene to reduce risk (Gunn, 1997), also necessitating an awareness the individual rights of service users.

Theoretically, services might also be held to account for failing to prevent the spread of HIV infection where the risk was known, although the more independent the person, the less likely that negligence would be proven (Gunn, 1997).

Safer Sex Education

The quality of information on HIV and AIDS, and safer sex is important for effective HIV prevention work with men with learning disabilities, raising challenges, including explicitness of image and accuracy and simplicity of message (Cambridge, 1998). Thompson (1997b), identifies particular issues for working with men with learning disability on safer sex, including issues of identity, knowledge, motivation, self-esteem, physical skills, access to condoms and lubricants, assertiveness and evaluating effectiveness.

Despite the mounting evidence about HIV risk to men with learning disabilities, resources available for sex education in learning disability remained predominantly heterosexual and avoided a detailed articulation of safer sex, mirroring the de-gaying of AIDS in the 1980s. Another tendency has been to focus HIV prevention in learning disability either on very unsafe sex, such as unprotected anal and vaginal sex (McCarthy & Thompson, 1992; McCarthy, 1997) or to be totally generic by promoting condom use for all sexual activities (FPANSW, 1993). Other resources have provided a biased heterosexual focus to HIV (SELHPS, 1992), neutralised gender (LSS, 1992) or avoided accurate details of anal sex or explicit homosexual images (WLHPA, 1994). This is despite a clear rationale for using explicit images in safer sex education (Deverell & Rooney, 1994) with consistent and sustained interventions to prevent reversion to unsafe sex (Davies *et al.*, 1993). Experience with direct educational work with men with learning disabilities stresses the need to invest effort in obtaining and effectively using extra strong condoms and water-based lubricants for anal sex, but also parallel work on developing effective communication strategies and empowering the man to negotiate safer sex. This requires practical work using condoms on model penises and assertiveness work (Thompson, 1997a,b; Cambridge, 1999). Yet experience similarly points to the immensity of the task, as many people with learning disabilities have very great difficulty understanding why the condom can only be put on a penis one way around, as well as using condoms in their actual sexual encounters.

HIV Testing

The complex social and medical implications of HIV antibody testing and their implications for informed consent from a person with a learning disability have been identified (Tachell, 1994; Cambridge, 1996b). Moreover, Gunn (1997) has observed:

Two difficult issues associated with having a test for HIV arise. These are concerned with the consequences which might flow from having a test. First, consequences flowing from the simple fact of having the test, and

second, the consequences where there is an HIV positive result. (Gunn, 1997, pp. 141–142.)

Staff guidelines should be explicit: HIV testing is dangerous territory because it is difficult to assess informed consent and if informed consent is absent, HIV testing amounts to battery and assault, given the vulnerability of people with learning disability when pressure is exerted on them. The implications of testing for the individual and the service are difficult to predict, particularly in relation to confidentiality. The person being tested also needs to understand the nature of the test itself, so there is also the possibility of negligence in relation to the provision of HIV prevention information to consider (Gunn, 1997).

Counselling work with men with learning disabilities who wish to test for HIV needs to reinforce important messages about the possible consequences of unsafe sex and HIV infection. These include the differences between HIV and AIDS, the time-scales relating to the development of AIDS after HIV infection, the potentials and limits of medical interventions, such as combination therapies and concepts of illness and death, all of which may be particularly difficult for someone with a learning disability to relate to themselves. The implication is that safer sex education work with people with learning disabilities needs to be as holistic as possible. It also needs to focus on basic adaptive behaviour skills in relation to obtaining and using condoms effectively, and social skills and assertiveness in relation to negotiating their use.

If HIV testing surfaces as a viable option, then there are advantages in accessing GUM services. These include anonymity, pre and post test counselling and relative objectivity from the service. However, these could be cancelled by the embarrassment and confusion relating to procedures and professional roles on the part of the man with learning disability (Thompson, 1997a,b) and the competence of GUM services to work with people with learning disabilities (Cambridge, 1997a). The emphasis towards discouraging testing is increasingly reflected in HIV policies in services for people with learning disability, the rationale being to help ensure agendas are not service led and the consequences for the service itself such as 'need to know criteria', confidentiality and valid consent have been considered (Horizon, 1996).

These are particularly important, as there is also evidence that many staff support the mandatory HIV testing of service users (Murray *et al.*, 1995). Yet the significant medical advantages of knowing if someone is HIV positive in order to access more effective combination therapies also need to be weighed up. If informed consent cannot be provided for HIV testing due to the degree of a person's learning disability, then a High Court order is required in order to test.

Emotions and Feelings

Men with learning disabilities are heavily socialised into hiding their emotions and feelings relating to sex and personal relationships because of the peer pressure from residents and staff alike. The reluctance of men with learning disabilities to talk

about sex is mirrored in their disbelief if staff or sex educators disclose that they masturbate as part of group or individual work. Guilt about sexuality, and the absence of opportunities to talk about feelings and emotions are re-enforced for men with learning disabilities by the general reluctance on the part of men to admit to emotions and feelings as part of their sexual experiences with women or other men. This can additionally lead to a failure to acknowledge the feelings of their sexual partners.

Group and individual sex educational work with men with learning disabilities therefore needs to ensure that space, opportunities and encouragement is provided to talk about emotions and feelings (McCarthy & Thompson, 1992; Cambridge & McCarthy, 1997). If feelings associated with past trauma, such as with being sexually abused are not addressed (between 30 and 40% of victims of sexual abuse in learning disability are men: Turk & Brown, 1993; Brown *et al.*, 1995; McCarthy & Thompson, 1996), then the man himself and others in the service will remain at risk.

Part of the problem undoubtedly lies in the widespread deprivation of love, affection and physical closeness within formal support regimes, with huge professional distance between service users and support staff. Displays of affection are likely to have been ignored or discouraged with the widespread invisibility of affection and inter-dependency within learning disability services. Services need to build new models and interpretations of Normalisation (Brown & Smith, 1992) if such barriers are to be crossed.

People with learning disability who have expressed a wish to have children should be supported to consider and plan reproduction and child-rearing through independent counselling. Services should be prepared to plan for and support such changing needs. Special effort and ongoing support work will be required to maximise the involvement of men with learning disabilities in such decision-making, encouraging them to positively meet their responsibilities as partners and parents.

Service Organisation and Process

Workshop and training events in sexuality and learning disability tend to be overwhelmingly attended by direct support staff with poor access to senior managers. Direct support staff are therefore often more knowledgeable about practice demands and priorities than managers. They are competent and willing to carry out direct support work but are sometimes unwilling to do so because of lack of management support or encouragement. Some managers are also more comfortable working on issues of adult protection in a generic context and sexuality in a heterosexual context, distancing question relating to sexual abuse, homosexuality and HIV risk management. The resolution of such questions would make pressing demands on management competence and on the capacity of services to manage risks outside overtly defensive practices.

Experience with training also demonstrates a range of issues for building management support, stressing the centrality of a common awareness of the issues. This also impacts on clarity of roles and responsibilities, realistic and shared

expectations, the development of practical policies and guidelines for undertaking work with men with learning disability (in the context of sexuality and adult protection policies more widely), and co-operation, support and safety for the work itself. Such a foundation is required to replace institutional controls with individual innovation, and to take account of the resource and planning implications of developing direct work with men with learning disabilities. It is also necessary to ensure that work on sexuality is incorporated into wider individual assessment and care and service planning systems, helping ensure that purchasing activities of budget holders, such as care managers are functionally integrated.

As a general principle, sexuality work with men with learning disabilities should be carried out by men, although there should be no rigid rules as individual experiences, preferences and needs of men with learning disabilities and the availability of workers will impact on such considerations. Same gender work with women with learning disability is informed by powerful arguments (McCarthy, 1996, 1997), but the rationale is different for working with men, as evidence of the abusive behaviour of some men with learning disabilities demonstrates (Thompson & Brown, 1998). The reality is that the majority of workers in services for people with learning disabilities are women and that many men who work on sexuality are gay identified. Such factors will necessarily both constrain and inform the organisation, planning and delivery of sexuality work with men with learning disabilities.

The key considerations for resolving potential conflicts include whether the man with learning disability has been sexually abused by a man, evidence that work with a woman would be more productive or if he had specifically requested work with a woman, although it should be noted that men with learning disability may assume an easier time with a woman if the work is a consequence of challenging or unacceptable sexual behaviour and the needs of women staff will need to be given prominence (Thompson *et al.*, 1997).

The concept of cultural hierarchy is helpful for resolving such questions (Craft & Brown, 1994; Malhotra & Mellan, 1996) and although men with learning disabilities come very low in this hierarchy, women with learning disabilities come even lower. The implication for work with men with learning disabilities is that issues of power should remain central. Referrals of men to sex education at Consent indicate a disproportionate number for *inappropriate sexual behaviour* (McCarthy & Thompson, 1997). On investigation, this usually means the sexual abuse of women or less able men with learning disabilities. Caution is therefore required with approaches which aim to empower men with learning disabilities, apart from situations where the men themselves are disadvantaged by their sexual encounters with more able men.

Experience with staff training and sexuality policy development in services for people with learning disability (Cambridge & McCarthy, 1997) and policy work on HIV and learning disability (Cambridge, 1997b; Brown & Cambridge, 1997), also indicate the need to include specific service responses tailored to culture and ethnicity. Fundamentalist Christian, Muslim and Jewish religions, for example, may not tolerate homosexuality, sex outside marriage, anal sex, contraception or the use of condoms for safer sex, raising pressing challenges for negotiating sex and safer sex

education work. While a key objective would be to match education and culture, the rights and preferences of individual men to sexual expression and their sexual health and safety must receive a priority, from both moral and legal viewpoints.

Agenda for Action

In conclusion, the following list provides summary pointers for group and individual sex education work with men with learning disabilities:

- Understanding the nature of sexuality within and outside relationships and relationships without sex.
- The sexual rights and responsibilities of individuals and understanding the responsibilities of men in relationships.
- The nature of informed consent to sex, the language and skills needed to negotiate sex and receptive and expressive communication for declining sex.
- Reciprocity, exchange and affection, and the feelings of sexual partners regarding different sexual acts, particularly anal and oral sex.
- The health, social and legal consequences of different sexual activities, especially high HIV risk sex and sex leading to pregnancy.
- The importance of privacy, confidentiality and appropriateness of place in relation to sex alone, the use of pornography and sex with another person.
- Cultural perspectives on sex with men with learning disabilities, sex in public places and on homosexuality more widely, with potential legal considerations.
- Social perspectives on sex between men and women with learning disabilities and the implications of pregnancy, with potential considerations for parenting.
- Assertiveness skills, personal safety skills, condom negotiating skills, escape strategies and appropriate personal disclosure.
- Integrated work on homosexuality, HIV risk and safer sex, with a focus on effective condom use for self and sexual partner.
- Linking sexual behaviour with considerations of sexual identity, socialised beliefs and the development of a positive self-image.
- Support and space to more appropriately express their feelings about sex, and share their emotions with others in a safe space and their sexual partners

REFERENCES

- ARC/NAPSAC (1997) *There Are No Easy Answers* (Nottingham, Association for Residential Care/National Association for the Protection from Sexual Abuse of Adults and Children with Learning Disabilities).
- BROWN, H. (1980) Sexual knowledge and education of ESN students in centres of further education, *Sexuality and Disability*, 3(3), pp. 215–220.
- BROWN, H. & CAMBRIDGE, P. (1997) Policies and their contribution to coherent decisionmaking, in: P. CAMBRIDGE & H. BROWN (Eds) *HIV and Learning Disability*, pp. 159–181 (Kidderminster, British Institute of Learning Disabilities).
- BROWN, H. & SMITH, H. (1992) *Normalisation: a reader for the nineties* (London, Routledge).
- BROWN, H. & STEIN, J. (1997) *But Now They've Got a Voice* (Brighton, Pavilion).

- BROWN, H., STEIN, J. & TURK, V. (1995) The sexual abuse of adults with learning disabilities: report of a second two year incidence survey, *Mental Handicap Research*, 8(1), pp. 1-22.
- BROWN, H. & THOMPSON, D. (1997) Service responses to men with intellectual disabilities who have unacceptable or abusive sexual behaviours: the case against inaction, *Journal of Applied Research in Intellectual Disabilities*, 10(2), pp. 176-197.
- BUCHANAN, A. & WILKINS, R. (1991) Sexual abuse by the mentally handicapped: difficulties in establishing prevalence, *Psychiatric Bulletin*, 15, pp. 601-605.
- BERGH, P., HOEKMAN, J. & PLOEG, D. (1997) Case file research: nature and gravity of sexual abuse and the work method of an advisory team, *NAPSAC Bulletin*, No. 18, January (University of Nottingham).
- BUTT, T. & HEARN, J. (1998) The sexualisation of corporal punishment: the construction of sexual meaning, *Sexualities*, 1(2), pp. 203-227.
- CAMBRIDGE, P. (1996a) Men with learning disabilities who have sex with men in public places: mapping the needs of services and service users in South East London, *Journal of Intellectual Disability Research*, 40(3), pp. 241-251.
- CAMBRIDGE, P. (1996b) Evaluating Sexual Health Outreach for Women with Learning Disabilities, *NAPSAC Bulletin*, No. 15 (University of Nottingham).
- CAMBRIDGE, P. (1997a) How far to gay: the politics of HIV in learning disability, *Disability & Society*, 12(3), pp. 427-453.
- CAMBRIDGE, P. (1997b) At whose risk? priorities and conflicts for policy development in HIV and intellectual disability, *Journal of Applied Research in Intellectual Disability*, 10(2), pp. 83-104.
- CAMBRIDGE, P. (1997c) *HIV, Sex and Learning Disability* (Brighton, PAVILION).
- CAMBRIDGE, P. (1998) Challenges for safer sex education and HIV prevention in services for people with intellectual disabilities in Britain, *Health Promotion International*, 13(1), pp. 67-74.
- CAMBRIDGE, P. (1999) Considerations for informing safer sex education work with men with learning disabilities, *British Journal of Learning Disabilities*, 27(4), pp. 123-126.
- CAMBRIDGE, P. & MELLAN, B. (1998) Heterosexist interpretations of sexual abuse, *VOICE Newsletter*, April.
- CAMBRIDGE, P. & MCCARTHY, M. (1997) Developing and implementing sexuality policy for a learning disability provider service, *Health and Social Care in the Community*, 5(4), pp. 227-236.
- CRAFT, A. (1983) *Sex Education and Counselling for Mentally Handicapped People* (Tunbridge Wells, Costello).
- CRAFT, A. (1987) *Mental Handicap and Sexuality: issues and perspectives* (Tunbridge Wells, Costello).
- CRAFT, A. (1991) *Living Your Life: a sex education and personal development programme for students with severe learning difficulties* (Wisbech, Learning Development Aids).
- CRAFT, A. & BROWN, H. (1994) Personal relationships and sexuality: the staff role, in A. CRAFT (Ed.) *Mental Handicap and Sexuality: issues and perspectives* (Tunbridge Wells, Costello).
- DAVIES, P., HICKSON, F., WEATHERBURN, P. & HUNT, A. (1993a) *Sex, Gay Men and AIDS* (London, Falmer Press).
- DAVIES, S. (1997) A provider perspective, in: P. CAMBRIDGE & H. BROWN (Eds) *HIV and Learning Disability*, pp. 61-70 (Kidderminster, British Institute of Learning Disabilities).
- DEVERELL, K. & ROONEY, M. (1994) *Using Sexually Explicit Materials for Safer Sex Work with Gay Men*, HIV Project (London, North Thames Regional Health Authority).
- DIXON, H. (1988) *Sexuality and Mental Handicap-chance to choose* (Wisbech, Learning Development Aids).
- DWORKIN, A. (1981) *Pornography: men possessing women* (London, Women's Press).
- DWORKIN, A. (1997) *Life and Death* (London, Virago).
- EL-BADRI, S. & ROBERTSHAW, B. (1998) Sexual fetishism associated with temporal lobe dysrhythmia and learning disability: two case studies, *British Journal of Learning Disabilities*, 26(3), pp. 110-114.

- FPANSW (1993) *Feeling Sexy, Feeling Safe* (New South Wales, Family Planning Association).
- GUNN, M. (1996) *Sex and the Law: a brief guide for staff working with people with learning difficulties* (London, Family Planning Association).
- GUNN, M. (1997) The Law, HIV and people with learning disabilities, in: P. CAMBRIDGE & H. BROWN (Eds) *HIV and Learning Disability* (Kidderminster, British Institute of Learning Disabilities).
- HARD, S. & PLUMB, W. (1987) *Sexual Abuse of Persons with Developmental Disabilities: a case study*, unpublished manuscript.
- HORIZON (1996) *Policy on HIV Infection and Testing for People with Learning Disabilities* (Abbots Langley, Horizon NHS Trust).
- JEFFREYS, S. (1985) Prostitution, in: D. RHODES & S. MACNEILL (Eds) *Women Against Violence Against Women*, pp. 59-70 (London, Only Women Press).
- JEFFREYS, S. (1990) *Anticlimax* (London, Women's Press).
- JONES, J. (1993) *Men with Learning Difficulties and Cottaging*, Saturday Seminars (London, North West Thames Regional Health Authority).
- JOHNSON, W. & KEMPTON, W. (1981) *Sex Education and Counselling for Special Groups* (Illinois, Springfield).
- KASTNER, T., HICKMAN, M. & BELLEHUMEUR, D. (1989) The provision of services to persons with mental retardation and subsequent infection with HIV, *American Journal of Public Health*, 79, pp. 1-4.
- KASTNER, T. NATHANSON, R. & MARCHETTI, A. (1992) Epidemiology of HIV infection in adults with developmental disabilities, in: A. CROCKER, H. COHEN & T. KASTNER (Eds) *HIV Infection and Developmental Disabilities*, pp. 127-132 (London, Brookes).
- KEMPTON, W. (1982) Sex and the mentally retarded, *British Journal of Sexual Medicine*, March, pp. 5-6.
- KING, E. (1993) *Safety in Numbers* (London, Cassell).
- LSS (1992) *Take Care of Yourself: safer sex and people with learning disabilities* (London, Lewisham Social Services Department).
- MCCARTHY, M. (1993) Sexual experiences of women with learning difficulties in long stay hospitals, *Sexuality and Disability*, 14(4), pp. 265-279.
- MCCARTHY, M. (1994) Against all odds: HIV and safer sex education for women with learning difficulties, in: L. DOYAL, J. NAIDOO & T. WILTON (Eds) *AIDS: setting a feminist agenda* (London, Taylor and Francis).
- MCCARTHY, M. (1996) The sexual support of people with learning disabilities: a profile of those referred to sex education, *Sexuality and Disability*, 14(4), pp. 265-279.
- MCCARTHY, M. (1997) HIV and heterosexual sex, in: P. CAMBRIDGE & H. BROWN (Eds) *HIV and Learning Disability*, pp. 85-96 (Kidderminster, British Institute of Learning Disabilities).
- MCCARTHY, M. (1998) Whose body is it anyway? Pressures and control for women with learning disabilities, *Disability and Society*, 13(4), pp. 557-574.
- MCCARTHY, M. & THOMPSON, D. (1992) *Sex and the 3 Rs: rights, responsibilities and risks* (Pavilion, Brighton).
- MCCARTHY, M. & THOMPSON, D. (1994) HIV/AIDS and safer sex work with people with learning disabilities, in: A. CRAFT (Ed.) *Practice Issues in Sexuality and Learning Disabilities* (London, Routledge).
- MCCARTHY, M. & THOMPSON, D. (1996) Sexual abuse by design: an examination of the issues in learning disability services, *Disability & Society*, 11(2), pp. 205-217.
- DUNNE, T. & POWER, A. (1990) Sexual abuse and mental handicap: preliminary findings of a community based study, *Mental Handicap Research*, 3, pp. 111-125.
- MCCARTHY, M. & THOMPSON, D. (1997) A prevalence study of sexual abuse of adults with intellectual disability referred for sex education, *Journal of Applied Research in Intellectual Disability*, 10(2), pp. 105-124.
- MALHOTRA, S. & MELLAN, B. (1996) Cultural and race issues in sexuality work with people with learning disabilities, *Tizard Learning Disability Review*, 1(4), pp. 7-12.

- MARCHETTI, A., NATHANSON, R., KASTNER, R. & OWENS, R. (1990) AIDS and state developmental disabilities agencies: a national survey, *American Journal of Public Health*, 80, pp. 54-56.
- MORRIS, S. (1997) Experiences of risk: the role of therapy in sexual health, in: P. CAMBRIDGE & H. BROWN (Eds) *HIV and Learning Disability*, pp. 97-110 (Kidderminster, British Institute of Learning Disabilities).
- MURPHY, G. (1997a) Treatment and risk management, in: J. CHURCHILL, H. BROWN, A. CRAFT & C. HORROCKS (Eds) *There are No Easy Answers*, pp. 109-125 (Chesterfield, ARC/NAPSAC).
- MURPHY, G. (1997b) Assessing risk, in: J. CHURCHILL, H. BROWN, A. CRAFT & C. HORROCKS (Eds) *There are No Easy Answers*, pp. 103-108 (Chesterfield, ARC/NAPSAC).
- MURPHY, G. (1997c) Defining sexual abuse, consent and the duty to report, in: J. CHURCHILL, H. BROWN, A. CRAFT & C. HORROCKS (Eds) *There are No Easy Answers*, pp. 30-35 (Chesterfield, ARC/NAPSAC).
- MURPHY, G. & CLARE, I. (1995) Adult's capacity to make decisions affecting the person: psychologists contribution, in: R. BULL & D. CARSON (Eds) *Handbook of Psychology in Legal Contexts* (Chichester, John Wiley).
- MURRAY, J., MACDONALD, R. & MINNES, P. (1995) Staff attitudes towards individuals with learning disabilities and AIDS: the role of attitudes towards client sexuality and the issue of mandatory testing for HIV infection, *Mental Handicap Research*, 8(4), pp. 321-332.
- PURI, B. & SINGH, I. (1996) The successful treatment of a gender dysphoric patient with pimozide, *Australian and New Zealand Journal of Psychiatry*, 30(3), pp. 422-425.
- SOBSEY, D. (1994) *Violence and Abuse in the Lives of People with Disabilities* (New York, Brooker).
- SOBSEY, D. & VARNHAGEN, C. (1989) Sexual abuse and exploitation of people with disabilities: towards prevention and treatment, in: M. WAPO & L. GOUGEN (Eds) *Special Education Across Canada* (Vancouver, Centre for Human Development and Research).
- S.E.L.H.P.S. (1992) *My Choice, My Own Choice* (video), South East London Health Promotion Service (Brighton, Pavilion).
- STEIN, J. & BROWN, H. (1997) *A Nightmare That I Thought Would Never End* (Brighton, Pavilion).
- TATCHELL, P. (1994) *Safer Sexy* (London, Freedom Editions).
- TAYLOR-LAYBOURN, A. & AGGLETON, P. (1992) *HIV Health Promotion Needs Assessment for Men who have Sex with Men in Camberwell: final report* (London, King's Healthcare).
- THOMPSON, B. (1994a) *Sadomasochism* (London, Cassell).
- THOMPSON, D. (1994b) Sexual experience and sexual identity for men with learning disabilities who have sex with men, *Changes*, 12(4), pp. 245-263.
- THOMPSON, D. (1997a) Profiling the sexually abusive behaviours of men with learning disabilities, *Journal of Applied Research in Intellectual Disabilities*, 10(2), pp. 125-179.
- THOMPSON, D. (1997b) Safer sex work with men with learning disabilities who have sex with men, in: P. CAMBRIDGE & H. BROWN (Eds) *HIV and Learning Disability*, pp. 71-84 (Kidderminster, British Institute of Learning Disabilities).
- THOMPSON, D. & BROWN, H. (1997) Issues from the Literature, In: J. CHURCHILL, H. BROWN, A. CRAFT & C. HORROCKS (Eds) *There Are No Easy Answers*, pp. 16-29 (Chesterfield, ARC/NAPSAC).
- THOMPSON, D. & BROWN, H. (1998) *Response-Ability: working with men with learning disabilities who have difficult or abusive sexual behaviours* (Brighton, Pavilion).
- THOMPSON, D., CLARE, I. & BROWN, H. (1997) Not such an ordinary relationship: the role of women support staff in relation to men with learning disabilities who have difficult sexual behaviour, *Disability & Society*, 12(4), pp. 573-592.
- TURK, V. & BROWN, H. (1993) The sexual abuse of adults with learning disabilities: results of a two year incidence survey, *Mental Handicap Research*, 6(3), pp. 193-216.
- WLHPA (1994) *Piece by Piece* (video), West London Health Promotion Agency (Brighton, Pavilion).

Ref. 2.1.e.

McCarthy, M. and Cambridge, P. (2006) Sexuality and intimate and personal care, in (Eds.) S. Carnaby and P. Cambridge, in *Intimate and Personal Care for People with Learning Disabilities*, Jessica Kingsley, London.

Sexuality and Intimate and Personal Care

Michelle McCarthy and Paul Cambridge

INTRODUCTION

Intimate care relates to the sexuality of people with learning disabilities primarily because it involves the exposure of private areas of the body and the sometimes difficult feelings associated with having these parts seen and touched by others or, indeed, seeing or touching other people's private areas of the body. More directly, these are also the sexual parts of the body – the breasts, vagina, penis, testicles and anus. They therefore take on an added status and relate directly to the sexuality of service users and to the feelings of staff undertaking such intimate care. In addition, however, there are also secondary aspects to sexuality that relate to a whole collection of activities associated with personal care that are relevant. Helping someone dress and look good or simply advising or supporting a person make their own choices about what to wear and how they look is relevant to self-image and the sexual self. The intimacy and closeness of personal care can also generate feelings on the part of staff and service users, both positive and negative, about how we feel about allowing our private and personal space to be occupied by someone else or how it feels to be in someone else's private and personal space and what this means.

For many people with learning disabilities, especially those with severe and profound disabilities, the only times they may have their bodies seen and touched by others will be during intimate and personal care (or medical examination or treatment). It is often assumed that people in such situations do not understand the significance of what is happening to them or their bodies. However, not only will they pick up messages from carers but they will also have sexual and physical feelings and sensations that may not be placed in an appropriate social context or be understood for what they represent to self or others.

They may of course have an explicit individual sexuality, and in some cases a sexual self or sexual life. We need to remember that not everyone receiving intimate care will have a severe learning disability, because there may be reasons related to physical disability why someone needs help with washing or bathing the sexual parts of their bodies. Even if they do have a severe learning disability, this does not mean that they will not have sexual aspects to their experiences. It is therefore very important to carry out personal care tasks in a way that is as respectful as possible to the person's sexuality and adult status.

Many people with learning disabilities will have experience of not having their privacy and dignity respected during personal care. They will not have been in a position to do very much about this and yet will still be dependent on others carrying out those care tasks for them. They may have had to 'harden' themselves to this emotionally and psychologically. They may therefore not appear to show any reactions or preference about how their care tasks are carried out, nor who helps them in this way. The challenge for service providers is, however, to make up for the mistakes of the past (McCarthy and Thompson 1998) and develop intimate care support that acknowledges their individuality as people with physical and sexual feelings, as adults and as individuals. Choice and positive interactions during intimate care are difficult to develop for people with more severe learning disabilities, but communication and other techniques are available for helping develop quality outcomes for both staff and service users (Cambridge and Carnaby 2000a). Unfortunately this is a hard task, as hard-pressed staff tend to want to complete the more unpleasant intimate care tasks as quickly as possible for the person and with minimal interaction (Carnaby and Cambridge 2002).

In some cases where people may have a less severe learning disability but possibly additional physical disabilities they will have a sexual life and a sexual identity, although this may not have been acknowledged by service providers or helped to become externalised. They may masturbate, they may have contacts and friendships with other people with learning disabilities, some possibly sexual and they may have experienced sex or sexual touching from someone without a learning disability. The latter is most likely to have been of a form that would be defined as sexual abuse, due to the probable lack of understanding or consent involved. It is therefore important not to assume that anyone receiving intimate care will not know, perceive, care, feel or understand or misunderstand something about what might be happening to them during intimate care.

MANAGING SEXUAL AROUSAL, MASTURBATION AND SELF-STIMULATION

Staff and family carers need to be helped to understand why it is that a person with a learning disability might become sexually aroused during intimate and

personal care and to respond to sexual arousal in appropriate ways. First, we need to realise that this is not a behaviour peculiar to them – the experience of having the sexual parts of your body seen and touched, even if it is in the course of an otherwise intrusive or unpleasant medical procedure, or within a professional context, can be sexually arousing or exciting for some people. Conversely, other feelings and emotions may also be aroused, such as embarrassment, distress, fear or shame. These emotions may be confused with sexual arousal, by the individual themselves or by carers or others close to the individual.

Second, people whose avenues for any kind of sexual expression may be extremely limited may find that they have to take what opportunities they can to feel and be sexual. For some people with severe and profound disabilities, especially those who are totally dependent on others for all their care and who usually wear incontinence pads, the only time they may have access to their own genitals or provide themselves with or experience sexual stimulation, even unintended on the part of the carer, may be during intimate and personal care. In these circumstances, it is neither surprising nor unreasonable, that some people will seek to use the opportunity to sexually stimulate themselves, or indeed try to get the other person to do it for them. However, the fact that this behaviour is to be expected does not necessarily make it any easier for staff and carers to accept it or respond appropriately to it.

It is therefore important to consider in advance how to respond if such behaviour surfaces during intimate care and there are several suggested courses of action.

First and foremost, staff should not go along with any physical prompts or verbal requests to provide sexual stimulation from people they are providing intimate care to. Staff are in a formal and professional relationship with the person they are providing intimate care to, unlike for example, helping a sexual partner during an illness or recuperating from hospital care when there may already be an established consenting sexual repertoire and understanding between the two people. Adult protection, intimate care and sexual abuse policies in services for people with learning disabilities, and more widely, all make clear that any direct sexual touching or stimulation is inappropriate. Indeed, it is an offence under the 2003 Sexual Offences Act for a member of staff or anyone else in services for people with learning disabilities to have sex (which includes touching intended as sexual) with a service user. To do this would indeed risk allegations and/or suspicions of sexual abuse and would likely be a criminal offence. If, for example, the individual tries to push a staff member's hand towards their genital area, the staff member should gently but firmly resist any such movement and explain why they are doing so (for example, 'No, I'm sorry, that's a private thing', 'I'm not going to do that', 'I don't want to' or 'It's not

allowed'). Even if people have very limited receptive communication skills, and won't understand the meaning of some or any of the words, it is possible they may pick up on the tone of voice and overall meaning.

If the individual is able to understand what is said to them, then the staff member should explain that what they seem to want (i.e. sexual stimulation) is a private activity, that they are not allowed to do it for them and that it should be attempted later when the person is alone. This possibility may of course only be realistically available to some individuals when they are in bed and others may not, for various reasons, be able to touch and stimulate the sexual parts of their own bodies themselves, and such limitations will need to be acknowledged in any response. If the individual is not able to, or doesn't respond to such reasoning, then if it is safe to do so, the member of staff could always withdraw from the immediate care interaction and leave the individual alone for a while. Clearly, if the individual is at any significant risk if left alone in particular circumstances, such as drowning if left unsupervised in the bath, this is not an option, but in many other circumstances it will be.

Under both of the above circumstances it is of course very important to record what has happened and discuss this with the manager or staff team. There may be a personal file, incident report book or changeover meeting at which such situations can be reported and discussed. Any concerns should also be discussed with the line manager in a way that respects the individual's dignity, that is, during a private conversation such as supervision, and not informally over coffee in the presence of other staff or other service users. As with other areas of sexuality, confidentiality, rights and need-to-know criteria will be important to consider.

A principle governing personal care is that it should be an aim for all people with learning disabilities to learn, as far as is possible, that their bodies belong to them and that no one may see or touch the private parts of their bodies unless they wish to engage in sexual contact with them (subject to legal considerations about who this is and the person being able to give informed consent) or when it is necessary for their personal or medical care. In order to put this principle into practice, individuals must therefore be given as much privacy as possible, for example, when they bathe, wash or use the toilet and be informed and consulted about personal care before and during such interactions. They can also be supported to do some things for themselves in some cases, which may take more time but will reinforce important messages about their body and who it belongs to. Carers being present on a routine basis, when this is not strictly necessary for safety or to help with hygiene, is not appropriate. When individuals do attempt to use such opportunities for sexual arousal (e.g. masturbating while in the bath or when having an incontinence pad changed) it is especially important that they be given the maximum privacy possible for this. Generally speaking, it is

never appropriate for a staff member or family carer to be present when an individual is masturbating. The individual with learning disabilities needs to be clear about this as much as anybody else. In other words, in order for individuals to learn that other people can only have access to (i.e. see or touch) the private parts of their bodies in strictly limited circumstances, it is necessary to, in fact, limit those circumstances. In this way, it maximises the chances of individuals developing the ability to recognise when something untoward might be happening and thus serves a protective purpose with regard to sexual abuse.

RESPONDING TO INAPPROPRIATE SEXUAL BEHAVIOUR

Masturbation or sexual self-stimulation are the most commonly reported inappropriate sexual behaviours experienced and reported by staff during intimate and personal care. Indeed, this is the case more widely in sexuality work, particularly for men but also less frequently, women with learning disabilities (McCarthy 1996), so we should not be surprised when such behaviours surface. Concerns primarily centre on four key and sometimes inter-related themes (Cambridge, Carnaby and McCarthy 2003):

1. The person is considered to be unable to masturbate properly, usually meaning that it is thought they are unable to reach orgasm/ejaculate.
2. The person does not know how to masturbate, usually meaning that they have been observed rubbing their penis or vagina, generally when exposed during intimate care.
3. The person is doing it too much, usually meaning that the duration or frequency of the masturbation is such that staff consider that it interferes with intimate or personal care.
4. The person is using inappropriate objects or means to help them masturbate, usually meaning that they are using objects not intended to aid masturbation or which could hurt them, such as soap or flannels or shampoo containers.

Of course, if masturbation happens at all during intimate care this is itself an inappropriate sexual behaviour, causing difficulties for carers or staff.

The understanding of such behaviours is often complicated when they are also associated with other challenging behaviours. Staff may relate hypotheses they have developed to help them understand or explain the behaviours they have observed during intimate care. An example is linking unsuccessful masturbation with sexual or other frustration, leading to challenging behaviour (e.g. Sheppard 1991). Causal links may therefore be constructed between masturbation, as it presents itself or is perceived to be a problem, and challenging behaviour.

Often underlying such considerations are issues of gender and sexuality. Masturbation is generally reported to be much more of an issue for men with learning disabilities than with women (McCarthy 2002). More widely it has been observed that the sexuality of men with learning disabilities is seen as relatively pathological, with a range of sexual behaviours reinforcing such perceptions (Cambridge 1997; Cambridge and Mellan 2000). Conversely, it has been observed that the sexuality and sexual experiences of women with learning disabilities has remained relatively hidden (McCarthy 1999; McCarthy and Thompson 1998). Such basic observations are mirrored in discussions in staff training in sexuality and learning disability (Cambridge and McCarthy 1997). This is one of the reasons why sexuality and gender need to be considered together in designing intimate care and responding to any sexuality issues that arise whether in relation to service users or the feelings of staff. The other is the known incidence of sexual abuse and the vulnerability of both men, and particularly, women with learning disabilities from sexual abuse during private care interactions from men.

What contributes to perceived problem behaviours, such as masturbation or self-stimulation during intimate care is the way services construct space and organise support, with communal and collective spaces such as living rooms, bathrooms and toilets, often merging along the public-private continuum with shared or individual spaces such as bedrooms (Parkin 1989). By and large, private space is at a premium in services for people with learning disabilities. In residential services someone may have their own bedroom, but its use may be discouraged during the day, there may be no locks on bedroom doors and staff and other service users may not respect privacy. This is why simple messages such as a right to privacy and respect have received prominence in some educational materials (e.g. Cambridge 1996; McCarthy and Cambridge 1996). Private spaces in day services or services for people with profound and multiple learning disabilities are even scarcer, and the only places available for someone to masturbate may be the toilets or during intimate care.

In addition to the tendency to disrespect or disregard privacy in services for people with learning disabilities, there is also a tendency to desexualise and to de-individualise people with learning disabilities (Carnaby 1997 and 1999). This can mean that ordinary sexual behaviours, when they do surface, are interpreted as inappropriate. Masturbation is, for example, crudely referenced as a behaviour problem on the Adaptive Behaviour Scale (Nihira *et al.* 1974, referenced and discussed in Felce, Lowe and De Pavia 1994).

The first step in responding is to clarify and accurately describe what is happening. Six key sets of questions (McCarthy and Thompson 1998) that can be asked about the actual behaviour, evidence and context are:

1. What is the actual behaviour? For example, is the person touching themselves sexually, what part of the body are they touching, how are they touching it, are they actually masturbating, are they trying to get the carer to touch them sexually during intimate care and so on?
2. How do staff respond to the situation? For example, is this consistent and do some staff or responses seem to be more effective than others?
3. Does the behaviour (for example, masturbation) vary between places or settings (such as home, day care or residential service) and what might explain this variation?
4. Is there a daily or temporal pattern to the person's masturbation and are there times when this is not a problem? For example, does it only happen during intimate and personal care?
5. Is this a new behaviour or has it been going on for some time and if the latter, what has been tried?
6. Does the nature or provision of intimate care vary between places, settings or people and does there seem to be a relationship to the inappropriate sexual behaviour reported during intimate care?

Depending on the individual situation or behaviour, more detailed questions are likely to need to be answered, for example:

- For a woman, does she directly stimulate her clitoris, vagina or breasts and is this done with her hands or with an object such as a sponge or flannel? Does she seem to achieve satisfaction, whether through orgasm or not?
- For a man, does he get an erection, does he stimulate his penis (or anus), does he use his hand or an object such as a flannel and does he ever ejaculate?

It should also be asked whether there is any suspicion or evidence that the person may have experienced sexual abuse. If so, and especially for people with very limited verbal communication, touching their genital area may be their only way of drawing attention to something having happened to that part of their body.

Answers to the above questions will help place the behaviour on a continuum between sexual arousal, self-stimulation and masturbation, which will inform the response. They will also help develop and test the hypothesis about the link between masturbation and other stimuli such as warm water or indirect contact through washing or hand over hand or indeed other challenging behaviours. In some cases, it may be necessary to collect information to help decide on the function of the masturbation and clarify the attribution if it is a challenging behaviour. This can be done using a simple but widely recognised ABC

(Antecedent, Behaviour, Consequence) approach to understanding setting conditions and triggers as part of behaviour analysis (e.g. Murphy 1994).

In many cases it will also be important to check out some even more basic, but often overlooked possibilities, particularly in relation to situations where the woman or man is considered to be unable to masturbate effectively. For example, does the person have a vaginal, penile or urinary tract infection? Are there any signs of a skin irritation or condition, such as thrush or eczema? Could having an erection cause pain for the man, as with a very tight foreskin? Is the person on any form of medication that could reduce their ability to masturbate or reduce their libido, such as anti-psychotic medication? All such possibilities are generally more easily checked out during intimate care than any other care situation.

In trying to understand a person's sexual behaviour, staff need to be encouraged to reflect on their own beliefs and values about sexuality. We draw on a range of models and sources for this, including our cultural backgrounds, subjective feelings ('gut reactions'), beliefs about how common or uncommon a certain type of sexual behaviour is, our understanding of the law, and so on. The models of 'normality' people hold can be influential in determining our responses and staff need to be helped to recognise that many of us make distinctions about what we think is 'normal' or 'abnormal' on an instinctive and subconscious level, rather than as a result of considered reflection.

Finding out more about a person's motivations and purposes will obviously require careful and respectful observation. Intimate and personal care or help with washing or bathing can sometimes provide the only such opportunities (Cambridge and Carnaby 2000a). If a person is able to discuss such matters, then private and respectful conversations can help. However, in many cases, if staff already consider that someone is unable to masturbate effectively, then they are likely to hold similar information or observations to support their concerns or will have collected evidence indirectly. It will remain important to check such evidence at staff meetings or case reviews in order to validate any assumptions or interpretations as a first step to planning responses or deciding on what additional information may be needed to inform any intervention or response. Considerations likely to surface from such work include links with activities and levels of meaningful engagement. If people lack meaning in most of their daily lives, which is often the case for people with profound and multiple learning disabilities requiring intimate care, they are more likely to engage in self-involved behaviours that serve the purpose of relieving boredom or frustration.

The need for structured sex education is likely to emerge for many people with learning disabilities, but again it is the more severely disabled people who are likely to have been excluded from sex education. Most will not have had their sexuality or sexual needs addressed directly at all in their lives and

consequently have not been given basic messages about masturbation being a normal and enjoyable activity, either on your own or with a consenting partner or about the importance of privacy. At least a discourse on sexuality has been initiated (Downs and Craft 1997) for people with severe learning disabilities and techniques are available to give people a positive response verbally or through other forms of communication (Ware 1996), that the behaviour is allowed and valued in certain places.

If a man is deemed to be masturbating too much or ineffectively, it is sometimes suggested that chemical responses using medication designed to suppress the male sex drive (such as Androcur) will help the situation. However, without the person's informed consent, which in the case of someone with a profound or severe learning disability would be very unlikely, this is not a realistic or ethical option to consider. In addition to the ethical problems, there is the question of effectiveness, as experience suggests that men who take this medication may still experience sexual feelings and attempt sexual activity but are unable to reach orgasm. This can then exacerbate the problem it was trying to solve. Rather, support staff need to be asking whether the individual concerned is having enough 'private' time. For example, if appropriate and safe, is he being given time to relax alone in the bath or shower, or have time to rest in bed when not actually sleeping, without wearing pads or restrictive clothing?

GENDER AND SEXUALITY

Most services today acknowledge that intimate and personal care is best carried out by staff members of the same-gender as the individual with learning disabilities. Indeed, many have guidelines and policies that stipulate that this should be the case. Providing a staff member of the same-gender as the individual receiving care is a concrete way of respecting the person's dignity and adult status. Given the predominance of women in direct care roles, there should always (except in highly unusual circumstances) be sufficient women staff to assist women with learning disabilities. Providing personal care to men with learning disabilities is more complex. The under-representation of men in direct care roles means that often there may not be enough male staff available to assist men. Moreover, there are gendered roles for caring that make it rightly or wrongly more socially acceptable for women, rather than men, to provide intimate care (Bradley 1993; Orme 2001; Williams 1993) and conversely for men, rather than women, to respond to challenging behaviour (Clements *et al.* 1995). Many men with learning disabilities will, for example, be used to women, whether mothers or sisters, providing intimate care for them.

The importance and complexity of gender, particularly when related to sexuality and sexual identity of staff, is something that managers and commissioners need to consider at a service-wide level and bear in mind when seeking to

recruit, train and retain staff. It must always be remembered that receiving personal care puts people with learning disabilities at an increased risk of sexual abuse, as it is conducted in private and largely outside scrutiny and can involve touch (Cambridge and Carnaby 2000b) and all available evidence suggests that male staff are far more likely than female staff to sexually abuse both women and men with learning disabilities. Clearly same-gender care rationales largely protect women with learning disabilities from the risk of sexual abuse but fail to protect men with learning disabilities from such risks, just as they fail to address issues of physical abuse or neglect (Cambridge and Carnaby 2000b).

Some lesbian and gay staff may feel anxious about providing same-gender personal care, because of the homophobic prejudices of others. Interviews with staff (Cambridge and Carnaby 2000b) have highlighted such issues (see Chapter 2). Any prejudices that surface will need to be vigorously challenged in services, to avoid reinforcing such barriers and the outcome of lesbian and gay staff not engaging positively and safely in intimate and personal care in the same way as other staff. Gay identified men risk particular vulnerability when providing intimate care to men in a similar way that heterosexual men might feel if expected to provide intimate care to women, when referencing the evidence on sexual abuse.

PARTICULAR ISSUES FOR WOMEN

Menstrual care

Helping women with learning disabilities understand and manage their periods is a task that should only be undertaken by women staff and carers, except at the request of an individual woman or where, in an extreme situation, there is no other choice. This assertion is based on the fact that when asked, women with learning disabilities consistently report an overwhelming preference for other women to assist them in their menstrual care (McCarthy 2002; Rodgers 2001). Women with learning disabilities reflect a generally held view in most, if not all known societies, that menstruation is 'women's business' and something that is generally kept private from men (Laws 1990).

Where women need direct assistance with menstrual care, then almost always they will be assisted to use sanitary towels. The use of tampons is an issue that is rarely discussed in services or indeed the literature, although occasionally staff and carers do ask for guidance on this and it is referenced in some training materials on intimate and personal care (Cambridge and Carnaby 2000a). Unless women can be taught to use tampons independently, then their use is not appropriate. Staff or family carers inserting tampons for a woman with learning disabilities is not an acceptable part of personal care. It is too intrusive a procedure and is not comparable to placing a sanitary towel or incontinence pad into

a person's underwear. Inserting tampons is more comparable with inserting vaginal pessaries or anal suppositories and these are procedures that staff would only be expected to undertake if medically necessary. Clearly, use of tampons is not medically necessary, although obviously many women find them convenient and preferable to sanitary towels.

How women with learning disabilities feel about their bodies and appearance

Traditionally it has been believed that one of the 'advantages' of having a learning disability was freedom from many of the pressures society places on individuals to conform to its standards. This may be true in some aspects of life, but evidence suggests that women with mild and moderate learning disabilities feel the same pressures around their appearance and body image as other women do (McCarthy 1998). This means that many often feel themselves to be unattractive, as measured by the unrealistic and impossibly high standards of eternal youth and beauty that society sets for women. Just like their non-disabled counterparts, many women with learning disabilities focus their dissatisfaction with their bodies upon their weight and express a desire for weight loss. However, unlike their non-disabled counterparts, women with learning disabilities often find that staff or family carers take decisions about weight loss out of their hands and make decisions for them: 'They say "You can't have this, you can't have that"; 'They won't let me have ice cream' (quotes taken from McCarthy 1998, p.561).

Evidence also suggests that even during life stages such as the menopause, where weight gain is expected and normal for women (though not inevitable), women with learning disabilities still find themselves under pressure from staff to maintain or lose weight (McCarthy 2002). Services also contribute to women's dissatisfaction about their weight in other ways, that is, prescribing and administering medication that causes (sometimes considerable) weight gain.

The suggestion here is not that the weight of women (or indeed men) with learning disabilities should never be of concern to staff or family carers. This is not the case, especially where individuals are clearly under- or over-weight or where they have conditions that predispose them to difficulties about controlling their eating, such as Prader-Willi Syndrome. Helping individuals to lose weight if that is what they personally want or where it is medically beneficial is an appropriate course of action. However, helping them to resist pressures to lose weight, because this meets arbitrary and unrealistic standards set by society is also appropriate.

With regards to other aspects of their appearance, such as the way they dress or do their hair, these can also be problematic areas for some women with

learning disabilities. It is an under-researched area, but evidence from women with mild and moderate disabilities suggests that some women resent the comments and control that others (staff and family carers) have over them: 'I like choosing my own clothes, but they never let me choose my own'; 'The staff didn't like it when I had blond highlights, they said I look like a tart' (quotes taken from McCarthy 1998, p.567).

Once again, it may, in some circumstances, be perfectly appropriate for staff and family carers to offer advice, guidance and indeed take some decisions on behalf of individuals if they cannot do so for themselves. Not to do so would mean the person's dignity and adult status could be seriously compromised. Nevertheless, when people can make their own choices and are denied the right to express their individuality through their appearance, this is an equal affront to their dignity and status.

PARTICULAR ISSUES FOR MEN

A potential reason why men with learning disabilities should ideally receive intimate and personal care from men is the general absence of positive male role models in services for people with learning disabilities. In many cases, male support staff are simply absent or occupy managerial or specialist posts. If men are not seen to be providing intimate care for male service users then this will reinforce negative stereotypes about gendered roles and caring and expectations about male behaviour. There is certainly enough evidence from sex education at one-to-one and group levels that men with learning disabilities hold relatively rigid stereotypical images about gender, based on names, dress codes, hair length and segregation (Cambridge and McCarthy 1997). This is mirrored in sexual identity, with most men with learning difficulties who have sex with men identifying as heterosexual rather than gay (Cambridge 1997).

At a practical level, however, there are clearly intimate and personal care tasks male support staff or carers will be potentially more competent at doing for and with men with learning disabilities, based on a knowledge of their own bodies, experience and perceptions. These are also likely to be tasks that it would be more appropriate for men to do and the most inappropriate for women carers to undertake for men with learning disabilities, either in relation to their own feelings or to how the man with learning disabilities might experience or interpret them. The most obvious example is genital hygiene. Cambridge and Carnaby (2000a) reference the comments of a male care worker who had no detailed individual guidelines to help him decide how to wash a male service user's penis during intimate care:

The care plan says something like 'ensure genitals and anus are clean'. This leaves it up to me to interpret inputs based on my own standards and knowledge. (Cambridge and Carnaby 2000a, p.4)

Issues such as genital hygiene have until recently been largely neglected for men with learning disabilities, despite medical evidence that such neglect can have serious health consequences. Conditions such as phimosis and paraphimosis (where the foreskin cannot be retracted over the glans of the penis or where a history of repetitive forceful retraction causes the formation of a fibrotic ring of tissue that restricts the penis) can result from incorrect circumcision or can be congenital, affecting around one per cent of men. They can cause problems such as urinary obstruction, hematuria and preputial pain and in acquired phimosis, there is likely to be a history of poor hygiene.

At the other end of the continuum, tasks such as dressing and shaving are also arguably better conducted by men. Men will have directly experienced the feeling of wearing different types of clothes or underwear, be able to make suggestions about positive aspects of male dress or appearance based on masculine self-image and have a first-hand understanding of the sensations and results of different approaches to shaving, to name a few examples.

What can potentially compromise positive interaction between male carers and male service users are differences and similarities in sexuality. For example, if a male carer is out as a gay man at work and the service user knows this, then there is the potential for this to be used either positively or negatively – refusing personal care from a gay man or, if they have homosexual feelings themselves, possibly using personal care as a way to receive sexual gratification. This is simply the reverse side of the heterosexual coin, as we know only too well how some men with learning disabilities sexually harass female staff during intimate and personal care.

Men with learning disabilities who have sex with men would benefit from the understanding and advice a gay identified staff member might be able to offer during one-to-one personal care situations, for example, on assertiveness, HIV risk or simply giving positive messages that it's OK to feel a certain way about another man. Positive gay role models could be hugely beneficial to men with learning disabilities who have sex with men and who are largely excluded socially or economically from developing a gay identity. Similarly heterosexual male carers could provide the same support to heterosexual service users, but generally without the risk that they would be compromising their status as a carer. Such problems and potentials need to be acknowledged when organising same-gender intimate and personal care between men.

Conversely, same-gender intimate care can be an excellent opportunity for male carers to give relatively 'informal' but structured and considered sex education and advice to service users, through an agreed care plan and in response to

assessed needs or requests for information on the part of the service user. It may be more ordinary and natural for men to talk about the male body and sexual parts in a comfortable and ordinary fashion when 'allowed for' by the circumstances and opportunities presented during regular personal or intimate care interactions. Personal care situations, one-to-one and private, are also likely to be a more appropriate and productive place to offer advice about personal appearance and personal relationships.

CONCLUSION

Sexuality and considerations of sexuality and gender clearly have a central role to play in designing and delivering intimate and personal care, both in terms of staff and service users. Intimate care sometimes provides a stark focus on the sexuality of service users, whereas it is more easily ignored in many other care situations or interactions. Personal care also provides hidden opportunities to work productively with individuals on issues of sexuality in its widest sense. Often individual care guidelines avoid being explicit about how particular care tasks should be conducted, developing a generic language around the sexual body parts and therefore risking inconsistent approaches and the neglect of health and hygiene.

Adult protection and sexuality policies clearly need to reference intimate and personal care and conversely, intimate and personal care policies need to recognise issues relating to sexuality of staff and service users. They also need to begin to unpack the restrictions as well as safeguards that same-gender intimate and personal care policies impose. Services need to initiate an intelligent debate about how service users' needs can be best met during intimate and personal care, not simply those related to the design and conduct of particular care tasks, but more holistic needs relating to self-image, identity, sexuality and so on. Whilst gender is clearly a very important consideration, it is not the only one, and users and carers need to be matched when considering a whole collection of attributes including sexuality and culture.

REFERENCES

- Bradley, H. (1993) 'Across the great divide.' In C.Williams (ed.) *Doing 'Women's Work'*. London: Sage.
- Cambridge, P. (1996) *The Sexuality and Sexual Rights of People with Learning Disabilities: Considerations for Staff and Carers*. Kidderminster: British Institute of Learning Disabilities, p.34.
- Cambridge, P. (1997) 'How far to Gay? The politics of HIV in learning disability.' *Disability & Society* 12, 3, 427–453.
- Cambridge, P. and Carnaby, S. (2000a) *Making it Personal: Practice and Policy in Personal and Intimate Care and People with Learning Disabilities*. Brighton: Pavilion Publishing.

- Cambridge, P. and Carnaby, S. (2000b) 'A personal touch: managing the risks of abuse during intimate and personal care for people with learning disabilities.' *Journal of Adult Protection* 2, 4, 4-16.
- Cambridge, P., Carnaby, S. and McCarthy, M. (2003) 'Responding to masturbation in supporting sexuality and challenging behaviour in services for people with learning disabilities.' *Journal of Learning Disabilities* 7, 3, 251-265.
- Cambridge, P. and McCarthy, M. (1997) 'Developing and implementing sexuality policy for a learning disability provider service.' *Health and Social Care in the Community* 5, 4, 227-236.
- Cambridge, P. and Mellan, B. (2000) 'Reconstructing the sexuality of men with learning disabilities: empirical evidence and theoretical interpretations of need.' *Disability & Society* 15, 2, 293-311.
- Carnaby, S. (1997) 'What do you think? A qualitative approach to evaluating individual planning services.' *Journal of Intellectual Disability Research* 41, 225-231.
- Carnaby, S. (1999) 'Individual programme planning: where is the individual?' *Tizard Learning Disability Review* 4, 3, 4-9.
- Carnaby, S. and Cambridge, P. (2002) 'Getting personal: an exploratory study of intimate and personal care provision for people with profound and multiple learning disabilities.' *Journal of Intellectual Disability Research* 46, 2, 120-132.
- Clements, J. et al. (1995) 'Real men, real women, real lives? Gender issues in learning disabilities and challenging behaviour.' *Disability & Society* 10, 4, 425-435.
- Downs, C. and Craft, A. (1997) *Sex in Context: A Personal and Social Development Programme for Children and Adults with Profound and Multiple Impairments*. Brighton: Pavilion Publishing.
- Felce, D., Lowe, K. and De Pavia, S. (1994) 'Ordinary housing for people with severe learning disabilities and challenging behaviours.' In E. Emerson, P. McGill and J. Mansell (eds) *Severe Learning Disabilities and Challenging Behaviours: Designing High Quality Services*. London: Chapman & Hall.
- Laws, S. (1990) *Issues of Blood: The Politics of Menstruation*. Basingstoke: Macmillan.
- McCarthy, M. (1996) 'The sexual support needs of people with learning disabilities: a profile of those referred for sex education.' *Sexuality and Disability* 14, 4, 265-279.
- McCarthy, M. (1998) 'Whose body is it anyway? Pressures and control for women with learning disabilities.' *Disability & Society* 13, 4, 557-574.
- McCarthy, M. (1999) *Sexuality and Women with Learning Disabilities*. London: Jessica Kingsley Publishers.
- McCarthy, M. (2002) 'Going through the menopause: perceptions and experiences of women with intellectual disability.' *Journal of Intellectual and Developmental Disability* 27, 4, 281-295.
- McCarthy, M. and Cambridge, P. (1996) *Your Rights about Sex: A Booklet for People with Learning Disabilities*. Kidderminster: British Institute of Learning Disabilities, p.20.
- McCarthy, M. and Thompson, D. (1998) *Sex and the 3R's*. Brighton: Pavilion Publishing.
- Murphy, G. (1994) 'Understanding challenging behaviour.' In E. Emerson, P. McGill and J. Mansell (eds) *Severe Learning Disabilities and Challenging Behaviours: Designing High Quality Services*. London: Chapman & Hall.
- Orme, J. (2001) *Gender and Community Care*. Basingstoke: Palgrave.
- Parkin, W. (1989) 'Private experiences in the public domain: sexuality and residential care organisations.' In J. Hearn et al. (eds) *The Sexuality of Organisations*. London: Sage Publications.
- Rodgers, J. (2001) 'The experience and management of menstruation for women with learning disabilities.' *Tizard Learning Disability Review* 6, 1, 36-44.
- Sheppard, R. (1991) 'Sex therapy and people with learning difficulties.' *Sexual and Marital Therapy* 6, 3, 307-316.
- Ware, J. (1996) *Creating a Responsive Environment for People with Profound and Multiple Learning Difficulties*. London: David Fulton.
- Williams, C. (1993) 'Introduction.' In C. Williams (ed.) *Doing 'Women's Work'*. London: Sage.

2.2. Using evidence to inform practice

Ref. 2.2.a.

Cambridge, P. (1994) A practice and policy agenda for HIV and learning disability. *British Journal of Learning Disabilities*, 22 (4), 134-139.

A Practice and Policy Agenda for HIV and Learning Difficulties

Paul Cambridge, Lecturer/Service Development Consultant, Tizard Centre, University of Kent at Canterbury.

The aim of this paper is to review how issues around HIV and learning difficulties come together to present a challenge for health promotion/HIV prevention and services for people with learning difficulties. This review will also identify the key practice issues which services for people with learning difficulties need to address in relation to HIV and offer a model for developing policy and resources for carrying forward work in this area. The information and arguments presented in this paper are my personal interpretations based on the experiences and issues generated by two areas of work.

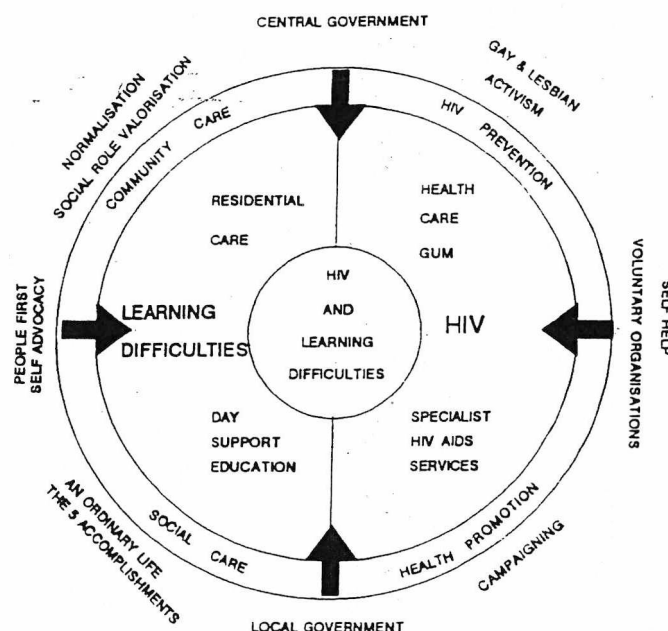
The first is a series of learning sets organised for South East Thames Regional Health Authority (SETRHA) on HIV and HEP B and services for people with learning difficulties. These were open to managers and staff working in learning difficulty services across agencies and sectors, and have recently been completed. (1) SETRHA Learning Sets. Organised by Paul Cambridge and Hilary Brown at The Tizard Centre. Inputs involved SE London Health Promotion Service (James Nichol) and the Sex Education Team (David Thompson). The second is a needs assessment exercise funded by South East London Health Authority (SELHA), covering the special and ordinary needs of men with learning difficulties who have sex with men in public places. (2) SELHA Needs Assessment Exercise. The steering group developed and conducted the study and included Paul Cambridge (Tizard Centre), Simon Davies (Southside Partnership), James Nichol (SELHPS) and David Thompson (Sex Education Team).

Context

Before plunging into the turbulent waters of HIV and learning difficulties, it is worth reminding ourselves where services for people with learning difficulties are at the moment (Figure 1).

Principles of normalisation and social role valorisation, stemming from Wolfensburger's work in the US (Wolfensburger, 1980, 1983), permeated services during the 1980s. Influential publications from the King's Fund

Figure 1 The politics of HIV and learning difficulties



Centre stressed the importance of *An Ordinary Life* (King's Fund Centre, 1980) for people with learning difficulties. For example, many residential services use ordinary housing, shared by say, five people with learning difficulties, with individually tailored staff support. In many services, the '5 Accomplishments' formulated by O'Brien (1987), have become important aims in relation to community living and the development of community support services, namely: community presence or integration in valued community settings; choice or autonomy in small everyday and large life-defining matters; competence or the ability to perform functional and meaningful activities; respect or having a valued place among a network of people; and roles in community life and participation of being part of a network of personal relationships. These have direct relevance to people's sexual and emotional lives and to sexual health and risk (Brown, 1992).

The links between risk and choice are inescapable and are reinforced by service philosophies which stress the importance of links with life in the community. *Ties and Connections* (King's Fund Centre, 1988) developed the concept of integration around the time people spend together, intensity and emotion, intimacy of confidences and reciprocity and sharing parts of life and work. Intimate sexual and emotional relationships will form a natural part of connections. These approaches can be reduced to a realisation of the rights of people with learning disabilities to have more ordinary lives and a commitment by services to enable this to happen. In this context, ordinary does not mean average, but to be an individual with ordinary opportunities, experiences and expression.

Most people with learning difficulties are now part of local communities, rather than being segregated in hospitals or institutionalised settings. The large mental handicap hospitals that closed during the 1980s were replaced, in the most part, by a wide range of dispersed services in the community (Knapp, *et al.*, 1992; Korman & Glennerster, 1990). This trend has been promoted by the further development of community care under the 1990 reforms and the organisational systems necessary to support people who now receive a range of services from a range of providers (Cambridge, 1992). People living in the community now face a different set of emotional, sexual and health risks than they did in hospital. Services better integrated in the community mean that people are more open and closer to the risks faced by all of us, rather than specific risks of exploitation and abuse found in institutions (Crossmaker, 1991).

We will make little progress until we recognise and accept the rights of people with learning difficulties to sexual and emotional expression, and this principle should underpin our thinking. However, it is not easy to take such a principle forward. Many services are 'protective' and many parents do not acknowledge the sexuality of their older children with learning difficulties.

But the facts remain and it is everyone's responsibility to respond to HIV in a positive and valued way whatever the setting. Many people with learning difficulties are sexually active, some within relationships and some outside relationships. Some are also in same sex relationships. Finally, some people with learning difficulties have HIV infection or AIDS and some have died from AIDS related illnesses.

The key question is, therefore, how services should respond, and there has to be concern on two fronts. First, the ability of mainstream health and specialist HIV services to respond to the special and ordinary needs of people with learning difficulties. Are counsellors at special clinics skilled at assessing informed consent for an HIV anti-body test from a person with learning difficulties who may have limited expressive or receptive verbal communication? Could a specialist AIDS support service respond appropriately to a referral of someone with a

learning difficulty? The second, is the ability of community services for people with learning difficulties to respond to the pressures placed on them by HIV and AIDS. Could a service or staff group with its own interests and agenda support a user to make an informed decision about having an HIV anti-body test? How would they support a user who was having unsafe sex inside and outside the service? Some of these questions will be revisited later in this paper.

HIV/HEP B learning sets

These were commissioned from The Tizard Centre by SETRHA (1). They were designed to help services for people with learning difficulties to respond in better ways to the issues thrown up by HIV and AIDS and to inform policy development, thus providing an important link between policy and practice. All too often there is an unbridgeable implementation gap between policy and practice and innovative services often find themselves marginalised. The structure and themes of the learning sets were designed to navigate this divide, by working through a basic process.

- A workshop on values identified the requirement for attitudes and practice to be built on a broad and shared value base which was non-sexist, non-heterosexist and non-racist.
- The workshop on knowledge demonstrated the complexities, technical, medical and conceptual, in understanding the virology of HIV, the development of AIDS, transmission, risk and safer-sex. This highlighted the mixed messages and uncertainties around oral sex and the extent to which we need to simplify key messages.
- The different techniques for passing on this knowledge to users in a form which they could understand and transfer to their sexual behaviours were explored by the workshop on education. It was evident how difficult it was to transfer the skills necessary for something relatively simple, such as using a condom for instance.
- The workshop on practice looked at the different options for services to respond to the issues around HIV and AIDS, with a focus on men who have sex with men and risk assessment. The fine line between aversive practices, such as keeping someone at home or restricting activities, and non-aversive practices, such as therapy or counselling, was identified.
- An insight into the sorts of emotions and feelings associated with HIV and AIDS and how these can dramatically affect people's personal, sexual and working lives and the sorts of support needed were identified by the workshop on feelings.
- The workshop on choices confronted the complex dilemmas facing services and moral, ethical and human rights issues. It identified many potential conflicts of interest between users, staff and services, including confidentiality, informed consent and privacy.

- Training packs and other safer-sex and health promotional materials were reviewed in the workshop on resources. This demonstrated how important it is to tailor education to group and individual needs, particularly around individual behaviour, communication skills and cognitive ability.

I will use an example of a service scenario developed for the groupwork in one of the workshops to illustrate the sorts of dilemma that some services for people with learning difficulties have already faced and most are likely to face in the near future. Although Mark's experience is fictitious, it has been constructed from actual experiences, with names and places changed.

Mark

Mark is a good looking 26 year old man. He has lived in a group home in the community for the last five years which he shares with another man and two women. He does most of his shopping locally once a week. He likes living in the city and uses local sports facilities. He is outward going, honest and attends adult education classes at the local college in literacy and cooking. He communicates well verbally and is self-determining in his daily activities. He doesn't need as much support as the other residents, although he values his keyworker day when he works out his weekly budget and visits friends he knew when living in hospital or his mother and father who live nearby. He spends some free afternoons and evenings visiting friends, and does his own washing, cooking and cleaning.

His care manager and keyworker had read hospital records which described 'inappropriate' sexual behaviour with other male residents. They had not noticed any inappropriate sexual behaviour since he moved out of hospital, but were working on sexuality, sexual health and personal relationships with him because he and one of the women residents were developing a sexual relationship. He and his partner had received sexuality counselling and safer-sex education around the use of condoms for penetrative sex.

His keyworker had heard rumours from the day centre that Mark used to attend three days a week that he and another male user had been caught 'playing around' in the toilet by a member of staff. Mark's view was that the embarrassment and questioning this had led to was one of the reasons he decided he didn't want to attend day care any more. His keyworker had become increasingly anxious after receiving a complaint from the sports centre Mark attended. Apparently, he had tried to initiate some sort of sexual contact in the shower with another member of the centre. The manager had complained to the service, and his keyworker had discussed the incident with him. The agreement was that Mark would not approach strangers for sex and would let his keyworker know when things like that happened.

Mark returned early from one of his evenings out visiting friends. He was crying and was accompanied by two policemen. He had been found having sex during a police raid on a public toilet. The other man had been detained at the police station. The police were not in a position to say whether they intended to prosecute for gross indecency in a public place.

When things had calmed down, and after counselling

sessions with Mark, it became apparent that he had been involved in anal and oral sex with unknown men on many occasions. Mark said that he had not thought that he had to use a condom because it was not with his girlfriend. After intensive counselling with an HIV worker, Mark decided he wanted an HIV test. The result was positive. Further work with his girlfriend revealed that she had received unprotected anal sex. She had only thought that she had to use a condom for 'sex at the front'.

Issues

Mark's experience, and those of many women service users, raises all sorts of difficult issues which services need to tackle. One set of issues revolve around the rights of users: the right to confidentiality, both in relation to sexual expression and to information about HIV and AIDS; the right to have access to counselling and support around sexuality and relationships; the right to information about the risks in sexual behaviour and about safer-sex; how to protect yourself and your partner. For many women, there is also the right to have a child and child rearing. But there are potentially conflicting rights between different users and between staff and users which will need to be confronted and resolved by services. In many instances, solutions will have to come from outside services, such as independent counselling resources.

A second set of issues revolve around considerations of practice. These include: the responsibilities of services to their users, staff and the community; skills in assessing risk and responding appropriately; the support of management both practically and through policy or guidelines for practice or risk taking. Methods of assessing informed consent for sexual relationships and for HIV antibody testing are of particular concern. Many services have not yet developed the competence to manage the conflict between individual rights and service responsibilities, and policy guidance from the Department of Health is needed to help define how far services should be protecting people.

A third set of issues are contextual, but relate to, inform and influence practice. These include the law as it relates to learning difficulty and sexuality in general including homosexuality. They cover sexual relationships between people with and without learning difficulties and influence responses to contraception, pregnancy and child rearing. There are also societal attitudes and the attitudes and experiences of staff to recognise and manage. While most agencies and providers have statements of aims and values, the politics of learning difficulties and HIV come together in community settings to confront services.

A fourth set of issues revolve around service responses and deficits in knowledge and skills. These concern the acceptance of homosexuality, language around sexuality, skills in communication or signing, the simplification of safer-sex messages and education work. They depend on basic understanding of transmission, risk and risk assessment. Because accessing and building these competencies are difficult, some services have developed defensive practice responses, illustrating the

need for guidance on how far their responsibilities for protecting users should go.

Needs Assessment

Having introduced some key issues for services and practice this paper now turns to the needs assessment work in SE London (2). This covered the Boroughs of Lewisham, Lambeth and Southwark and was commissioned by SELHA as part of their HIV prevention strategy.

The first stages involved: contacting services and mapping activities; developing a network of people interested in the project; providing special staff training; counselling; one-to-one sex education and resources; and facilitating user advocacy.

This work helps illustrate how we can refine our understanding of HIV prevention work. Strategies are designed to target groups believed to be at relatively high risk. The information coming from this work confirms that men with learning difficulties who have sex with men in public places are a particularly high risk group. There are a number of explanations. One is that most men with learning difficulties do not have access to safer sex information about same sex behaviour, and that those who have sex with other men do not automatically link into the networks and peer support provided by gay men. Other important factors also need to be considered for this group, and these are more widely applicable to all people with learning difficulties who are sexually active.

Economic and social marginalisation still means that people with learning difficulties have restricted access to the range of services and facilities in the community. They may be excluded from loving relationships, from opportunities to meet other people and so on. Even if people are supported by a service with around £10 pocket money a week, have access to condoms and know how to use them on themselves or their partners they might not be able to afford them.

Issues of power, control and roles affect every relationship to some degree, but people with learning difficulties may lack the assertiveness needed to negotiate consensual sex or insist on safer sex thus making sex potentially more abusive or exploitative. Limited cognitive ability may mean difficulties in associating HIV with AIDS, or with death, or associating sex or particular types of sex with HIV. And, of course, we need to acknowledge that people with learning difficulties, both in hospital and the community have often been the subjects of abuse and exploitation, both within and outside services. Abuse is frequently of a sexual nature (Turk & Brown, 1992), and, as the case study also illustrates, the sexual abuse of power by men with learning difficulties as well as men in general, needs to be acknowledged.

HIV Testing

Brown & Turk's (1992), work on sexual abuse and learning difficulty provides a simple model for helping to decide whether sex is abusive. This can be transferred to issues around HIV antibody testing. Consent would not be informed, and the test may be illegal, if the person *withholds* their consent, is *unable* to give their consent or some other *barrier* to consent is present. A barrier to con-

sent could include pressures or bribes, a lack of understanding about the implications or consequences of taking a test, or lack of appreciation of the context or reasons for taking a test. When it becomes known that a service user has been having unsafe sex or when there is concern that a user may have AIDS, some services see HIV testing as the logical next step, without thinking through the consequences and complications for the service or the individual.

Service Lessons

It is evident that learning difficulty services should be building the skills and competencies needed to move towards valued and appropriate responses to issues around HIV. The starting point is to move along the continuum, from aversive to non-aversive support, from punitive to non-punitive work with users, for example, from keeping someone at home and restricting behaviour, to enabling users to engage in informed and consenting behaviour which is both safe and rewarding. This does not mean discouraging homosexual behaviour but providing support around safer-sex, assertiveness work and counselling. Supervision and control has frequently been the only response available in a limited service repertoire.

For people who need it or are likely to need it, this also means providing information on HIV and safer-sex in a safe environment and in ways which people can apply to their own behaviour. This will often be through one-to-one support with the use of special resources, such as videos, line drawings and models, individually tailored to assessed behaviour and cognitive ability.

Knowledge and practice of safer-sex reflects the information available and preferred behaviours. For instance, the uncertainty around the risks attached to oral sex, and a range of intervening variables, has led to mixed messages which influence judgements about what is an acceptable risk in the context of individual priorities. Safer-sex work with people with learning difficulties may need to further simplify messages around risk and behaviour, for instance by concentrating on very unsafe sex. This is the approach adopted by the Sex Education Team at Harperbury Hospital (McCarthy & Thompson, 1993).

We also need to consider language around relationships and sexuality used by service users. This is usually very different from that used by community support staff, nurses or medical practitioners. We need to be able to speak in a straight forward way with users about sex using words and labels used and understood by users themselves.

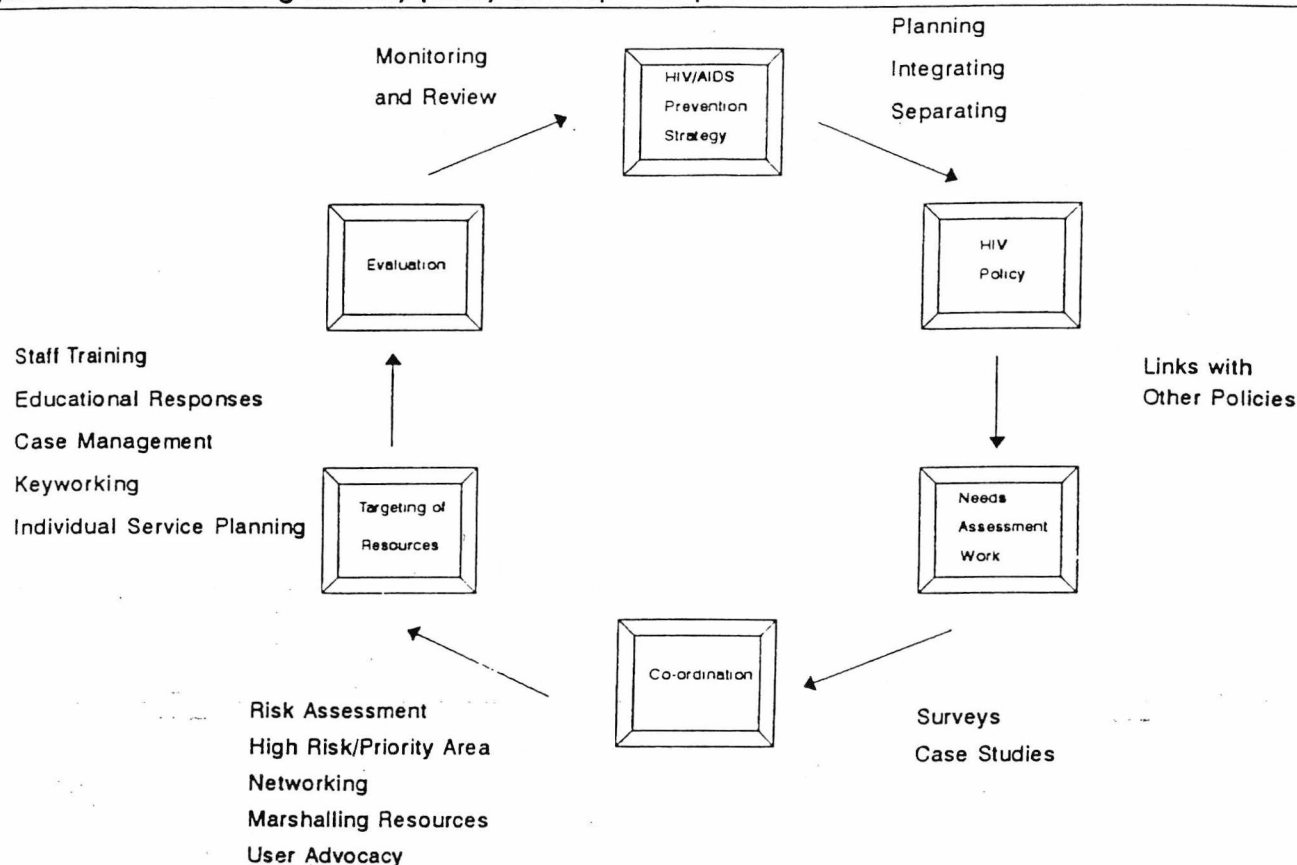
Policy Lessons

The SELHA funded work is an excellent example of how resources can be matched to needs. People working in and outside services had identified this as a practice issue that had not been properly addressed.

The needs assessment work was designed to inform both policy and practice, and such work should be built into a wider process of development and review (Figure 2).

A process which provides for a more strategic evaluation of practice and review of policy needs to be con-

Figure 2 HIV and learning difficulty policy development process



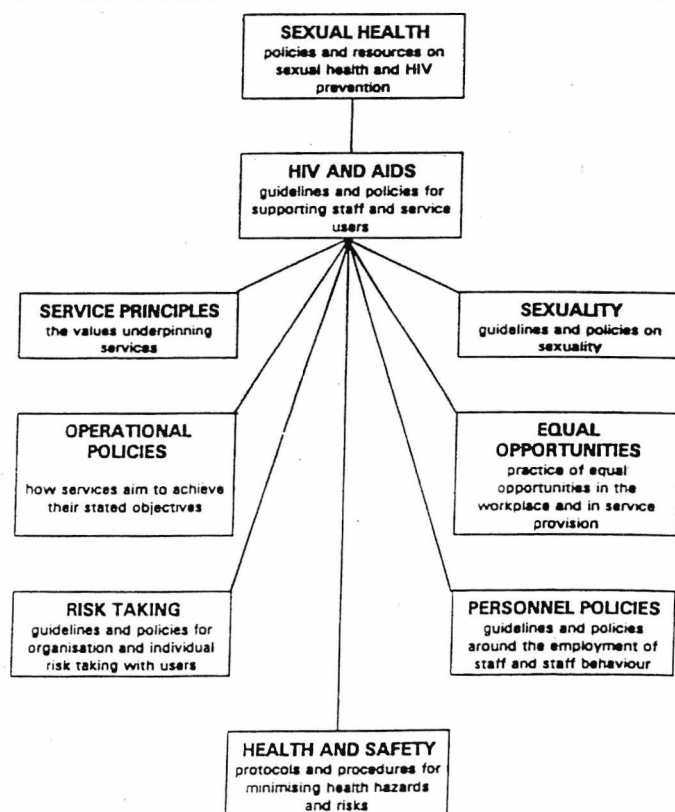
sidered in the context of wider organisational conditions. These include the micro-organisation of services and inter-agency working, and the relationship between the commissioners and purchasers of services and those providing services. These are becoming increasingly complex as the mixed-economy of social care develops and the range of public sector, voluntary and commercial providers extends in a diverse and fragmented care market.

There are two primary routes for building HIV policies into learning difficulty services. One is through commissioning and the inter-agency and inter-service interests that are reshaping around this function. For instance, in SETRHA, the work on learning sets described above can inform guidelines for commissioning services and link into the 'provider confederation'. Key objectives will be some sort of shared development between mainstream HIV and learning difficulty policies and between the commissioners and providers of services. The learning sets sought to achieve a framework for policy which staff could take back to their agencies and use to formulate local policies and guidelines. They confirmed the need to review HIV policy in relation to other policy areas (Figure 3) and tackle HIV as a systems-wide issue. The second route is through staff and providing agencies hammering out local guidelines relevant to local issues.

Conclusions

The key role users themselves can and will increasingly play in providing resources around HIV prevention, sexual health and peer education has, so far,

Figure 3 The links between HIV and the main policy domains



received little attention. One important lesson from the gay community is that self-help and self-organisation is essential to respond to the group and individual demands imposed by AIDS in a difficult political, economic and social environment. Partnerships with local government and work through voluntary organisations can achieve what central government cannot. It can provide the sort of valued information and practical support that people at risk of HIV infection or with AIDS want and need.

People with learning difficulties are beginning to organise themselves in similar ways. Peer education and self-advocacy resources like People First are working alongside innovative services to provide special and ordinary support for people with learning difficulties. Wandsworth One-to-One (Morris, 1993) provides individual therapy and groupwork for men with learning difficulties who have sex with men. They have produced leaflets in plain English and pictures explaining cottaging (sex in toilets) and cruising (sex in other public places) for men with learning difficulties who need to know about being safe. Partnerships with public sector and provider organisations are also creating valuable resources such as the safer-sex video, *My Choice, My Own Choice* (1992), acted by people with learning difficulties and supported by South East London Health Promotion Service.

Such examples are rare. In the most part, the design and development of services continues to deny the needs for people in most need of resources, for example men with learning difficulties who have sex with men. This paper has suggested how the scarce resources available for HIV can be better and more equitably targeted and how learning difficulty services can build the sorts of specialist resources and generic skills needed to better respond to HIV.

Correspondence

Correspondence should be directed to Paul Cambridge, Centre for Applied Psychology of Social Care, The University, Canterbury, Kent CT2 7LZ.

References

- Brown, H. (1992) Sexual issues for people with learning difficulties. *Nursing Standard* 7, 54-5.
- Brown, H. and Turk, V. (1992) Defining sexual abuse as it affects adults with learning disabilities. *Mental Handicap* 20, 44-54.
- Cambridge, P. (1992) Case management in community services: Organisational responses. *British Journal of Social Work* 22, 495-517.
- Crossmaker, M. (1991) Behind locked doors. Institutionalised sexual abuse. *Sexuality and Disability*, 9 (3).
- King's Fund Centre (1980) *An Ordinary Life*. London: King's Fund Centre.
- King's Fund Centre (1988) *Ties and Connections*. London: King's Fund Centre.
- Knapp, M., Cambridge, P., Thomason, C., Beecham, J., Allen, C. and Darton, R. (1992) *Care in the Community; Challenge and Demonstration*. Ashgate: Aldershot.
- Gorman, N. and Glennerster, H. (1990) *Hospital Closure*. Milton Keynes: Open University.
- McCarthy, M. and Thompson, D. (1993) *Sex and the 3 R's, Rights, Responsibilities and Risks. A Sex Education Package*

for *Working with People with Learning Difficulties*. Brighton: Pavilion Publishing.

- Morris, S. (1993) Protect and survive. *Community Care*, 30 December, 12-13.
- O'Brien, J. (1987) A guide to life style planning. In B. Willcox and G. Bellamy (eds) *The Activities Catalogue*. Baltimore: Brookes.
- South East London Health Promotion Service (1992) *My Choice, My Own Choice*. Brighton: Pavilion Publishing.
- Turk, V. and Brown, H. (1992) Sexual abuse and adults with learning disabilities: Preliminary communication of survey results. *Mental Handicap* 20, 56-8.
- Wolfensburger, W. (1980) The definition of normalization. In R. Flynn and K. Nitsch (eds) *Normalization, Social Integration and Community Services*. Austin, Texas: University Park Press.
- (1983) Social role valorization. *Market Retardation* 21, 234-9.

Please mention
**British Journal of
Learning Disabilities**
when answering
advertisements



THE UNIVERSITY
OF BIRMINGHAM

SCHOOL OF EDUCATION
DISTANCE EDUCATION COURSES

We offer courses (full-time or distance education) in a wide range of specialisms, including the following distance education courses:

LEARNING DIFFICULTIES

(Diploma; BPhil(Ed); MEd)

MULTI-SENSORY IMPAIRMENT (DEAFBLINDNESS)

(Advanced Certificate; Diploma; BPhil(Ed); MEd)

PROFOUND & MULTIPLE LEARNING DISABILITIES

(BILD Certificate; Advanced Certificate)

These courses are designed for people (usually, but not always, teachers) working with learners with these disabilities. Students remain in their own work setting, and the courses consist of regional and national day and weekend seminars, together with materials specially developed for home study.

Applications are now being accepted for courses beginning September 1995. For more information, please contact:

The Admissions Office, Faculty of Education and Continuing Studies, The University of Birmingham, Birmingham B15 2TT. Tel: 021-414-4887.

Ref. 2.2.b.

Cambridge, P. (1997b) Assessing and responding to local needs in HIV and learning disability. In P. Cambridge and H. Brown (Eds.) *HIV and Learning Disability*. (pp. 1-28), Kidderminster, British Institute of Learning Disabilities.

services characterise their stance as primarily one of protection or empowerment, as if the two were in opposition. The result is that services, which seek to 'allow' people to enjoy sexual options, frequently operate in a laissez-faire mode, thereby avoiding contentious issues or explicit advocacy and support, whereas services which operate in a protective mode close off positive options.

And yet, as Paul Cambridge and many of the writers of chapters in this book demonstrate, good practice in this area demands clarity and the courage of explicit convictions. If the civil liberties of people with learning disabilities are to be restored and maintained, their rights to the sex they seek and to protection from sex which they do not want, or cannot consent to, must be *actively* supported. Within this commitment an equivalent stance must be taken on behalf of men with learning disabilities who want and have sex with men. Dilution or rejection of this experience as legitimate works against their interests when it comes to safer sex education, counselling and advocacy.

Until and unless rights to same sex relationships are guaranteed and those relationships valued and made visible in services for people with learning disabilities, individuals are at double jeopardy in their sexual lives. They remain unsafe and unsupported in the very services which exist to act on their behalf. This is a potentially fatal situation for the people themselves and represents a stance which borders on negligence on the part of service agencies. It is an abdication of responsibility which all those concerned in the provision of services must counter.

Chapter 1

Assessing and Responding to Local Needs in HIV and Learning Disability

by Paul Cambridge

Commissioners have the duty to specify and purchase a comprehensive range of local services designed to meet the needs of the populations they serve. This chapter looks at the level of competence in needs assessment and commissioning in HIV and learning disability and the value and appropriateness of different resources and specialist services. Evidence on the location and nature of need is examined in relation to men with learning disabilities who have sex with men and the best ways to meet needs are discussed. The context of the care market and the structural and organisational disincentives to effective service planning and development are also considered. Pointers for best practice in developing safer sex, educational resources, and HIV risk assessment and risk management skills are suggested, with an overview of the service options in HIV and learning disability.

The Evidence

The epidemiology of HIV infection in Britain has been characterised by as much myth as has AIDS itself. The *gaying* of AIDS in the early years of the epidemic was represented by the scapegoating of gay men and further pathologising of homosexuality, with variations of *gay plague* headlines and articles in the popular press. The *de-gaying* of AIDS in the late 1980s was partly a response to this irrational homophobia but also to the fear that HIV would cross into the general (heterosexual) population, with AIDS developing into a more widespread epidemic. It was exemplified by health promotion campaigns and Government television advertising aimed primarily at preventing heterosexual transmission, promoting safer sex and discouraging casual sex. The *re-gaying* of AIDS in the 1990s was a political response by organised gay men to the reality of where HIV risk and AIDS related needs continued to be located in the population, namely with gay men and other men who have sex with men. By this time other high risk groups were also evident, such as haemophiliacs who had received infected blood products and people who shared needles for intravenous drug use, but gay men remained most affected.

The *re-gaying* of AIDS helped a reappraisal of how HIV prevention work could be most productively targeted and where health and social care services were required. It helped to bring gay led organisations like Gay Men Fighting AIDS (founded in 1992) more prominently into campaigning against homophobia, promoting safer sex and monitoring the provision of specialist services. This shift helped to compensate for over a decade of neglect, as King (1993) has observed:

'With the benefit of hindsight ... one can only conclude that the dehomosexualisation of AIDS has led directly to the marginalisation of gay men's unparalleled experience and contributions to fighting the epidemic, and has ultimately exacerbated the harmful effects of the epidemic on those who are most at risk'. (p.170).

This reappraisal of HIV risk and need, driven by the reality of experience, also has implications for HIV prevention work in learning disability. The arguments presented in this chapter are based on the hypothesis that sex education and HIV prevention resources for people with learning disabilities have failed to respond effectively to HIV risk and that there are areas where HIV prevention work in services for people with learning disabilities could productively learn from the experience of sexual health promotion for and by gay men. In effect, I will argue for the re-homosexualisation of HIV and AIDS in services for people with learning disabilities. But in making these arguments I do not intend to distract attention from the risk of HIV to women with learning disabilities or fail to acknowledge their particular sexual experiences (McCarthy, 1994 - see also Chapter 6).

Men who have sex with men continue to be disproportionately represented in the UK statistics from voluntary named testing for known HIV infection and reported AIDS cases.

'By the end of 1993, there had been a cumulative total of 13,015 men with HI V-1 infection acquired via sex with other men, 62% of total infections reported since 1984... AIDS cases amongst gay and bisexual men comprised 78% of all the adult AIDS cases reported since the start of the epidemic, and 70% of adult cases reported from January to December 1993' (Rooney, 1994, p.53).

Despite overpowering evidence of where need lies in relation to HIV and AIDS in the UK population (the over-representation of gay and bisexual men in the HIV and AIDS statistics represents a hugely disproportionate impact on minority communities), the *de-gaying* of AIDS led to HIV prevention

resources being poorly targeted and therefore ineffectively used. This argument is powerfully articulated by King (1993) who observed only three years ago that out of the fifteen or more posts in HIV or AIDS that the Health Education Authority had established, only one was specifically for men who have sex with men, with evidence of budget reductions in HEA funding for campaigns targeting gay men and that these campaigns represented under 20% of the overall AIDS budget (Pink Paper, 1992). The mis-targeting of HIV prevention resources and initiatives is echoed by others involved in HIV prevention activities

'It is dismayed that two thirds of the agencies surveyed reported that they were not engaged in any kind of HIV prevention work targeting gay or bisexual men' (King, Rooney & Scott, 1992, p.23).

It is important to acknowledge the diversity of sexual behaviours found in any community of interest or identity, be it lesbian, bisexual, gay or people with learning disabilities. This is necessary in order to appreciate the complexities of HIV prevention work. While the aggregate statistical evidence points to gay men and other men who have sex with men as a high HIV risk group, there is also evidence to suggest a diversity of sexual behaviours, lifestyles and responses to HIV risk within this population. More importantly, while there is evidence to support the assumption that safer sex interventions work in reducing HIV infection (Berkelman et al, 1989), wider data suggests that an increase in knowledge about safer sex is not necessarily associated with the practice of safer sex (Davies et al, 1993). Project SIGMA (Social-sexual Investigation of Gay Men and AIDS) tracked a cohort of more than 1,000 men over a four year period to examine their social and sexual behavioural responses to HIV. It revealed a high level of knowledge about safer sex but variable responses to HIV risk. Previous research into homosexual behaviour had also suggested a similar variety in relationships, numbers of sexual partners and sexual identities (Kinsey, 1948). Needs assessment work, HIV prevention campaigns and direct safer sex education should therefore recognise and respond to this diversity, including work in learning disability.

No service for people with learning disabilities or any service commissioner is immune from HIV as a management or practice issue. The evidence from sex education (McCarthy & Thompson, 1994), peer education (People First, 1994), counselling and therapeutic services (Morris, 1993), sexual health

outreach (Jones, 1993) and research (Cambridge, 1996a) indicates significant levels of risk or case examples of high risk sexual activities and the imperative to develop appropriate HIV prevention responses. More widely, little is known about the epidemiology of HIV infection in people with learning disabilities (Simonds & Rogers, 1992), although it is known that people with learning disabilities have become infected with HIV (Kastner et al, 1992; 1989). As with other individuals and populations, the nature and level of risk varies: the person with profound learning disabilities who cannot communicate verbally and who is sexually abused; the man with learning disabilities who frequently has unsafe sex with anonymous partners in public toilets; the woman with learning disabilities who sometimes has sex for money or cigarettes; and the young person with learning disabilities developing their first sexual feelings or relying on intimate care. All have different needs for education and protection. Segregation in services is not the same thing as isolation from the wider community and provides no protection against HIV.

Assessing Need

In recognition of the political and moral imperative behind the re-gaying of AIDS, South East London Health Authority funded research and training for men with learning disabilities who have sex with men in public places, putting the question firmly on the commissioning agenda (Cambridge et al, 1994). The needs assessment component of the project indicated that a number of men with learning disabilities in SE London were at high risk of HIV infection and that some services had difficulties responding to this risk (Cambridge, 1994). This alerted commissioners to the risks of not responding to the needs of this group of men, although evidence from sex education (Thompson D, 1994) and needs assessment in mainstream sexual health (Taylor-Laybourn & Aggleton, 1992) also indicated that some men with learning disabilities were at high risk of HIV.

There are many potential explanations as to why men with learning disabilities are likely to be vulnerable to HIV risk from having sex in public places and these are summarised in Box 1. They include both individual and environmental considerations and some can be influenced by the power of the support services.

Box I VULNERABILITY TO HIV

histories of institutionalisation, social de-skilling and the development of acquiescence and dependency in congregate settings

community services find normalisation and community integration difficult principles to practice, and this is reflected in difficulties supporting sexuality

poor sex and safer sex education, lack of access to condoms, little assertiveness training and poor negotiation skills for safer sex

poor staff training, low competence to recognise and respond to HIV; need and lack of policies and guidelines on sexuality

secrecy and guilt about sexualities; pathological view of homosexuality and disincentives to identify as gay

emotional vulnerability and desire to seek out friendships and social contacts; easy targets for intimidation and control and hence abuse and exploitation

lack of privacy, confidentiality, dignity and respect in residential and other support services

little politicisation, self organisation and peer support, with isolation in services

invisibility of homosexual role models; lack of opportunities to choose sexual options and low economic status to facilitate participation.

SELHA was responsible for funding both learning disability services and HIV/AIDS services and had earmarked resources for HIV prevention and health promotion (the context is explained by James Nichol in Chapter 3). The results highlighted important considerations for commissioners and providers on the needs of the high HIV risk group of men who have sex with men, with a focus on men with learning disabilities who go cottaging (have sex in public toilets). These are summarised below (see Cambridge, 1996a for a more detailed report)

- there was a significant prevalence of men with learning disabilities known *and* reported to be possibly or definitely cottaging (the total in Lewisham, Lambeth and Southwark was 34). This is likely to be an under-estimate considering the problems associated with the

recognition and reporting of similar issues such as sexual abuse (Brown et al., 1995). Many men in this situation hide their behaviour because they think it is wrong or because it contradicts their social and sexual identity (Thompson, 1994).

- men with learning disabilities who have sex with men in public toilets are at an especially high risk of HIV. Rarely are they in a position to insist on or practice safer sex, they have different sexual partners and they are usually penetrated anally or orally by men from a high risk group. One service responded *'he visits the local cottage up to seven times a week and has regular unprotected anal intercourse'*, and another observed *'the client meets men in public toilets and goes back to their homes with them'*.
- the median age of the men in the sample was 30, and 80% had good communication skills. They were therefore a relatively young and able group of men, although they were supported by a wide range of residential services, including hospitals, hostels, group homes and unstaffed housing, therefore need is clearly spread across the range of formal support services. A number of indicators of risk were identified and these included the obvious: a history of STD or being escorted home by the police and the less obvious: regular absence from services and reluctance to say where they had been.
- over 40% of the men in the sample definitely had sex with other men with learning disabilities and over 21% definitely had sex with women with learning disabilities. This raises critical questions for managing HIV risk within services. For example *'he has a steady girlfriend and several other women friends with whom he may also be having sex'*. Service users have freedoms and rights as well as responsibilities in relation to minimising HIV risks to sexual partners. This raises conflicting service responsibilities for protecting people from an unacceptable risk of HIV, while promoting and safeguarding rights and respecting privacy and confidentiality.
- risk assessment and risk management skills were poorly developed, although this in part reflected the skills of men in hiding their behaviours and their reluctance to talk with staff about what they did. Most providers did not hold a refined understanding of HIV or safer sex

or the competence to provide educational inputs, for instance one service responded that a man they supported *'was advised to use condoms and given a supply but does not like using them and gives inconsistent replies'* and another that *'the staff team can only speculate at this moment in time. If he is cottaging, then we don't know if he is practising safer sex.'*

HIV and learning disability is an area where joint commissioning offers considerable potential. There is currently an implementation gap in commissioning and providing learning disability services competent at working in HIV and HIV and AIDS services, such as genito-urinary medicine (GUM) clinics, competent at working with people with learning disabilities. Some specialist services bridge the gap, but most people with learning disabilities fail to get support for managing informed consent for sex, assertiveness for determining sex and using condoms, providing condoms, assessing valid consent for HIV testing and access to pre - and post - test counselling. Approaches to HIV testing can indicate levels of competence in the management and practice of HIV and is revisited later in the chapter.

Managing the Market

Consideration needs to be given to the market in social and community care (the separation of purchasing and providing and the contract), when assessing how to recognise, respond and *most effectively* meet needs in HIV and learning disability. This is because needs are largely met through market formulated responses, and effective service development in HIV and learning disability will require an assessment of local market conditions. The market, as it has been operating and developing since the 1990 health and community care reforms, has demanded increasing management skills (HMSO, 1992; DoH, 1993). Processes such as joint commissioning, community care planning and care management and the contract itself can be used to help manage the market more pro-actively and assertively. For instance, commissioning can be used to specify radical service models, such as sex education or counselling services, within a coherent philosophy and local strategy. Individual contracts can be used to specify requirements for group or individual sex education or HIV risk management and involve people in determining their own services (Brown & Cambridge, 1995).

Commissioners should give preference to those arrangements they believe, or there is evidence to suggest, generate the most productive outcomes in the

lives of the people who use services. There is little objective evidence about such associations in sexual health and learning disability and there has been limited experience or time to develop radical models. Pilot demonstration services, properly evaluated for effectiveness, are needed to better inform commissioning, although there have been isolated examples (Cambridge, 1996b). Some of the accounts in following chapters represent an informal approach to posing and answering related questions about the effectiveness and values of model services. Commissioners do not live in a different political or social world to others. They are as open to ignorance and bigotry about HIV and AIDS and to homophobia as anyone else, although the political context to commissioning is significant, as the SE London work illustrates, and it is on such information that services should be developed.

The people who use learning disability services cannot be compared with consumers in most other markets (they are more like *customers* travelling with a warrant on a partly privatised railway system). To think of people with learning disabilities as consumers with resources and choices is fantastic, other than for the few people in advocacy or service brokerage schemes. What has increasingly happened over the last five years, is that the people who use services have at best been exchanged between agencies and at worst traded as commodities. Their behaviours, skills, abilities and needs, including their needs for visible things like housing and practical support for life skills and less visible things like friendships, personal relationships and sexual expression and health have been priced and marketed. Political and financial accountability has become blurred because those who provide services are further away from those who fund them and lines of management accountability have become dislocated.

It is unusual to find sexuality and HIV referenced in contracts. Most people are still unable to choose where they live, who they live with or which agency supports them, let alone who they have sex with, what type of sex they have and whether they have safer sex. The case studies and accompanying rationales provided by Simon Davies and David Stewart in their chapters demonstrate a competence which is difficult to specify through the contract, as it depends on individual values and commitment. Similarly, the innovative work described by David Thompson and Stephen Morris in their chapters is grounded in a sexual politics which can be used to inform the nature of intervention and the professional stance. It is not just the difficulty of putting best practice into words and assessing performance in meaningful ways, but also of resolving

what amount to politically contentious issues through the contract, such as responsibility for managing HIV risk and paying for educational and health services. Examples of radical approaches include: the empowerment of women at risk of sexual exploitation or HIV, sex education within a feminist discourse, sexual health outreach, support for the whole person, the provision of safe space outside services and advocacy and peer education. Such models depend on a radicalism and political activism likely to frighten commissioners. Getting radical services is a structural problem to do with who holds power more widely in society and people with learning disabilities remain socially, politically and economically marginalised, as reflected in their sexual exploitation and abuse (Turk & Brown, 1993; Brown et al, 1995).

The other side of the equation is service provision and practice. The competence of providers to recognise need, take considered steps to protect people from sexual abuse and HIV, and support people to make more informed choices or take more informed risks is also limited. Moreover, there is evidence to suggest a need to intervene to modify staff attitudes to issues such as HIV testing, as the results of a study by Murray and colleagues indicates (Murray et al, 1995). Only a small minority of providers have taken the lead in this area (the initiative to manage risks and rights described by Simon Davies in Chapter 4 is a rare example). Few providers have developed sexuality policies, especially ones based on staff needs and user experiences (Cambridge & McCarthy, 1996) and are consequently not in a good position to lobby commissioners for more resources.

Recognising Need

There is a scarcity of specialist counselling, sex education and therapeutic services in sexuality and HIV for people with learning disabilities. This is especially the case for the high HIV risk and not uncommon behaviour of men with learning disabilities who have sex with men (McCarthy & Thompson, 1994). A few specialist sexuality services working specifically in HIV and learning disability and often also in sexual abuse (as we will read in Stephen Morris's chapter), have emerged but rarely from pro-active commissioning.

Respond, the service described at the end of Stephen Morris's chapter, developed from committed individuals who recognised that an important need for counselling and therapeutic interventions within a safe space remained unmet. It has to charge for its services although local commissioners have funded some limited projects, such as sexual health outreach (Cambridge,

1996b). The individuals referred are funded by their local commissioners or providing organisations, creating real resource disincentives to access such services, as a longer term commitment is usually required.

The Sex Education Team (originally funded by Herts Health Promotion Unit but now Horizon NHS - learning disability - Trust) provides sex education at no direct cost to services or users in its area, regardless of agency or sector (although staff training is charged for), but, as a consequence, is not able to reach out beyond local boundaries (see the services described by Michelle McCarthy and David Thompson in Chapters 6 and 5).

The Tizard Centre provides some clinical work as well as staff training and policy development, but however competent specialist services are, their current dispersal and location does not facilitate equity in access, or guarantee that a balance can be struck between individual contracts and longer term development funding, making planning for the future difficult. Some local initiatives have unexpectedly had their funding cut, therefore in addition to pump-priming resources, longer term funding commitments are needed for services to have an impact on what is a longer term issue requiring ongoing investment. People working in and using specialist services cannot demand integrated and co-ordinated individual service planning, as there are also organisational and professional barriers to overcome.

Part of the dilemma of gaining funding for HIV prevention activities for any group or community extends beyond the recognition of need to include the acknowledgement of outcomes which cannot be realistically assessed. An evaluation of the interventions described in this book would require elaborate longitudinal experimental designs and control groups. This would amount to an immorality by definition of the exclusion of potentially life saving interventions to people at risk of HIV infection. As Davies et al. (1993) have commented:

'HIV prevention programs are bedevilled 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' (p.173).

The task of commissioners is to respond to HIV risk in learning disability by commissioning services targeted on need, despite the probability of reactionary political pressures. An equivalent task faces those charged with responsibility for developing effective HIV prevention resources.

Images in Pictures and Language

'Resources and education campaigns have been remorselessly targeted at those at least risk of contracting HIV, as if the priority of preventing an epidemic among heterosexuals had been established at the expense of halting the epidemics that are actually raging throughout the developed world' (Watney, 1993, quoted in King, 1993, p.69).

Until the early 1990s, resources available for sex education and learning disability were predominantly heterosexual and largely avoided HIV. Mirroring the *degaying* of AIDS in the late 1980s, they missed the needs of those most at risk of HIV, namely men with learning disabilities who have sex with men (Craft, 1991; Dixon, 1991), although the significance and impact of pioneering work in sexuality should not be understated, as different demands operated. More recent resources make limited reference to HIV, safer sex and homosexuality between men (McCarthy & Thompson, 1992; SELHPS, 1992) or use pictures which neutralise gender through androgynous images (LSS, 1992). A sex education video uses puppets to represent people, with sequences of personal hygiene, social skills, masturbation and penetrative anal and vaginal sex (WLHPA, 1994). Although condoms are used for the latter two sequences, the anus on the men in the homosexual sequence is shown as a seam with shadow penetration, while there is an explicit representation of a vagina and vaginal penetration in the heterosexual sequence. Critical safer sex messages, such as how to use a condom properly during anal sex, after ejaculation and when withdrawing the penis are consequently blurred for a high risk behaviour and high risk group. Although more explicit, both in its use of actors and in the directness of sexual images, an Australian video resource (FPANSW, 1993) similarly avoids close ups of penetrative anal sex between two men while happily showing details of penetrative vaginal sex. Homosexuality continues to be marginalised, despite it being central to properly targeted and effective HIV prevention work.

Explanations for this *visible* reluctance to show clear images of men having sex with men include the possibility of homophobia in that homosexual sex is seen to be of less emotional or physical value than heterosexual sex, commercial or political concerns in relation to the marketability of such resources or legal qualms about representing homosexuality or anal sex. Recent video and photographic sex educational materials produced for and by gay men (THT, 1994; Tatchell, 1994) illustrate that explicit images of men

having sex with men, hard penises and semen can be effectively represented in a safer sex educational context.

'... 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 & Rooney, 1994, p.7).

Services and educators need positive, explicit and accurate images of men having sex with men for effective safer sex education in learning disability. This argument extends to the use of erotic images in the context of safer sex education for gay men. Any debate about the level of explicitness of such materials is a distraction from the imperative of HIV prevention, although sexual imagery produced or used outside an educational rationale is potentially pornographic. Resources for safer sex work in learning disability are still inhibited by societal constraints about sex and homosexuality which do not reflect the reality and diversity of sexual experience, but there are problems associated with using erotic images as a vehicle to deliver safer sex education in learning disability. The message could be misread or the educator could find the material offensive. Images need to be accurate and culturally appropriate and what is culturally appropriate for one gay man may not be for another gay man or other men who have sex with men who hold a heterosexual social identity. The latter are more likely to include men with learning disabilities who have sex with men.

Holding a positive self-image and self-worth is a necessary prerequisite to practicing safer sex and becoming politically active and assertive. Organisations like OUTRAGE, Gay Men Fighting AIDS, BigUp and The Sisters of Perpetual Indulgence directly challenge homophobia and the political and social devaluation of homosexuality. This is in part a response to the ways in which homosexuality has been further pathologised since AIDS by parts of the media and some politicians. But it is no co-incidence that these same organisations are also active in sexual health campaigns and outreach work. Social exclusion makes this option largely inaccessible for men with learning disabilities

The potential for erotic images of men having safer sex with men extends beyond simply drawing attention to the underlying message about safer sex to promoting positive self images. These are required to help combat the guilt and secrecy sometimes associated with the sexual behaviours of men

who have sex with men, including men with learning disabilities (Thompson D, 1994). There is therefore a rationale for safer sex educational materials in learning disability to use positive images where appropriate, for instance when describing consenting sex or safer sexual practices. The line between eroticism and positive image is a fine one, but it is essential that it is explored in sex education for men with learning disabilities who have sex with men. This is not to say that all images of men having sex with men need to be positive. It is important to acknowledge exploitation and abuse in a homosexual as well as heterosexual context. We know that most abusers are men who abuse men as well as women with learning disabilities. We also know that a high proportion of the men who abuse other people with learning disabilities are service users themselves (Brown et al, 1995). This reality, however unpleasant, also needs to be represented.

One of the most creative and innovative resources available for work in learning disability (a comment also echoed by staff in staff training exercises) was produced in the Netherlands for sex education with young people (Marneth, 1994), using effective combinations of photographs, line drawings and overlays.

These include pictures of both negative and positive personal contexts to sex, different sexual behaviours, erect penises, semen, condoms on penises, semen in condoms and other considerations essential for explaining consent, safer sex and HIV risk.

Similar constraints to the use of visual images have also applied to the use of language, also creating barriers to effective communication. This stopped when gay men started producing materials and information relevant to the lives and needs of gay men. A classic example of woolly language in safer sex messages is *avoid the exchange of body fluids*. In practical safer sex terms, this means *don't fuck or suck off without a condom*. Some language used in resources designed for work with people with learning disabilities has been similarly ambiguous, although good resources should encourage the educator to use peoples' own words. An example of the latter is the video on safer sex acted by people with learning disabilities (SELHPS, 1992), which used direct words and images. This contrasts markedly with the Australian video (FPANSW, 1993) which imposes professional language onto people with learning disabilities. Most of the other experience accumulated by gay men in relation to safer sex education is also transferable to some extent to work in learning disability (Box 2).

Box 2

LESSONS FROM GAY MEN'S SAFER SEX EDUCATION EXPERIENCE

- don't pathologise individuals or their behaviours
- don't impose a moral framework: work to individuals, own assumptions and agenda
- don't marginalise HIV as an issue in services or general day to day work with people
- recognise the reality of high risk groups and risk behaviours and develop risk assessment skills
- respond with practical support to reduce or replace risk behaviours, rather than trying to limit sexual expression
- reflect the realities of sexual experience through language and image
- encourage positive images about self and sexual preference (identity for gay men or behaviour for men who have sex with men)
- promote assertiveness and negotiation for safer sex within and outside relationships
- use HIV testing only as part of an individual strategy to manage HIV risk
- provide a safe and confidential environment for this work

Straight Messages About Complex Issues

The complexities surrounding the transmission and virology of HIV and the development and treatment of AIDS have always been simplified to some extent in health promotion and HIV prevention work, including safer sex work with people with learning disabilities. HIV risk activities are presented as high, medium or low and key messages about reducing the number of sexual partners or using protection for penetrative sex are presented outside co-factors which help assess risk, such as how condoms are used or the presence of other infections. This has also been the case in safer sex education in learning disability. There are sound arguments for not distinguishing between HIV and AIDS or concentrating on high risk behaviours (see David Thompson's and Michelle McCarthy's arguments in Chapters 5 and 6 David Stewart's account of sex education for young people in Chapter 9). Many people with

learning disabilities who are sexually active are also relatively able however, and the importance of maintaining safer sexual behaviour could be reinforced by a more refined understanding of HIV than simply that *you could get ill and die if you have sex without a condom*.

The central question is how best to meet the needs of people with learning disabilities for information on HIV, AIDS and safer sex without excluding them from sexual opportunities or exposing them to avoidable risk. The differences between HIV and AIDS are also very real in terms of lifestyle implications (such as hospitalisation, medication and social care) and the uncertain timescales between HIV infection and the development of AIDS creates an additional dilemma. The simplified links between sex and AIDS (and illness and death) might be conceptually appropriate for some people with learning disabilities but is also potentially misleading if people do not understand uncertainty or do not have an appreciation of long timescales.

A very challenging example is HIV testing. I would argue that it is not possible to give informed consent for HIV antibody testing (for anyone, with or without a learning disability) without a basic understanding of HIV infection and the differences between being HIV negative or positive (which is what the test indicates) and having an AIDS related illness. Ten key questions help illustrate the argument (with some more complex secondary questions in brackets). These can be used to help to assess informed consent for an HIV test with a person with learning disabilities (Box 3), and relate in part to some of the legal considerations for services identified by Michael Gunn in Chapter 10. There are compelling arguments that such assessments should also give weight to the potential drawbacks of taking an HIV test (Tatchell, 1994). These have been adapted to help further explore questions of informed consent for a person with a learning disability (Box 4).

Box 3

QUESTIONS TO HELP ASSESS INFORMED CONSENT FOR AN HIV TEST

what is a blood test/HIV test? (how it is taken and how long you will have to wait for the result?)

do you know what it shows/tells and does not show/tell you? (do you know it will not tell you if and when you might get AIDS, get ill or die or whether or not you will get HIV or AIDS in the future?)

do you want an HIV test? (why/what reasons?)

do you think you have HIV? (how could you have got it and why?)

how do people get HIV? (and what can people do so they don't get HIV or give it to others?)

how will you feel if you are HIV positive? (what will you do/feel like doing if you are HIV positive/negative?)

how will you feel about having sex and safer sex, relationships and friendships? (now and in the future and telling people)

what happens to someone with HIV? (do you know what AIDS is, how long it may take to get AIDS and what happens to people who have AIDS?)

who would you tell and why? (what do you think they would say/do/think/tell?)

what help and support do you think you will/would need? (in thinking/worrying/coping with HIV/AIDS?)

Box 4

PROS AND CONS OF HIV TESTING

The Advantages

Knowing your HIV status can help people who have become ill through worry

If you have HIV and get ill, more effective and immediate treatment could result

If you know you are HIV positive you can avoid exposure to other health risks

Having the test can help concentrate priorities and lead to safer sexual choices

You can benefit from regular medical monitoring if you know you are HIV positive

Knowing your HIV status can be empowering for making informed choices

Focusing the mind in relation to safer sex in relationships

The Disadvantages

A positive test does not tell you when you will develop AIDS

A negative test does not guarantee your status (it takes up to six months for antibodies to show up after infection) or protect you from HIV in the future

There are no lasting treatments or cures for HIV or AIDS

Personal trauma and depression may result from a positive test

Problems gaining access to financial services if you are HIV positive (unlikely consequence for a person with a learning disability as they are already largely excluded)

Potential problems with employment and housing (staff support for a person with a learning disability is similarly a potential problem)

Prejudice, abuse and rejection from family and friends may ensue

(adapted from Tatchell, 1994)

Responding to Need

Some of the considerations referenced above were used to help inform the content of a set of booklets on HIV and AIDS for people with learning disabilities and their staff and carers (Cambridge, 1996c). The original set made no reference to same sex relationships or sex outside established relationships, with a heterosexual monogamous relationship portrayed as ideal. A balance was struck by also representing homosexuality and casual sex, better matching the messages about HIV and safer sex to the diverse sexual experiences of people with learning disabilities. The possibility of an HIV test was presented as sometimes being a bad idea because of the importance that people are fully aware of its limitations and possible negative consequences for them.

The differences between HIV and AIDS were also explained. The booklet on HIV and AIDS produced through self advocacy and peer education in learning disability (People First, 1994) makes similar connections as does an educational package comprising booklets and a video produced by people with learning disabilities (Lawnmowers, 1994). People with learning disabilities constantly receive direct and indirect messages and information about both HIV and AIDS and this ideally needs to be matched to safer sex inputs related to their sexual behaviours and understanding of risk. Simply linking unsafe sex with AIDS and death is neither helpful nor relevant to the sexual lives of many people with learning disabilities.

More careful attention also needs to be paid to the potential risks of HIV infection through oral sex in sex education and training resources in learning disability. Men with learning disabilities are as likely to be in a receptive position in relation to oral sex with men as they are known to be with anal sex (David Thompson explores the reasons for the latter in his chapter). If there is a low risk of HIV from oral sex then it lies in possible transmission through semen and pre cum. Until evidence about the risk of oral transmission to the person sucking is clearer, particularly in relation to other infections like gum disease, then educational resources should have the capacity to address this question and give men and women the information they need to better protect themselves or take more informed risks. The Australian video (FPANSW, 1993) always portrays oral sex with a condom, taking an opposite stance to most British resources, which have tended to prioritise high risk activities such as penetrative anal or vaginal sex in relation to condom use. Neither approach adequately addresses questions of informed choice or risk taking however, although this is difficult to articulate in sex education for

people with learning disabilities who may not even have informed choices about sex in the first place.

A decision was also made to use direct words like *fuck*, *suck*, *spunk* and *cock* in the user booklet, because most people know what they mean, even if not culturally appropriate to everyone. Men with learning disabilities in a sex education group were familiar with these words and used them to describe sexual behaviours and body parts. More medical terms like intercourse, semen, oral sex and anus are usually associated with practitioners in positions of authority over people with learning disabilities. Words like fuck are certainly words more able and sexually active people with learning disabilities are likely to know or encounter and should be helped to learn because they are less ambiguous than phrases like doing it or getting on top. People need to be empowered through language to communicate more precisely about consent, body parts, and their preferences for particular sexual behaviours, including safer sex.

Meeting Need

When working on a Department of Health funded HIV risk management resource for men with learning disabilities who have sex with men (Cambridge, forthcoming), ten guiding principles were developed to inform the content and style of the sex educational materials.

1. Present sexuality as positive except in abusive or exploitative situations
2. Show safer sex as empowering
3. Represent the reality of sexual experience of men who have sex with men, including men with learning disabilities
4. Provide explicit images of sex and safer sex and unambiguous language to describe them
5. Include diversity in ethnicity and disability
6. Differentiate between HIV and AIDS in straightforward ways
7. Represent visible aspects of learning disability
8. Minimise irrelevant details and focus on event and place
9. Depict contemporary appearances but also diversity in style
10. Include event sequences, consequences and outcomes

The resource has the additional task of addressing a range of possible situations, including cottaging, casual sex and sex with both men and women. In addition to portraying mutual and enjoyable safer sex, it also needed to include abusive and exploitative sex, prostitution and stylised sexual behaviours (Thompson B, 1994) all of which have the potential to impact on men with learning disabilities. Most men with learning disabilities who have sex with men are not in the more fortunate position of gay identified men who can more easily tap into self help groups, informal support networks or dedicated HIV or AIDS services, although gay men often bring their experience to such groups in learning disability.

It was also important to consider what issues such a dedicated resource should address and what it might contain. Practitioners in both HIV and learning disability were consulted and also men in a group sex education setting in learning disability services. The responses confirmed my own interpretations of needs and ways to meet them and are reflected in the staff training materials and specifications for the sex education materials. These include: empowerment to practice safer sex through pictures, words and symbols; acknowledging the differences between HIV and AIDS, timescales and uncertainties; where to get condoms and how to use them effectively; fostering self-image and worth for same sex; showing assertiveness for consenting to sex and saying no to unsafe sex; acknowledging risks and opportunities; representing emotions and feelings; and showing the different places where sex happens.

Micro-organisation and Care Management

It is easy to say that commissioners should undertake needs assessment in HIV and learning disability, design an appropriate array of services to meet identified needs, commission services through contract specification and review effectiveness through monitoring quality and outcomes. It is difficult to articulate this process in relation to specialist learning disability services (HMSO, 1993), let alone sexual health in learning disability. Most people with learning disabilities do not have their sexual, emotional or sexual health needs adequately assessed and identified. Reasons include their lack of meaningful involvement in case reviews and individual planning meetings and lack of power in asserting or communicating their needs and wants. Put this alongside asexual models of service design and delivery and there is a real gap to addressing sexuality and identifying and meeting sexual needs, including safer sex education and other HIV related needs. Commissioners,

who are usually responsible for the core tasks of care management, including assessment and individual service planning, must therefore take responsibility for ensuring that sexuality and sexual health are properly represented. Box 5 identifies ten key areas for integrating work on sexuality and HIV into individual programme planning and skill teaching programmes.

Box 5

KEY AREAS TO BE CONSIDERED IN INDIVIDUAL SERVICE PLANNING

negotiating skills (*negotiating use of condoms and consent to sex and risk*)

expressive and receptive communication skills (*understanding requests and saying or signing yes and no to sex, safer sex and condom use*)

assertiveness skills (*confidence when to say yes and reject unwanted or unsafe situations*)

life skills (*access to condoms and sexual opportunities, including knowledge about HIV and safer sex*)

social skills (*ability to utilise sexual and social opportunities to affect constructive experiences and learning opportunities*)

adaptive behaviour skills (*ability to use condoms properly and effectively during sexual encounters*)

personal presentation skills (*self care and ability to affect positive personal image*)

self-motivation skills (*motivation to protect sexual and emotional health through a positive self-image and self-worth*)

independence skills (*determining own wants and life goals and functional capacity to achieve them*)

personal relationship skills (*capacity and robustness to make and break personal relationships and express emotions*)

Macro-organisation and Joint Working

There needs to be a wider choice of services and resources for meeting different needs, and for service substitution as needs change. It has already been illustrated that expertise is currently localised and that access is restricted. To

achieve this change, commissioners need to adopt a longer term perspective than the usual planning and commissioning cycle. This requires an investment in service development and pump-priming resources to get new specialist services off the ground, and staff training to increase mainstream competence in HIV and sexuality in services for people with learning disabilities. Policy development will similarly be needed and this will have to involve providers and users themselves if policy guidelines are to be effective for managers and practitioners (see Cambridge & McCarthy 1996, for a development model).

Other more familiar disincentives to effective joint commissioning remain. In addition to adopting a short term perspective, agencies tend to minimise the cost or impact to their own budgets. With budgets declining in real terms as well as in relation to specific areas of need, the decision not to provide sex education and safer sex education and counselling in HIV for people with learning disabilities may be easier to make when another agency such as the NHS will have to pick up the tab for the health care consequences of doing nothing. Joint commissioning is potentially no different. Territorial disincentives also remain for many health authorities and social services departments whose boundaries are not coterminous. This makes the development of strategy and integrated services difficult or expensive.

Services and Priorities

Even within a multi-agency approach to sexual health in learning disability there remain barriers between mainstream sexual health services (GUM and HIV testing and counselling), GP purchased services and specialist services working in HIV and learning disability. A solution is to top slice both the learning disability and HIV budgets to protect adequate resources for sexual health in learning disability. With or without ring-fenced budgets, commissioners should consider the following interventions and service models in HIV and learning disability. Preferred options and combinations will depend on local needs and how they are planned to be met.

- specialist sex education through one-to-one work and group workshops (see the work described by David Thompson and Michelle McCarthy in Chapters 5 and 6)
- self advocacy and peer education have proved an effective model in HIV and safer sex education for young people and there are examples of peer education in HIV and learning disability (see work described by Fiona Barber and Paul Redfern in Chapter 8)

- joint projects involving young gay men and men with learning disabilities who have sex with men could also be developed, including befriending and support schemes
- specialist counselling and therapeutic services for people with learning disabilities who are at risk of HIV (see the approach described by Steve Morris in Chapter 7), to cope with issues such as HIV antibody testing, valid consent and confidentiality
- sex education for young people with learning disabilities and parallel training for parents and staff in special schools (see the model explored by David Stewart in Chapter 9)
- training for staff and managers in learning disability services on sexuality and HIV to develop the competence of services, not only to support the sexuality of services users, but on risk assessment and risk management
- specialist training for certain staff to develop key roles and functions within services in relation to sexuality and HIV, such as sex and safer sex education, leading risk assessment and reporting and managing sexual abuse
- policy development on sexuality, including HIV (and sexual abuse), to go hand in hand with staff training and an assessment of user needs. This is necessary to pick up on key practice issues and to develop tailored local responses
- assertiveness training for users, including communication and negotiation skills. This would need to be part of wider work helping people to develop positive self images and to say no to abusive or unsafe sex
- training in learning disability for staff and managers in genito-urinary medicine (GUM), HIV counselling, nursing and other HIV/AIDS provided by the NHS and voluntary organisations
- staff training and sex educational resources which place a priority on risk and convey unambiguous messages about sex and safer sex in relation to the sexual realities and experiences of people with learning disabilities

I would give preference to a dedicated sex education and counselling service, open to referrals from all individuals, agencies and sectors locally and provided free and according to need (HIV and emotional risk). Such a resource would benefit from links with other services such as counselling for sexual abuse and GUM services. I would identify the priority for pro-active providers to develop inhouse competence in management and practice through training and to build safeguards through user involvement such as advocacy and workshops for sex and safer sex education. Both commissioners and providers should share the front loaded costs of consultancy and the direct management and staff time needed to develop the policies and guidelines required to support management and practice. This could well include the costs of developing or accessing specialist services such as those detailed above.

Services and service users would above all benefit from more strategic local approaches, with good multi-agency working, a facilitative and specialist function for health promotion and the integration of social care, health care and educational inputs. This framework should be grounded in a philosophy of empowerment and a culture of delegated responsibility in order to generate innovative, radical and effective service interventions. These should be sensitive to considerations of race, gender, culture and sexuality which are all important for providing appropriate support and responses in HIV and learning disability.

References

- Berkelman, R., Thomas P., Kerndt, P., Rutherford G. & Stehr-Green, J. (1989) *Are AIDS cases among homosexual males levelling? Paper presented at the 5th International Conference on AIDS, Montreal*
- Brown, H. & Cambridge, P. (1995) *Contracting for Change: Making Contracts work for People with Learning Disabilities, in (Eds.) T. Philpot and L. Ward, Values and Visions: Changing Ideas in Services for People with Learning Difficulties, Butterworth Heineman, London.*
- Brown, H., Stein, J. & Turk, V. (1995) *The Sexual Abuse of Adults with Learning Disabilities: Report of a Second Two Year Incidence Survey, Mental Handicap Research, Vol.8, No.1.*

- Cambridge, P., Davies, S., Nichol, J., Thompson, D., Morris, S., & Corbett, A. (1994a) *Men with Learning Disabilities who have sex with Men in Public Places, Tizard Centre, University of Kent, Canterbury.*
- Cambridge, P. (1994) *A Practice and Policy Agenda for HIV and Learning Difficulties, British Journal of Learning Disabilities, Vol.22*
- Cambridge, P. (1996a) *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. Vol.40, No.3.*
- Cambridge, P. (1996b) *Evaluating Sexual Health Outreach for Women with Learning Disabilities, Bulletin No.15, National Association for the Protection from Sexual Abuse of Adults and Children with Learning Disabilities, University of Nottingham.*
- Cambridge, P. (1996c) *What You Need to Know about HIV and AIDS, BILD, Kidderminster.*
- Cambridge, P. (forthcoming) *HIV, Sex and Personal Relationships: a Staff Training and Sex Education Resource with a focus on Men with Learning Disabilities who have Sex with Men, Pavilion, Brighton.*
- Cambridge, P. & McCarthy, M. (1996) *Developing and Implementing Sexuality Policy for a Learning Disability Provider Service, Health and Social Care in the Community.*
- Craft, A. (1991) *Living Your Life: a sex education and personal development programme for students with severe learning difficulties, Learning Development Aids, Wisbech.*
- Davies, P., Hickson, F., Weatherburn, P. & Hunt, A. (1993) *Sex, Gay Men and AIDS, Falmer Press, London.*

- DoH (1993) *Monitoring and Development: A Special Study of Purchasing and Contracting*, Department of Health, London.
- Deverell, K. & Rooney, M. (1994) *Using Sexually Explicit Materials for Safer Sex Work with Gay Men*, HIV Project, North Thames Regional Health Authority, London.
- Dixon, H. (1991) *AIDS and People with Learning Difficulties*, BIMH, Kidderminster.
- FPANSW (1993) *Feeling Sexy, Feeling Safe*, Family Planning Association of New South Wales.
- Jones, J. (1993) *Men with Learning Difficulties and Cottaging*, Saturday Seminars, North West Thames Regional Health Authority, London.
- HMSO (1992) *Community Care: Managing the Cascade of Change*, HMSO, London.
- HMSO (1993) *Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs*, HMSO, London.
- Kastner, T., Hickman, M. & Bellehumeur, D. (1989) *The provision of services to persons with mental retardation and subsequent infection with HIV*, American Journal of Public Health, 79,1-4.
- Kastner, T., Nathanson, R. & Marchetti, A. (1992) *Epidemiology of HIV Infection in Adults with Developmental Disabilities*, in (Eds.) A. Crocker, H. Cohen & T. Kastner, HIV Infection and Developmental Disabilities, Brookes, London.
- King, E. (1993) *Safety in Numbers*, Cassell, London.
- King, E., Rooney, M., Scott, P. (1992) *HIV Prevention for Gay Men: a Survey of Initiatives in the UK*, National AIDS Manual/Gay Men Fighting AIDS/HIV Project/Terrence Higgins Trust.
- Kinsey, A. (1948) *Sexual Behaviour in the Human Male*, Saunders, Philadelphia.

- Lawnmowers (1994) *The Big Sex Show*, Them Wifies, Newcastle.
- LSS (1994) *Take Care of Yourself: Safer Sex and People with Learning Disabilities*, Lewisham Social Services, London.
- McCarthy, M. (1994) *Against All Odds: HIV and Safer Sex Education for Women with Learning Disabilities*, in (Eds.) L. Doyal, J. Naidoo & T. Wilton, AIDS: Setting a Feminist Agenda Taylor and Francis, London.
- McCarthy, M. & Thompson, D. (1992) *Sex and the 3 Rs: Rights, Responsibilities and Risks*, Pavilion Publishing, Brighton.
- McCarthy, M. & Thompson, D. (1994) *HIV/AIDS and Safer Sex work with People with Learning Disabilities*, in (Ed.) A. Craft, Practice Issues in Sexuality and Learning Disabilities, Routledge, London.
- Marneth, A. (1994) *Geen Kind Meer: Seksuele voorlichting aan jongeren met een verstandelijke handicap vanaf 12 jaar*, Rutgers Stichting, Utrecht.
- Morris, S. (1993) *Protect and Survive*, Community Care, 30 December, 12-13.
- Murray, J., MacDonald, R. & Minnes, P. (1995) *Staff attitudes towards individuals with learning disabilities and AIDS: the role of attitudes towards client sexuality and the issue of mandatory testing for HIV infection*, Mental Handicap Research, Vol.8, No.4, pp321-332
- People First (1994) *Everything you ever wanted to know about Safer Sex but nobody bothered to tell you*, People First, London.
- Pink Paper (1992) *AIDS Budget Slashed*, 214,1 March.
- Rooney, M. (1994) *Information File*, HIV Project, North Thames Regional Health Authority, London.
- Simonds, R. & Rogers, M. (1992) *Epidemiology of HIV Infection in Children and other Populations*, in (Eds.) A. Crocker, H. Cohen & T. Kastner, HIV Infection and Developmental Disabilities, Brookes, London.

- SELHPS (1992) *My Choice, My Own Choice* (video), Pavilion Publishing, Brighton.
- Tatchell, P. (1994) *Safer Sexy*, Freedom Editions, London.
- Taylor-Laybourn, A. & Aggleton, P. (1992) *HIV Health Promotion Assessment for Men who have Sex with Men in Camberwell: Final Report*, King's Healthcare, London.
- THT (1994) *Gay Men' Guide to Safer Sex* (video), Terrence Higgins Trust, London.
- Thompson, B. (1994) *Sadomasochism*, Cassell, London.
- Thompson, D. (1994) *Sexual Experience and Sexual Identity for Men with Learning Disabilities who have Sex with Men*, *Changes*, Vol.12, No.4.
- Turk, V. & Brown, H. (1993) *The Sexual Abuse of Adults with Learning Disabilities: Results of a Two Year Incidence Survey*, *Mental Handicap Research*, Vol.6, No.3.
- Watney, E. (1993) *Powers of Observation: AIDS and the writing of history, in Practices of freedom*, Rivers Oram, London.
- WLHPA (1994) *Piece by Piece* (video), West London Health Promotion Agency, London.

Paul Cambridge is Lecturer in Learning Disability and Service Development Consultant at the Tizard Centre, University of Kent at Canterbury. He has undertaken research on HIV and learning disability and has worked on staff training and policy development in sexuality and learning disability. He is currently developing a staff training and sex education resource with a focus on men with learning disabilities who have sex with men. Prior to 1992, Paul worked in the Personal Social Services Research Unit and in local government.

Chapter 2

The Facts About HIV, Transmission and Treatment

by Jan Welch

History of AIDS

Acquired Immune Deficiency Syndrome (AIDS) was first identified in 1981 in the United States. Cases of *Pneumocystis carinii* pneumonia, a severe disease which only occurs in immunocompromised people, were identified in groups of people with no apparent reasons for their immune systems to be functioning poorly. AIDS was first described in the population of homosexual men and later in haemophiliacs, intravenous drug users and Haitians. Subsequently it was reported from other countries, notably from sub-Saharan Africa where it appeared to be most common in affluent urban heterosexuals.

Initially a variety of causes were suggested, but as more became known about the condition an infection became the leading contender. In 1983 Luc Montagnier's group identified a new retrovirus from a patient with swollen lymph nodes. This virus, now called human immunodeficiency virus type 1 (HIV-1), is generally accepted to be the cause of HIV disease and AIDS.

What is HIV

HIV is one of a group of viruses called retroviruses, which are characterised by the possession of an enzyme called reverse transcriptase. This is a special protein which enables retroviruses to reverse the usual direction of flow of genetic information, by making virus-specific DNA from the RNA of the virus. The new DNA is then inserted into the chromosome of the infected cell in the form of a provirus. This can then be used as a template for the RNA required for virus production. As the provirus has become part of the infected cell it persists within that cell, and in subsequent cells produced from it, resulting in a lifelong infection.

The vast majority of HIV infections worldwide are caused by HIV-1. A slightly different virus, HIV-2, is found in West Africa and occasionally elsewhere. It appears to be milder in its effects, with a longer incubation period.

Ref. 2.2.c.

Cambridge, P. (1998a) Challenges for safer sex education and HIV prevention for people with intellectual disabilities in Britain, *Health Promotion International*, 13 (1), 67-74.

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

P. CAMBRIDGE

Tizard Centre, University of Kent, Canterbury CT2 7LZ, UK

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 (Cam-

bridge, 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 approach. Some workers have tackled the 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 men's 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 sex educational initiatives, implying the importance of recognising homosexuality between men with intellectual disabilities, or men with intellectual disabilities and other men. This mirrors a wider necessity for frank and straightforward discussion about sex in relation to addressing HIV and AIDS through education about HIV transmission (Garfield, 1995).

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:

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.

Address for correspondence:

P. Cambridge
Tizard Centre
University of Kent
Canterbury CT2 7LZ
UK

REFERENCES

- Barber, F. and Redfern, P. (1997) Safer sex training for peer educators. In Cambridge, P. and Brown, H. (eds) *HIV and Learning Disability*. British Institute of Learning Disabilities, Kidderminster.
- Brown, H. (1980) Sexual knowledge and education of ESN students in centres of further education. *Sexuality and Disability*, 3, 215-220.
- Brown, H. (1987) Working with parents. In Craft, A. (ed.) *Mental Handicap and Sexuality: Issues and Perspectives*. Costello, Tunbridge Wells.
- Brown, H. and Smith, H. (1992) Assertion, not assimilation. In Brown, H. and Smith, H. (eds) *Normalisation: A Reader for the Nineties*. Routledge, London.
- Brown, H. and Thompson, D. (1997) Service responses to men with intellectual disabilities who have unacceptable or abusive sexual behaviours: the case against inaction. *Journal of Applied Research in Intellectual Disabilities*, 10, 176-197.
- Brown, H., Stein, J. and Turk, V. (1995) The sexual abuse of adults with learning disabilities: report of a second two year incidence survey. *Mental Handicap Research*, 8, 1-22.
- Cambridge, P. (1994) A practice and policy agenda for HIV and learning difficulties. *British Journal of Learning Disabilities*, 22, 134-139.
- Cambridge, P. (1996a) 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. (1996b) *The Sexuality and Sexual Rights of People with Learning Disabilities: Considerations for Staff and Carers*. British Institute of Learning Disabilities, Kidderminster.
- Cambridge, P. (1996c) Assessing and meeting needs in HIV and learning disability. *British Journal of Learning Disabilities*, 24, 52-57.
- Cambridge, P. (1996d) *Evaluating Sexual Health Outreach Work for Women with Learning Disabilities*, Bulletin No. 15, March. National Association for the Protection from Sexual Abuse of Adults and Children with Learning Disabilities, Nottingham, pp. 8-13.
- Cambridge, P. (1996e) *HIV and AIDS and People with Learning Disabilities: What You Need to Know about HIV and AIDS*. British Institute of Learning Disabilities, Kidderminster.
- Cambridge, P. (1997a) *HIV, Sex and Learning Disability*. Pavilion, Brighton.
- Cambridge, P. (1997b) At whose risk? priorities and conflicts for policy development in HIV and learning disability. *Journal of Applied Research in Intellectual Disabilities*, 10(2), 83-104.
- Cambridge, P. (1997c) How far to gay? the politics of HIV in learning disability. *Disability and Society*, 12, 427-453.
- Cambridge, P. and McCarthy, M. (1997) Developing and implementing sexuality policy for a learning disability provider service. *Health and Social Care in the Community*, 5, 227-236.
- Corbett, J. (1994) A proud label: exploring the relationship between disability politics and gay pride. *Disability and Society*, 9, 343-357.
- Craft, A. (1983) *Sex Education and Counselling for Mentally Handicapped People*. Costello, Tunbridge Wells.
- Craft, A. (ed.) (1987) *Mental Handicap and Sexuality: Issues and Perspectives*. Costello, Tunbridge Wells.
- Craft, A. (1991) *Living Your Life: A Sex Education and Personal Development Programme for Students with Severe Learning Difficulties*. Learning Development Aids, Wisbech.
- Cruikshank, M. (1992) *The Gay and Lesbian Liberation Movement*. Routledge, London.
- Davidson-Paine, C. and Corbett, J. (1995) A double coming out: gay men with learning disabilities. *British Journal of Learning Disabilities*, 23, 147-151.
- Davies, P., Hickson, F., Weatherburn, P. and Hunt, A. (1993) *Sex, Gay Men and AIDS*. Falmer Press, London.
- Davies, S. (1997) A provider perspective. In Cambridge, P. and Brown, H. (eds) *HIV and Learning Disability*. British Institute of Learning Disabilities, Kidderminster.
- Deverell, K. and Rooney, M. (1994) *Using Sexually Explicit Materials for Safer Sex Work with Gay Men*, HIV Project. North Thames Regional Health Authority, London.
- Dixon, H. (1991) *AIDS and People with Learning Difficulties*. British Institute of Mental Handicap, Kidderminster.
- Downs, C. and Craft, A. (1997) *Sex in Context*. Pavilion, Brighton.
- Family Planning Association of New South Wales (FPANSW) (1993) *Feeling Sexy, Feeling Safe*, video. FPANSW, Sydney.
- Garfield, S. (1995) *The End of Innocence: Britain in the Time of AIDS*. Faber, London.
- Greenwich Social Services Department (1993) *Recognising and Responding to the Sexual Abuse of Adults with Learning Disabilities*. Greenwich Social Services and Greenwich Health Authority, London.
- Gunn, M. (1996) *Sex and the Law: A Brief Guide for Staff Working with People with Learning Difficulties*. Family Planning Association, London.
- Gunn, M. (1997) The law, HIV and people with learning disabilities. In Cambridge, P. and Brown, H. (eds) *HIV and Learning Disability*. British Institute of Learning Disabilities, Kidderminster.
- Jones, J. (1993) *Men with Learning Difficulties and Cottageing*, Saturday Seminars. North West Thames Regional Health Authority, London.
- Kastner, T., Hickman, M. and Bellehumeur, D. (1989) The provision of services to persons with mental retardation and subsequent infection with HIV. *American Journal of Public Health*, 79, 1-4.
- Kastner, T., Nathanson, R. and Marchetti, A. (1992) Epidemiology of HIV infection in adults with developmental disabilities. In Crocker, A., Cohen, H. and Kastner, T. (eds) *HIV Infection and Developmental Disabilities*. Brookes, London.
- Kempton, W. (1982) Sex and the mentally retarded. *British Journal of Sexual Medicine*, March, 5-6.
- King, E. (1993) *Safety in Numbers*. Cassell, London.
- King's Fund. (1980) *An Ordinary Life: Comprehensive Locally-based Residential Services for Mentally Handicapped People*. King's Fund Centre, London.
- Lawnmowers (1994) *The Big Sex Show*. Them Wives, Newcastle.

- Malhotra, S. and Mellan, B. (1996) Cultural and racial issues in sexuality work with people with learning disabilities. *Tizard Learning Disability Review*, 1, 7-12.
- Marchetti, A., Nathanson, R., Kastner, T. and Owens, R. (1990) AIDS and state developmental disabilities agencies: a national survey. *American Journal of Public Health*, 80, 54-56.
- McCarthy, M. (1994) Against all odds: HIV and safer sex education for women with learning difficulties. In Doyal, L., Naidoo, J. and Wilton, T. (eds) *AIDS: Setting a Feminist Agenda*. Taylor & Francis, London.
- McCarthy, M. (1997) HIV and heterosexual sex. In Cambridge, P. and Brown, H. (eds) *HIV and Learning Disability*. British Institute of Learning Disabilities, Kidderminster.
- McCarthy, M. and Cambridge, P. (1996) *Your Rights about Sex: A Booklet for People with Learning Disabilities*. British Institute of Learning Disabilities, Kidderminster.
- McCarthy, M. and Thompson, D. (1992) *Sex and the 3 Rs: Rights, Responsibilities and Risks*. Pavilion, Brighton.
- McCarthy, M. and 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*. Routledge, London.
- McCarthy, M. and Thompson, D. (1996) Sexual abuse by design: an examination of the issues in learning disability services. *Disability and Society*, 11, 205-217.
- Morris, S. (1997) Experiences of risk: the role of therapy in sexual health. In Cambridge, P. and Brown, H. (eds) *HIV and Learning Disability*. British Institute of Learning Disabilities, Kidderminster.
- O'Brien, J. (1987) A guide to lifestyle planning: using the activities catalogue to integrate services and natural support systems. In Willcox, B. and Bellamy, G. (eds) *The Activities Catalogue: An Alternative Curriculum for Youth and Adults with Severe Disabilities*. Brookes, Baltimore, MD.
- People First (1994) *Everything You Ever Wanted to Know about Safer Sex but Nobody Bothered to Tell You*. People First, London.
- Richardson, D. (1981) Theoretical perspectives on homosexuality. In Hart, J. and Richardson, D. (eds) *The Theory and Practice of Homosexuality*. Routledge, London.
- Seidman, S. (1993) Identity and politics in a 'postmodern' gay culture: some historical and conceptual notes. In Warner, M. (ed.) *Fear of a Queer Planet: Queer Politics and Social Theory*. University of Minnesota, Minneapolis, MN.
- Senker, J. (1997) Gender, race and sexual behaviour: issues in service responses to HIV/AIDS. *British Journal of Learning Disabilities*, 25, 58-63.
- Simonds, R. and Rogers, M. (1992) Epidemiology of HIV infection in children and other populations. In Crocker, A., Cohen, H. and Kastner, T. (eds) *HIV Infection and Developmental Disabilities*. Brookes, London.
- South East London Health Promotion Service (SELHPS) (1992) *My Choice, My Own Choice*, video. SELHPS, Pavilion, Brighton.
- Taylor-Laybourn, A. and Aggleton, P. (1992) *HIV Health Promotion Needs Assessment for Men who have Sex with Men in Camberwell: Final Report*. King's Healthcare, London.
- Thompson, D. (1994) Sexual experience and sexual identity for men with learning disabilities who have sex with men. *Changes*, 12, 254-263.
- Thompson, D. (1997) Safer sex work with men with learning disabilities who have sex with men. In Cambridge, P. and Brown, H. (eds) *HIV and Learning Disability*. British Institute of Learning Disabilities, Kidderminster.
- Turk, V. and Brown, H. (1993) The sexual abuse of adults with learning disabilities: results of a two year incidence survey. *Mental Handicap Research*, 6, 193-216.
- West London Health Promotion Agency (WLHPA) (1994) *Piece by Piece*, video. WLHPA, Pavilion, Brighton.
- Wistow, G., Knapp, M., Hardy, B. and Allen, C. (1994) *Social Care in a Mixed Economy*. Open University, Buckingham.
- Wolfensberger, W. (1980) The definition of Normalisation: update, problems, disagreements and misunderstandings. In Flynn, R. and Nitsch, K. (eds) *Normalisation, Social Integration and Community Services*. University Park Press, Baltimore, MD.
- Wolfensberger, W. (1984) A reconception of Normalisation as Social Role Valorisation. *Mental Retardation* (Canadian), 34, 22-25.

Ref. 2.2.d.

Cambridge, P. (2001b) The HIV testing of a man with learning disabilities: informed consent, confidentiality and policy, *Journal of Adult Protection*, 3 (4), 23-28.

The HIV testing of a man with learning disabilities: informed consent, confidentiality and policy

Paul Cambridge

Senior Lecturer in Learning Disability, Tizard
Centre, University of Kent at Canterbury

abstract

Informed consent, confidentiality, disclosure, policy and the wider consequences of HIV testing are issues explored in this paper concerning a man with learning disabilities who tested positive for HIV. The events and outcomes are summarised, with lessons identified for policy and practice in HIV risk management and adult protection in services for people with learning disabilities.

key words

HIV testing
informed consent
disclosure
confidentiality
counselling
sex education

Introduction

Over the last year I have received four telephone calls from services supporting people with learning disabilities who have tested positive for HIV and from a number of others who are worried about the risks service users are taking in relation to HIV infection. In a paper six years ago (Cambridge, 1996) I outlined the risks of the sexual transmission of HIV to men with learning disabilities who have sex with men, and their male and female sexual partners in services. This evidence was later placed in the context of the re-homosexualisation of HIV in services for people with learning disabilities and issues of sexual health and sexual identity (Cambridge, 1997a). This was at a time when AIDS was being 're-gayed' as an issue by gay men who were aware that their sexual health needs as a group remained high compared to heterosexuals, at the same time as HIV prevention resources were being directed away from them. Considerations for HIV policy development and HIV testing were also articulated (Cambridge, 1997b), as were considerations for working with men with learning disabilities who have sex with men (Cambridge, 1999; Cambridge & Mellan, 2000).

Anonymous discussions soon revealed that three of the calls concerned men with learning disabilities who had sex with men without learning disabilities and one a woman with learning disabilities who had sex with men with and without learning disabilities. This anecdotal evidence fits the known high risks of unprotected anal and vaginal sex, particularly to the receptive partner, and the known sexual behaviours and sexual health risks assessed from sex education for both men and women with learning disabilities (Thompson, 1994, 1997;

McCarthy, 1996, 1997). Clearly, therefore, HIV risk management remains high on the adult protection agenda for many people with learning disabilities who are sexually active and given service responsibilities for protecting people with learning disabilities from sexual exploitation and unreasonable risks of HIV transmission (Gunn, 1997).

I was not particularly surprised therefore when I received a call from a provider service in the south-west of England, asking for help with resolving the issues and concerns arising from a male service user who had tested positive for HIV (names have been changed to preserve anonymity).

A number of key considerations are evident for considering informed consent to HIV testing, and these are particularly important for people with learning disabilities (Cambridge, 1997b, 1999). They draw on wider experience with HIV testing (Tatchell, 1994), the relative advantages and disadvantages of knowing an HIV status and the legal considerations regarding informed consent (Gunn, 1997). The latter particularly relate to the consequences that might flow from having a test and possible carer liability. Critical questions concern in whose interest the test is being conducted and who the testing agent is, as both can affect the issues of competence and pre and post-test counselling (Cambridge & Mellan, 2000).

To give informed consent, without which an HIV test amounts to assault, the person would need to know what the test entailed, understand what might happen as a result of testing positive or negative and consider the wider implications for themselves. For someone with a learning disability, considerations of confidentiality, disclosure, future sexual behaviour, possible treatment and illness would all need to be included. For these reasons, most HIV and learning disability policies make testing without informed consent dependent on a High Court decision (Horizon, 1996).

Case profile

'Peter' was placed out of area into a private provider service, of which the staffed group home where he lived was a component. He had previously been placed with another out of area provider in another part of the country. His parents and placing authority social worker/care managers were fully involved. He had moderate learning disabilities, with Klienefelter's syndrome. When Peter first joined the service, concerns were raised about his physical health, with general health screening arranged from a local private hospital. It was reported that the hospital subsequently telephoned the house manager to ask if Peter was able to give consent to an HIV test, with an affirmative answer. Consequently, an HIV test was included in the general health screening.

It was reported that a positive HIV test result was related to the service over the telephone. Following this disclosure, a case conference was arranged, which included Peter's parents, who had been told the test result, myself and his social worker, as well as the service and operations manager of the provider organisation. Background information on HIV transmission and HIV risk was provided at the meeting, with the importance of re-testing acknowledged (false positives are very rare with proper testing procedures. False negatives can also occur if the person has recently been infected with HIV). Discussion also revolved around the possible routes of HIV transmission, including via sexual contact or medical procedures. There were reported to have been 'sexual issues' at his previous placement but these were unclear. Peter was also reported to have regularly absconded, which might fit the hypothesis of sexual contact outside the service as a receptive partner (considering Klienefelter's).

Peter's social worker agreed to make background enquiries regarding his previous



placement. I agreed to talk with Peter about his HIV positive status following re-testing, particularly about safer sex and also to talk with the staff group about HIV and HIV risk management. At this point the service also expressed concern about their ability to continue to support Peter and his parents wanted greater clarity about how he might have contracted HIV.

The service was subsequently notified by telephone of a positive re-test result and I arranged to meet Peter.

The day before I planned to see him the service telephoned to say that a second re-test from the sample had been sent to the public health laboratory and had tested negative. A negative HIV status was confirmed through a third re-test via the public health laboratory. Although I met with Peter later, the basis of this work had changed to general sex education, consent, safer sex education, assertiveness work and personal safety.

The explanation provided by the private consultant in relation to the false positive test is relevant in relation to ascertaining informed consent to an HIV test. In the case of Peter it was related that consent for the HIV test was ascertained (judged) in relation to the possible effect on his care of a positive result. As an 'inadequate' blood sample was reported on the first test, due to discomfort for Peter, the opportunity to repeat the test at a reference laboratory was said not to have arisen. Regardless of the details, the experience of this case raises a number of concerns relevant to adult protection, in particular informed consent, the management of confidentiality and disclosure, the need for guidelines and the wider consequences of HIV testing in services for people with learning disabilities.

Concerns and issues raised

1. It could be argued that informed consent

to an HIV test in Peter's case was not properly obtained (see outline discussion above). This might apply in relation to the potential personal implications for Peter, the checking out of capacity to consent over the telephone and the consequences for his support in the service. Adequate pre and post-test counselling was also arguably lacking.

2. The poor management of confidentiality in relation to a service user's known or suspected HIV status. This relates to the absence of 'need to know' criteria and ad hoc disclosure to staff and third parties. In particular, a lack of rationale for informing the service user and their parents in relation to the initial test, the re-test and the relay of information on HIV status over the telephone.
3. The failure to reference and engage guide lines on HIV and HIV testing and the inadequacy of the guidelines themselves. In times of stress or crisis, policies and guidelines can be inaccessible or not give the guidance on the detailed decisions and processes needed. Guidelines need to reference action, line management, accountability and responsibilities in services for people with learning disabilities.
4. HIV testing and HIV risk assessment and risk management activities conducted in the absence of wider work on sexuality. Personal relationships and sexuality policies and guidelines need to be integrated with those on HIV and implemented through sex education work with service users and staff training.
5. Inter-agency co-ordination for HIV testing in services for people with learning disabilities. Learning disability services do not have the detailed knowledge about HIV testing needed, and specialist health services, be they private or public, do not have the detailed skills needed to work with people with learning disabilities.

Wider experience

Research reported in 1997 (Cambridge, 1997a) and by Murray and colleagues (Murray *et al*, 1995, 2001) suggests that services have a variety of motives for wanting to support HIV testing for people with learning disabilities, without necessarily thinking through the consequences for the person or the service itself. In particular, the consequences of knowing about an HIV positive or negative status and how this will affect support and HIV risk management. Usually, services and staff really just want to know whether someone is HIV positive as they believe this will help in their support and in managing HIV risk. However, best practice service responses to someone assessed as high HIV risk should be technically the same as someone known to be HIV positive.

In the case study the consequences for HIV risk management had clearly not been considered. Cambridge (1996) reports on a variety of service responses to HIV risk management including escorting someone when out and keeping someone at home in the service, although less aversive responses such as safer sex education and counselling were also mentioned. Davies (1997) provides a case study of a valued service response to a man assessed as high HIV risk. This included assertiveness and safer sex work with the man himself and a variety of work and support for the staff group, such as through management supervision, exploring the boundaries between the law and individual rights, and staff training.

However, a recent case in New Zealand starkly illustrates how things can go wrong if information is mis-managed and considerations of confidentiality, 'need to know' and disclosure not properly thought through. Christopher Truscott, a man with learning disabilities living in Christchurch, was kept in confinement by his service, with one-to-one support. News of his HIV positive status had

been released and his name repeatedly appeared in local and national newspapers. It was alleged that health care workers had tried to keep his HIV status secret, but that the Ministry of Health was tipped off that he was having unprotected sex with a large number of partners (*Otago Daily Times*, 28 April and 12 May, 1999; *Sunday Star Times*, 16 May, 1999).

He was arrested on a charge of criminal nuisance after admitting having unprotected sex without disclosing he had HIV following a complaint to the police from one of the men he had had sex with. He was given a suspended sentence and a supervision order was issued, with name suppression refused (*Otago Daily Times*, 28 April 1999). Truscott repeatedly absconded from his care and the police repeatedly checked out his 'old haunts', including 'public toilets' and other 'gay rendezvous' (*The Press*, 10 and 11 October, 2000).

The Truscott case highlights complex issues regarding individual rights and responsibilities of people with learning disabilities and others and the responsibilities of the public service and law enforcement agencies. Fortunately, Truscott is receiving advocacy from the Justice Action Group (personal correspondence, October 2000) which seeks to change laws, lives and attitudes for people with disabilities (PO Box 9407, Newmarket, Auckland). Rarely do so many competing forces come together in adult protection practice.

Lessons and conclusions

1. The HIV testing of people with learning disabilities should only proceed on the basis of informed consent, pre and post-test counselling and independent objective assessment. If this does not happen, testing agents or those supporting people with learning disabilities risk assault and



failure in their duty of care.

2. HIV policies and guidelines are needed which specify the management of confidentiality and information on a service user's known or suspected HIV status according to transparent 'need to know criteria'. They should detail and specify the steps and checks required before HIV testing and following HIV testing, with service responsibilities and support expectations clearly articulated.
3. Work on HIV should be firmly located in the context of wider sexuality work, including sex education interventions and staff training initiatives. In particular, the specific and broader adult protection issues and concerns in relation to this broad raft of issues should be made visible in adult protection policies and procedures.

Another service recently spoke with me about a young man with learning disabilities they support who identifies as gay and who meets other gay men. However, he was reported to be naïve and vulnerable in his sexual encounters and in his responses to HIV risk. He has a mobile phone on which he keeps the numbers of the men he knows and keeps the details of his sexual life very secret. Having a number of sexual partners would certainly not be an uncommon experience for many young men or young gay men, nor would some unsafe sex. Nor would secrecy within a predominantly heterosexual social environment. However, a special challenge exists for supporting men with learning disabilities who have sex with men in relation to their personal safety and to safer sex, as well as safeguarding their individual rights.

One of the potentially most powerful models but one which is little explored or evaluated, would be to have a positive and assertive gay role model in the man's life, in whom he could confide and who could give regular support and advice. This might be a gay identified key worker or citizen advocate,

although boundaries and responsibilities would need to be carefully defined and good support and advice provided for the person themselves.

What we need to strive for, and what Davies (1997) achieved in his intervention, is not to impose impossible restrictions on the man's life, as happened in the Truscott case. Here, the man's name became well known throughout New Zealand and his private and personal life became public property, as well as that of health agencies, the police and his secure service. As a consequence, labels like 'male prostitute', 'HIV carrier', 'escape' and 'irresponsible' were given more prominence than his welfare and valued support.

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) At whose risk? Priorities and conflicts for policy development in HIV and intellectual disability. *Journal of Applied Research in Intellectual Disabilities* **10** (2) 83-104.
- Cambridge, P. (1999) Considerations for informing safer sex education work with men with learning disabilities. *British Journal of Learning Disabilities* **27** 123-126.
- 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.
- Davies, S. (1997) A provider perspective. In: Cambridge, P. & Brown, H. (Eds) *HIV and Learning Disability*. Kidderminster: British Institute of Learning Disabilities.
- 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 Disabilities.
- Horizon (1996) *Policy on HIV Infection and Testing for People with Learning Disabilities*. Hertfordshire: Horizon NHS Trust.
- McCarthy, M. (1996) The sexual support of people with learning disabilities: a profile of those referred to sex education. *Sexuality and Disability* **14** (4) 265-279.
- McCarthy, M. (1997) HIV and heterosexual sex. In: Cambridge, P. & Brown, H. (Eds) *HIV and Learning Disability*. Kidderminster: British Institute of Learning Disabilities.

Murray, J., MacDonald, R., & Minnes, P. (1995) Staff attitudes towards individuals with learning disabilities and AIDS: the role of attitudes towards client sexuality and the issue of mandatory testing for HIV infection. *Mental Handicap Research* 8 (4) 321-332.

Murray, R., MacDonald, R., & Levenson, V. (2001) Sexuality: policies, beliefs and practice. *Tizard Learning Disability Review* 6 (1) 29-35.

Tatchell, P. (1994) *Safer Sex*. London: Freedom Editions.

Thompson, D. (1994) Sexual experience and sexual identity for men with learning disabilities who have sex with men. *Changes* 12 (4) 245-263.

Thompson, D. (1997) Safer sex work with men with learning disabilities who have sex with men. In: Cambridge, P & Brown, H. (Eds) *HIV and Learning Disability*. Kidderminster: British Institute of Learning Disabilities.

Pavilion in association with Salomons present a two-day adult protection symposium.

Adult Protection Coordinators Network Symposium

Date: 29 – 30 April 2002

Venue: Salomons, Canterbury Christ Church University College, Tunbridge Wells, Kent

With the implementation of 'No secrets' in October 2001, Social Services Departments across England have had to develop structures and systems to meet the new requirements.

So how is it going? Six months down the line this event will give adult protection professionals a chance to discuss and evaluate 'No secrets'.

Issues to be addressed during the two-day residential course include:

- how the implementation literature can help develop effective adult protection policies and procedures
- lessons and issues that have arisen from the implementation so far
- designing a 'rolls royce' training strategy
- financial protection for vulnerable adults
- intergenerational conflict

The symposium also features a keynote address from **Trish Davies, Department of Health** who will be briefing delegates on the role of the Commissions for Care Standards, and a half day seminar on how to set up and run a whole systems training event.

With expert speakers drawn from many fields of adult protection policy, research and practice this symposium will be an essential event for everyone concerned with the implementation of 'No secrets'.



Pavilion



Salomons

For a full conference programme contact: Pavilion, tel 01273 623222, fax 01273 625526 or email info@pavpub.com. Book online at www.pavpub.com

Ref. 2.2.e.

Cambridge, P. (2007a) Taking risks: assessing and managing risks, in
(Ed.) S. Carnaby, *Learning Disability Today*, (pp. 51-63), Tizard
Centre and Pavilion Publishing, Brighton.

McCarthy M and Cambridge P (2006) Sexuality and intimate and personal care. In: S Carnaby and P Cambridge (Eds) *Intimate and Personal Care with People with Learning Disabilities*. London: Jessica Kingsley Publishers.

McCarthy M and Thompson D (1994) *Sex and Staff Training*. Brighton: Pavilion Publishing (Brighton) Ltd.

Morris P (1969) *Put Away*. London: Routledge.

Robb B (1967) *Sans Everything: A case to answer*. London: Nelson.

Sobsey D (1994) *Violence and Abuse in the Lives of People with Learning Disabilities*. London: Brookes.

Spreat S, Lipinski D, Hill J and Halpin M (1986) Safety indices associated with the use of contingent restraint procedures. *Applied Research in Mental Retardation* 7 475–481.

Townsend P (1962) *The Last Refuge*. London: Routledge.

Williams C (1995) *Invisible Victims: Crime and abuse against people with learning difficulties*. London: Jessica Kingsley Publishers.

Wolfensberger W (1975) *The Origin and Nature of our Institutional Models*. Syracuse: Human Policy Press.

Chapter 5

Taking risks

Assessing and managing risks

Key words

informed risk-taking, risk assessment, risk management, exploitation, consent, policies, policy guidelines

Risk management in services for people with learning disabilities happens along a continuum, from 'informal' risk management to 'formal' risk management. Some things we do automatically, like stopping someone that we know has no understanding of danger from crossing a busy main road on their own (**informal**). Other things we do in a more considered way, such as supporting someone to boil a kettle and make a cup of tea, because this is in their individual plan (**formal**). Occasionally, risk-taking itself is referenced through formal policies that are designed to support staff to assess and manage risks – usually relating to clients. These are not always about reducing risk per se, but about supporting someone to make informed choices in their life and support them through the consequences. However, there is a 'risk' that poorly developed risk management is more about defensive practice than user choice and empowerment. The part that other policies play in risk management is explored later.

Why take risks?

At one time, segregation in institutions was perceived to be the main way of managing the safety and security of people with learning disabilities (Alaszewski *et al*, 1999). However, risk management and risk-taking in

community services for people with learning disabilities provides the basis for helping service users to develop their potential as individuals and become more independent. They are also central to some particular areas of practice – such as supporting people with challenging behaviours – and include the risks to the person, other service users or staff. People with learning disabilities often lack the knowledge and experience to take **informed risks** – they may not be aware of exactly what the risk is, or how risky it is. Services therefore, have responsibilities beyond simply providing information or advice to clients.

Keeping records

Risk assessment is designed to identify the level and nature of risk. Risk management looks at the more complex relationships between risk-taking and other demands on services, such as the duty of care, responsibilities for protecting vulnerable people and individual rights. It therefore usually leads to an action plan or intervention, with allocated responsibilities.

Such decisions should be part of the service user's individual plan, and be developed from the person-centred plan. They will generally be subject to the approval of managers or the guidance provided by policies. It is important to **record** all risk-taking decisions with the reasons for and against the course of action taken, the rationale for particular decisions made, or risk-management strategy adopted. Being able to demonstrate that decisions involving risk were professionally and responsibly made will not only help to protect the service from claims of negligence, but are also basic to best practice.

In this chapter, intimate and personal care is used to explore how carefully policies need to be formulated to avoid hidden risks. HIV is used as a worked example to consider the issues inherent in risk assessment and risk management, the processes involved and the different approaches that staff and services can take.

Basic risk management

Risk-taking is directly related to participation in life and taking up opportunities to develop as individuals, whatever an individual's level of learning disability. It would therefore be unrealistic to try to achieve a risk-free life for service users. Some lifestyle risks, such as those associated with smoking or diet, are increasingly being recognised as important for

supporting clients, and reflect national health promotion initiatives. Much will depend on what is made visible and said about risk-taking in regular policies and guidelines, individual plans and, occasionally, specific risk-taking policies. Risk management has its roots in cost-benefit analysis, and has been more prominent in health than social care (Eby, 2000).

A basic model for risk management and decision-making in social care will usually include the following criteria or actions (developed from Carson, 1990).

- Draw up lists of competing considerations ('pros' and 'cons') regarding the risk (benefits and costs) to the client.
- Do the same for the staff or service (advantages and disadvantages).
- Consider both the length of the respective lists as well as the relative importance and weighting of the different factors.
- Identify who is responsible for making the decision and what model of decision-making is best (single worker, team, senior manager, director, specialist adviser).
- Consider the frequency of likely occurrence of the risk events (how often they might happen).
- Identify any action that could be taken to reduce uncertainty.
- Consider the steps that could be taken to make the benefits or advantages more likely to occur.
- Consider long-term gains and risks against short-term gains and risks.
- Record the decisions made and responsibilities for the actions recommended.

Although the Jay Committee (Jay, 1979) and Social Services Inspectorate (Fruin, 1998) both stressed the importance of risk-taking and related policies, Alaszewski *et al* (1999) also observed that only a small minority of agencies surveyed had risk or whistle-blowing policies. Key findings from their study also highlighted the different perceptions of risk on the part of service users, relatives and professionals, with the conclusion that effective risk policies should comprise:

- a clear statement of aims and the purpose of the policy
- a clear definition of risk, identifying issues, consequences and probability
- a clear statement of components, including planning and assessment, and decision-making
- recording a clear statement of policy and practice for risk management.

The role of policies in risk management

There are critical areas of practice where risk and policy merge. Some policies and procedures, such as those on infection control, are specifically designed to reduce or minimise a particular risk to staff and clients. Policies on control and restraint (physical interventions) are designed to ensure that agreed individual procedures are adhered to when responding to challenging behaviours, which should minimise risks of abuse and harm to clients (Harris *et al*, 1996; Harris, 2002). In other policies, such as those on sexuality, risk management is likely to be referenced in relation to particular issues, such as HIV and sexual abuse (Cambridge & McCarthy, 1997). As can be seen in *Chapter 4*, adult protection policies are largely about assessing, managing and responding to risk in a specific area of national and local policy. They are designed to guide managers and practitioners through procedures that allocate responsibilities, and specify processes to follow and decisions to make, with the aims, for example, of keeping clients safe and removing perpetrators. Therefore, risk and risk management in services for people with learning disabilities are also affected by how well policies are developed, implemented and reviewed, and staff skills and training (Brown & Cambridge, 1997). To be effective, policies should link risk management with key practice issues such as decision-making and accountability (O'Sullivan, 1999; Cambridge & Parkes, 2004; Eby, 2000) (see *Box 1*).

HIV risk assessment

Without knowing the nature or level of risk, it cannot be effectively managed. In relation to HIV, we know the main ways HIV can be transmitted, providing the basic information we need to undertake HIV risk assessment.

Most HIV infections are transmitted through infected blood, semen or vaginal fluid. Therefore, the main potential and actual routes of infection are through:

- high HIV-risk sex (unprotected anal or vaginal sex, either as the insertive or receptive partner) with a person infected with HIV
- sharing needles for intravenous drug use (rather than using new, clean needles each time drugs are injected)
- medical procedures using contaminated blood, blood products or tissue (screening or treatment has now eliminated this in the developed world)
- vertical transmission from mother to child during pregnancy or childbirth.

Box 1: Policy case study

As with other policies, those on intimate and personal care are designed to improve practice and the quality of care provided to service users, yet may also unwittingly ignore or bring additional risks. Therefore, it is important to review policies regularly to ensure that they are as effective as possible. In intimate and personal care for example (Cambridge, 2006), most policies will be based on same-gender care due to the fact that intimate care may involve washing or bathing someone or changing continence pads. This is because of the perceived risks to female clients of sexual abuse from male carers and the cultural inappropriateness of cross-gender care from men to women. However, sometimes this is given priority, in order to keep to the policy, resulting in a service user receiving intimate care from agency staff who do not know them or understand their care needs. This may lead to assumptions that intimate and personal care is best conducted by women – regardless of the gender of the client. In reality, women are often expected to provide intimate care to men because, in general, fewer men than women work in frontline caring roles. Lesbian and gay staff might also be placed in a difficult position by same-gender policies. A categorical approach to gender may distract attention from other risks, such as sexual abuse towards men, as well as the high risks of physical abuse and neglect from care interactions, which are conducted in private and closed settings. However, on the positive side, good intimate and personal care policies will refer to individual care guidelines, which support care to be delivered in appropriate and consistent ways, outlining how to respond appropriately and safely if someone gets sexually aroused during a care interaction and how to communicate effectively with a client who has limited expressive or receptive communication. For example, exploring consent to touch and explaining reasons for touch.

In reality, we will need to know much more to undertake an effective HIV risk assessment in a particular risk area, such as sexuality. For example, detailed consideration would include recognising that:

- using a condom for penetrative anal or vaginal sex reduces, but does not eliminate, the risk of HIV infection – condoms can split or come off during penetrative sex and the use of water-based lubricants and extra strong condoms for anal sex can help prevent this from happening
- the receptive partner is at more risk than the insertive partner
- anal sex is higher risk than vaginal sex
- oral sex is generally considered as very much safer than unprotected penetrative sex, even without the use of condoms, unless semen is exchanged or blood is present.

In Britain, most known cases of Aids and HIV infections are accounted for by men, the majority of whom have had sex with other men. Heterosexual transmission and infections accounted for by women are steadily increasing, and infections accounted for by intravenous drug use and contaminated blood products/tissue are decreasing proportionately. HIV risk is also related to global factors, such as the high incidence of HIV infection among people in parts of Africa, south east Asia and eastern Europe. Clearly, we would need to know a lot about someone's sexual life and encounters in order to undertake an effective HIV risk assessment, as key factors would include:

- type of sex (high risk if anal or vaginal penetrative sex, low risk if oral sex)
- whether condoms are used regularly and effectively (safer penetrative sex)
- frequency of unsafe sexual behaviours (the more frequent, the more risk of HIV)
- the risk group of the sexual partner (potentially higher if with men who have sex with men, people from Africa or intravenous drug users who share needles, for example)
- sex and safer sex education (knowledge of sex and safer sex)
- ability to practise safer sex (including assertiveness and negotiating skills)
- reported realities of sexual encounters (from keyworking or sex education).

In addition, **indirect indicators of risk** might need to be used to help assess the likelihood that sex and high HIV-risk sex might be taking place. For example, for men with learning disabilities who have sex with men without learning disabilities (Cambridge, 1996), various things might indicate that someone may be at increased risk, such as:

- being seen hanging around public toilets, parks or other places that men meet to have sex
- talking about homosexuality or gay sex
- having a gay identity
- talking about friendships with other men
- being absent from the service for long periods without explanation
- having unexplained money or presents
- having an unexplained sexually transmitted infection
- being secretive or refusing to talk about activities.

The majority of men with learning disabilities at risk of HIV are also likely to be having sex with other men and women with learning disabilities

(Cambridge, 1996; 1997a), raising additional considerations for HIV risk assessment and management.

HIV risk management

HIV infection is potentially a much less likely risk than sexual abuse (the prevalence of sexual abuse is known to be high: Brown *et al*, 1995; McCarthy & Thompson, 1997). However, it is potentially a more serious risk, because life is invariably at stake and there are major social and economic costs, such as quality of life and drug treatments. HIV is also an easy risk to ignore, as high HIV-risk behaviours may be invisible (such as unsafe sex outside services), the consequences may be longer-term (long timescales between HIV infection and illness) and the difficulties in attributing specific events to infection. Individual rights to sexual activity and opportunities for sexual expression have to be judged in relation to the risks involved for the person and others. Such considerations make HIV risk management decisions difficult.

Drawing a bold line between acceptable and unacceptable HIV risk is impossible, as people attach different values and benefits to risk-taking. However, services can ask some basic questions about people's understanding and appreciation of sex, safer sex and HIV. This helps to assess informed risk-taking and the nature of possible HIV preventive (risk management) activities (Cambridge, 1997b).

- Is the contact mutual or exploitative? If it is exploitative there is a clear case for intervening to stop it, regardless of HIV risk.
- Is the behaviour high risk? If someone is having unprotected anal or vaginal sex there is clearly a significant risk to be managed, whereas oral sex or other sexual contact could be assessed as low risk – requiring a lower priority intervention.
- Is the behaviour frequent or likely to reoccur? A one-off medium- to high-risk event is likely to require a very different response from a situation of repeated risk-taking, which is likely to continue.
- Does the person at risk know about safer sex and are they physically able to practise it? If not they should receive intensive safer sex education, have access to condoms and receive ongoing staff support and monitoring.
- Is the person at risk able to insist on safer sex and that they or their partner(s) use condoms for high HIV-risk activities, such as penetrative anal or vaginal sex? If not, then they should receive HIV counselling, intensive safer sex education and training for assertiveness and negotiating skills.

Most responses will involve safer sex education and assertiveness work (Cambridge, 1999), but in some cases risk will be so high, or knowledge so low, that short- or long-term measures might need to be taken to restrict or eliminate high HIV-risk behaviours. However, such decisions need to take account of rights and responsibilities at both the individual client and service levels. *Table 1* illustrates an increasingly complex level of decision-taking and risk management in relation to HIV, for an individual case. Similarly, the potential legal risks for services will increase as the level of risk increases (Gunn, 1997).

Conclusions

In summary, a number of possible HIV risk management responses can be identified:

- testing for HIV (see below)
- keeping someone at home
- escorting someone when out
- limiting someone's activities when at home
- providing safer sex education
- counselling for HIV
- referral to specialist GUM service
- referral to gay men's support/advocacy group.

The potential responses vary in their approach and acceptability and have various advantages and disadvantages, which will need to be considered on an individual basis. Simply encouraging a gay identity will not, for example, be a preferred option for many men with learning disabilities, who have sex with men who usually retain a heterosexual identity (Cambridge, 1997a). The evidence from sex education suggests a wide gap between the knowledge and practice of safer sex, for people with learning disabilities (McCarthy & Thompson, 1998). Restricting someone's activities might infringe their liberty or lead to an increase in challenging behaviour.

HIV testing is potentially a very important part of HIV risk assessment and risk management. If an HIV test is thought necessary, then it may only legally be done if the individual can give informed consent to it. Without informed consent, an HIV test amounts to assault. To give informed consent (as opposed to saying yes) a person must not be encouraged, or otherwise pressured, to have the test, and must appreciate the potential consequences and limitations (Cambridge, 1997c).

Table 1: Decision-making for HIV risk assessment and risk management – example of a sexually active male client

| Level of decision | Examples of level of risk | Examples of decision taking |
|-------------------|--|--|
| 1 | Change in known sexual behaviour raises possible sexual health issues | Keyworker or support worker informs house manager and care manager |
| | Need for safer sex education discussed as part of individual person planning | |
| 2 | Referral for client to have safer sex education | House manager consults with service manager, with advice from sexuality co-ordinator |
| | HIV risk assessment undertaken | |
| 3 | Decision not to involve parents in discussion of client's sexuality at request of client | Service manager informs operations manager, with advice from sexuality co-ordinator |
| | High HIV risk disclosed/assessed (client sometimes has unprotected insertive or receptive anal sex with men without learning disabilities) | |
| | Assertiveness programme designed to help client negotiate and practise safer sex (basic HIV risk management) | |
| 4 | Safer sex education continued, counselling regarding HIV risk and consequences, and messages reinforced and targeted at known high HIV-risk behaviours | Meeting between house, service and operations managers and sexuality co-ordinator |
| | Further disclosures through sex education that client sometimes has sex with other men and women with learning disabilities | |
| | Decision to provide others with individual sex and safer sex education | |
| 5 | Local HIV risk management strategy developed | Operations manager, with advice from sexuality co-ordinator and ethical committee or independent adviser |
| | Client requests HIV test and referred to specialist counselling GUM (genito-urinary medicine, ie. sexual health) clinic | |
| | HIV risk management programmes for individual clients at risk are established | |

In particular they should:

- understand the nature of HIV/Aids
- appreciate the nature and limits of the HIV test
- be able to demonstrate why they want a test
- be able to consider confidentiality and disclosure
- appreciate the emotional and social consequences of testing positive or negative.

Testing for HIV

Only people with mild learning disabilities are likely to be able to give such informed consent. If a test is considered without the individual's informed consent, this must be legally sanctioned by a court of law. Moreover, counselling would need to be provided, and protocols for managing confidentiality would need to be in place (Cambridge, 2001). However, the rationale for testing is strong, as known HIV-positive status can bring access to effective combination drug therapies and healthcare monitoring. Dedicated HIV policies and the inclusion of sexual health issues in sexuality policies are needed to guide service responses and risk management in this area of practice, with safer sex education available for all sexually active clients. This should be targeted at men with learning disabilities who have sex with men, and women with learning disabilities who sell sex, or have many men without learning disabilities as sexual partners (Cambridge, 1999).

Policies and practice

At a more general level, risk management policies and procedures can help, but these need to be accessible and practical for service managers and staff to use effectively. One way of achieving this is for risk management to be fully placed within specific policies that relate to the area of practice. For example, risks that relate to HIV can be addressed through sexuality policies (Cambridge & McCarthy, 1997) or specific HIV policies (Horizon, 1996).

Summary

Guidelines for risk management in services for people with learning disabilities need to empower staff and managers to take positive risks in relation to supporting service users in routine things (such as developing life skills) and complex things (such as increasing their independence and participating in the community).

The following checklist should help to achieve an operational relationship between promoting individual rights and protecting people from

danger – and enable services to develop a positive culture of risk-taking.

For every risk situation it is important to think about the following points:

- the potential benefits or gains to the person's functioning, quality of life and life experience *as well* as the risks to the person and the service
- the costs, to services and staff *as well* as to service users, of perpetuating institutionalised dependency relationships through a reluctance to take risks
- the learning and mutual respect that can be developed *between staff and service users* from supporting positive risk-taking in people's lives
- the risks of developing a culture of introspection (ie. self-scrutiny) through excessively defensive management and practice.

Every risk, whether routine and low level (such as boiling a kettle), or higher level (such as road safety and HIV) can be addressed through a basic risk assessment in a person's individual plan, with actions and responsibilities made clear. However, not all risk-taking will necessarily have positive outcomes – otherwise it would not be risk-taking. The outcome is to minimise risk and maximise gain. In so doing, we also need to consider the support that both staff and service users may need if risk-taking goes wrong. Learning from negative, as well as positive, outcomes of risk-taking can happen at case review and service review, but only if we do not develop a culture of blame and fault. More importantly, good policies and procedures should support risk-taking in key areas of practice. **Chapter 4** provides a worked example of adult protection and **Box 1** (page 55) shows how a policy focusing on a particular area of practice, such as intimate and personal care, can help with effective risk management. Increasingly, service-providing agencies are developing specific risk management policies and procedures, but we need to make sure that they work well for service users, as well as managers and practitioners.

Further reading

McCarthy M (1997) HIV and heterosexual sex. In: P Cambridge and H Brown (Eds) *HIV and Learning Disability*. Kidderminster: BILD.

Thompson D (1997) Safer sex work with men with learning disabilities who have sex with men. In: P Cambridge and H Brown (Eds) *HIV and Learning Disability*. Kidderminster: BILD.

References

Alaszewski H, Parker A and Alaszewski A (1999) *Empowerment and Protection: The development of policies and practices in risk assessment and risk management in services for people with learning disabilities*. London: Mental Health Foundation.

Brown H and Cambridge P (1997) Policies and their contribution to coherent decision-making. In: P Cambridge and H Brown (Eds) *HIV and Learning Disability*. Kidderminster: BILD.

Brown H, Stein J and Turk V (1995) The sexual abuse of adults with learning disabilities: report of a second two year incidence survey. *Mental Handicap Research* 8 (1) 1–22.

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 (3) 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) At whose risk? Priorities and conflicts for policy development in HIV and intellectual disability. *Journal of Applied Research in Intellectual Disability* 10 (2) 83–104.

Cambridge P (1997c) *HIV, Sex and Learning Disability*. Brighton: Pavilion Publishing (Brighton) Ltd.

Cambridge P (1999) Considerations for informing safer sex education work with men with learning disabilities. *British Journal of Learning Disabilities* 27 (4) 123–126.

Cambridge P (2001) The HIV testing of a man with learning disabilities: informed consent, confidentiality and policy. *The Journal of Adult Protection* 3 (4) 23–28.

Cambridge P (2006) Developing policies, procedures and guidelines for intimate and personal care in services for people with learning disabilities. In S Carnaby and P Cambridge (Eds) *Intimate and Personal Care with People with Learning Disabilities*. London: Jessica Kingsley Publishers.

Cambridge P and McCarthy M (1997) Developing and implementing sexuality policy for a learning disability provider service. *Health and Social Care in the Community* 5 (4) 227–236.

Cambridge P and Parkes T (2004) Good enough decision-making? Improving decision-making in adult protection. *Social Work Education* 23 (6) 711–729.

Carson D (1990) Taking risks with patients – your assessment strategy. In: *Professional Nurse: The staff nurse's survival guide* pp83–87. London: Austen Cornish.

Eby M (2000) The challenges of being accountable. In: A Brechin, H Brown and M Eby (Eds) (2000) *Critical Practice in Health and Social Care*. London: Sage.

Fruin D (1998) *Moving into the Mainstream: The report of a national inspection of services for adults with learning disabilities*. London: Department of Health.

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

Harris J (2002) From good intentions to improved practice – developing effective policies. In: D Allen (Ed) *Ethical Approaches to Physical Interventions*. Kidderminster: BILD.

Harris J, Allen D, Cornick M, Jefferson A and Mills R (1996) *Physical Intervention: A policy framework*. Kidderminster: BILD.

Horizon (1996) *Policy on HIV Infection and Testing for People with Learning Disabilities*. Abbots Langley: Horizon NHS Trust.

Jay P (1979) *Report of the Committee of Enquiry into Mental Handicap Nursing and Care*. London: HMSO.

McCarthy M and Thompson D (1997) A prevalence study of sexual abuse of adults with intellectual disability referred for sex education. *Journal of Applied Research in Intellectual Disability* 10 (2) 105–124.

McCarthy M and Thompson D (1998) *Sex and the 3Rs: Rights, responsibilities and risks*. Brighton: Pavilion Publishing (Brighton) Ltd.

O'Sullivan T (1999) *Decision-making in Social Work*. London: Palgrave.

Ref. 2.2.f.

Cambridge, P. (2008d) *An Ethical Model for Responding to the Sexual
Fetish of a Man with Intellectual Disability*, IASSID 13th World
Congress, Cape Town, August.

An Ethical Model for Responding to the Sexual Fetish of a Man with Intellectual Disability

13th IASSID 2008 Cape Town

Paul Cambridge
Senior Lecturer
Tizard Centre, SSPSSR
University of Kent at Canterbury, England

Abstract

- *Aim* This paper outlines an ethical model for developing individual psycho-educational work aimed at supporting the sexual fetish of a man with intellectual disability relating to infantilism and the use of nappies
- *Method* A case study analysis will be used to describe the approach adopted and the issues that arouse. These include the management of conflicts between individual rights and service responsibilities and the implementation of solutions identified. Qualitative and experiential data will be utilized
- *Results* It was found that a rights based approach which emphasized advocacy achieved positive quality of life outcomes for the person. Mediated dialogue provided an effective technique for resolving conflicts of interest and experience between the person and the service
- *Conclusions* Clarity in the values and principles underpinning individual psycho-educational work on sexual fetish is required in order to safeguard the rights of the person to safe sexual expression and combat a pathological response to the expression of sexual fetish

Background – previous discourses

- Protection - sexual abuse
- Rights - and responsibilities
- Sex education – information and methods
- Men with ID - risk and dangerousness
- Culture and race
- Homosexuality and HIV
- How women with ID experience sex

Background – new and emerging discourses and insights

- Masculinities - Men with ID relate their sexuality (Wheeler, 2005)
- Homosexuality - Secret Loves, Hidden Lives (Abbott and Howarth, 2005)
- New identities - Lesbian, gay, bisexual and trans-gender identities in ID (Allen, 2003; Wilson, 2006)
- Reframing sexual health - Living Safer Sexual Lives (Johnson et al, 2002)
- Selling and buying sex - Use of prostitutes by men with ID (Cambridge, 2001) and work in Aus. and NZ.
- Dating services – facilitating and supporting relationships for people with ID (Jenner and Gale, 2006)
- *Little written on fetish – cross-dressing, foot, baby*

'In working psychotherapeutically, we must be prepared to tolerate the fact that there is no cure for our patients' organic impairments. The best we can hope for is that secondary and emotional disabilities are diminished, thus contributing immeasurably to someone's quality of life'

(Hollins, S. 2003: Counselling and Psychotherapy, in W. Fraser and M. Kerr, seminars in the Psychiatry of Learning Disabilities, London, Royal College of Psychiatrists, p. 197).

'When using a person centred approach there are core conditions that are considered essential in promoting change. As supporters, workers, nurses or social workers we are clearly not therapists; nevertheless, the knowledge and use of the core conditions is both relevant and recognizable and should underpin our work'

(Thomas, D. and Woods, H. 2003: Working with People with Learning Disabilities, London, JK, p. 153)

The core conditions

- **Congruence** – genuineness, authenticity or realness e.g. no discrepancy between words and actions, openness, equality
- **Unconditional positive regard** – acceptance e.g. person intrinsically valued and non-judgemental
- **Empathy** – sensing the person's world, experience of what it is like to be that person, requiring emotional engagement

Systemic approach

'...a system is any unit structured on feedback...a system is seen as existing when we can identify an entity made up of a set of interacting parts which mutually communicate with and influence each other...In turn these continually interacting parts are connected together such that they display identifiable coherent patterns... - a system is more than simply the sum of its composite parts. It is the observed pattern that connects the parts in a coherent and meaningful way'

(Dallos, R. and Draper, R. 2000: An Introduction to Family Therapy: Systemic Theory and Practice, Buckingham, Open University)

Steve's system and world

- Shame of his disability – autistic spectrum
- His bedroom and private space
- His family - mother, sister and nephews
- His service manager
- Professionals – psychiatrist, psychologist, care manager
- His house-mates
- His key-worker and support staff
- Other people he has contact with in shops and the sports centre

Principles

- Advocate on behalf of the person
- Put their rights first
- Be open them and others
- Be non-judgemental (about fetish)
- Provide good information and advice
- Resolve conflict
- Reach least restrictive outcome

Techniques and process

- One to one work
- Information and education
- Elicit stakeholder perspectives
- Suggest options
- Mediate dialogue
- Suggest best solution
- Develop written agreement
- Provide information and advice re consequences
- Negotiate implementation and change
- Review progress

How Steve related his sexual interest in nappies

- He was deeply ashamed of his fetish and was fearful that his mother, staff and other service users would find out
- He could not bring himself to say the word 'nappy'
- Eventually he wrote the word 'nappy' down on a piece of paper
- He acknowledged he kept scrap books of babies and nappies annotated with violent images

What Steve wanted

- To be able to buy nappies
- To wear nappies in private
- To use them to masturbate
- To have a rubber sheet and pillowcases
- To keep a scrap book
- To look after his nephews
- Not to be supervised
- To have other baby paraphernalia

What the manager wanted

- No more scrap books
- To resolve the nappy problem
- Steve to be aware of consequences of disclosure
- Steve to understand confidentiality
- To reduce the risk of Steve offending
- To consider reducing Steve's supervision

Characteristics of Steve's life T1

- Spent most of the time in his room when at home but went to a work project and formal recreational activities once a week
- Secretly kept scrap books of babies in nappies which were removed when they were discovered
- His sexuality was policed and he was not allowed to access nappies
- Nappies repeatedly taken away from him when he obtained them
- Supervision – could not leave the house alone and constant supervision when out or visiting his family

Response

A written agreement between Steve and his service manager was developed. This specified his rights to safe and private sexual expression using nappies. Also his responsibility not to produce violent sexual images of babies in scrap books and the legal and service consequences of this. It specified a process for monitoring and reviewing progress.

Characteristics of Steve's life T2

- Steve buys his own nappies with the support of his manager
- He uses them in his bedroom at night to masturbate
- He monitors their use himself in a diary
- He keeps them locked away in his room during the day
- He disposes of them himself
- He does not keep a 'scrap book'
- He is still supervised when he goes out

Positive outcomes

- Written agreement regarding safe expression of Steve's sexual fetish
- Adult protection alert – disclosure of past sexual abuse
- Steve able to take control of his fetish and more control over his life overall
- Steve's challenging behaviour reported to have decreased
- Steve's functioning and assertiveness increased
- Greater positive self-regard and happier in his life

Less positive outcomes

- Supervision maintained
- Risk of offending reduced?
- Steve broke confidentiality boundaries
- Change of service manager - new manager less supportive, different attitudes
- Some interpreted Steve's nappy interest in relation to their childrearing experience

Unresolved issues

- The function of the scrap book. Was this Steve expressing his hatred of himself and his disability or his sexual interest in babies?
- The function of the fetish. Is it an expression of potentially dangerous behaviour or his regression to a safe childhood without a disability?
- The nature of his risk to babies and children? If there is a risk how has the intervention impacted on this? Did taking the scrap book away and allowing him access to nappies increase or decrease his risk?
- The influence of his mother on his self-image and fetish and how he perceives himself in relation to his nephews.
- Insights on his risk and behaviour to be gained from access to psycho-therapy/forensic risk assessment?

Person- centred psycho- educational model

- Get to know the person
- Find out what they want
- Understand how they are feeling
- Help them reflect and contextualise
- Provide information and choices
- Provide positive suggestions for change
- Help the person decide for themselves
- Highlight possible consequences
- Advocate for the person in negotiating change

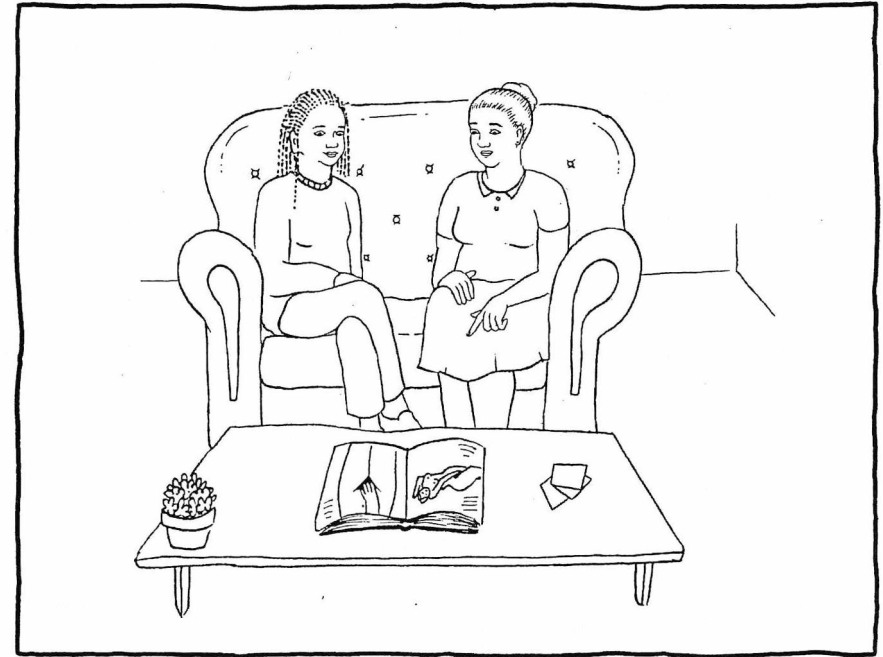
Ref. 2.2.g.

Cambridge, P. (2010) Masturbation and people with learning disabilities, in (Eds.) M. McCarthy and D. Thompson, *Handbook on Sexuality and People with Learning Disabilities*, Pier Professional, Brighton.

Chapter 2

Masturbation

Paul Cambridge



Introduction

Masturbation is a key consideration when supporting the sexuality of people with learning disabilities for the following key reasons:

- ▶ it is the most frequent form of sexual expression including for people with learning disabilities
- ▶ many of the difficulties reported in relation to sexuality and people with learning disabilities concern masturbation
- ▶ responding to masturbation can create tensions between the rights of service users and the responsibilities of carers
- ▶ sexual self-stimulation is likely to be the only form of sexual expression available to people with profound and multiple learning disabilities.

Despite this, little guidance exists for carers on how to respond effectively when masturbation presents as a support challenge. The aim of this chapter is therefore to provide pointers for responding to some of the most frequently experienced situations concerning masturbation.

Background

Sometimes people with learning disabilities experience difficulty expressing their sexuality through masturbation and a number of factors help explain this. Many people with learning disabilities have been told or believe that

masturbation is wrong and consequently feel ashamed of or deny such behaviour. People with learning disabilities are also unlikely to have received good education and advice about masturbation, including how and where to do it and that it is an OK thing to do. The ways shared and private spaces are organised in services can also create difficulties. Moreover, problems associated with masturbation are generally more visible when they concern men than women, with the needs of women with learning disabilities remaining relatively neglected in relation to masturbation (McCarthy, 1999).

Staff and carers tend to identify a range of concerns in relation to masturbation (see Cambridge *et al*, 2003 for a more detailed discussion).

- ▶ The person does not know how to masturbate appropriately, for example, they stimulate themselves sexually by rubbing their vagina or penis through their clothes or against objects.
- ▶ The person is thought to be unable to masturbate effectively, for example, a man might have difficulties with having an erection or ejaculation or a woman might not be able to reach an orgasm – possibly causing frustration.
- ▶ The person is masturbating too much, for example, they are doing it too frequently or for too long and as a consequence miss out on other opportunities or activities, or cause soreness.
- ▶ The person is masturbating when other people are around, for example, doing it in a public place or a shared room in a service.
- ▶ The person is using inappropriate objects to aid masturbation, there may be a risk or evidence of injury.

The factors which influence how staff and carers interpret and respond to masturbation are therefore complex.

Not recognising that masturbation can be important for people with learning disabilities

In the past it was considered that people with learning disabilities did not need to know how to masturbate or staff and carers were too embarrassed to provide advice about masturbation. The only message that people often received was that masturbation was wrong. Staff and carers also need support and guidance about how to respond positively and sexuality policies or individual care guidelines are helpful in this regard. Attending sexuality training can also help staff feel more confident to provide support.

Lack of effective and accessible sex and relationships education

Special line drawings and videos have been produced which show masturbation for education with people with learning disabilities. However, staff and carers may not know how to get hold of these or feel able to use them confidently and effectively. People with more profound and multiple learning disabilities are even less likely to have received relevant sex education partly because there are few such materials available.

Lack of privacy

The ways services and support for people with learning disabilities are organised heavily influence what happens in people's lives. For example, in congregate service provisions such as day centres and residential services, many spaces are shared. This limits privacy and can make it difficult for someone to find an appropriate place to masturbate. The lives of people with learning disabilities are also often highly scrutinised, with the result that their masturbation is likely to be more known about than other people.

Individual needs

Problems associated with masturbation might be attributed to attempts to communicate, to avoid particular people or situations or to gain attention. Whilst such factors may be significant, they also risk distracting attention from a person's need to express their sexuality safely and appropriately.

Gender and culture

Masturbation is generally reported to be more of an issue for men than for women with learning disabilities. This is because the sexuality of women with learning disabilities is generally less visible and more hidden, including masturbation. For women with learning disabilities there may be additional embarrassment and reluctance to talk about the subject. There are also culturally specific views about masturbation which may need to be taken account of when supporting someone from a minority ethnic or cultural group.

Information

When masturbation presents as a problem, it is important to find out as much as possible about what is happening.

How is the person masturbating?

Questions for a woman with learning disabilities may include 'does she directly stimulate her clitoris, vagina or breasts' and 'is this done above or beneath clothing'? For a man: 'does he get an erection, get his penis out, use his hand or ever ejaculate'? If masturbation is happening in a private place such as a bedroom or toilet, such questions are likely to be more difficult to answer, but indirect evidence such as the presence of semen on sheets may prove helpful. If possible, the best approach will be to elicit accounts directly from the person through individual sex education.

Is there a pattern to the masturbation?

It is helpful to clarify the actual behaviour and its context and check if anyone else has any ideas about what is happening and what might explain the behaviour. This will include considerations such as whether a particular response seems to be more effective than another and whether the behaviour varies between different places or times of the day or occurs if certain staff or service users are present.

Is this an indicator of sexual abuse?

Due to the high level of sexual abuse experienced by people with learning disabilities (McCarthy & Thompson, 1997; Murphy, 2007; Cambridge *et al*, 2010) it will also be important to consider the possibility that inappropriate masturbation is a sign that the person has or is being sexually abused, or is a way to communicate abuse.

Are there any other explanations?

Possible medical reasons may need to be checked out with a GP, including a vaginal, penile or urinary tract infection or a skin condition such as thrush or eczema. Sometimes medication can make it difficult for a man to masturbate effectively and some conditions such as Prader-Willi syndrome are associated with the immature development of the sexual organs, which may also make it difficult to masturbate.

Responding

The following case studies are taken from real situations, illustrating some of the challenges masturbation can present and suggesting possible responses.

Masturbation and self-injury

Case study

Anila is a young woman with severe learning disabilities who uses very little spoken language. The support staff use a small number of signs and some pictures to support communication. Her key worker has been worried for some time about blood found on Anila's sheets when changing her bed. Yesterday she found a coat hanger in the bed with dried blood on it. She was unable to find out from Anila where the blood had come from and removed the coat hanger before speaking with her manager.

Sometimes people with learning disabilities use inappropriate objects for sexual stimulation which risk injury. These may be inserted into the vagina or anus because the person has found that this is sexually stimulating or helps them achieve orgasm or ejaculation during masturbation.

In Anila's situation, her support worker took the correct action in removing an object which might be causing her injury. This idea could be checked out through individual work with Anila by monitoring or observation that respected her privacy (for example checking the sheets regularly when she is out of her room) and by speaking with others who provide support for her. Meanwhile, it would be sensible to provide Anila with the opportunity to use a safer object such as a soft dildo by leaving it on her bed. The possibility of past or current sexual abuse would also need to be considered (p46).

Masturbation during intimate care

Case study

Peter is a man with profound and multiple learning disabilities (PMLD) in his mid-30s living in a residential care home and he relies on staff for all aspects of his personal care. Three days a week are spent at a special care unit which is part of a local day centre. At the home team meeting a female support worker reports that Peter has recently been getting an erection and attempts to touch his penis when his continence pad is removed. This often happens when his penis and anus are washed using warm soapy water (using disposable wipes and protective gloves). No other home staff report that this has happened but when the manager checks at the day centre she finds that this had also happened with a male care worker there.

Much regular support work for people with PMLD revolves around routine tasks such as washing, bathing and continence care. People with PMLD are unlikely to know about masturbation and may be physically unable to masturbate. It is not uncommon for sexual arousal to take place when their continence pad is changed and the sexual parts of their bodies are washed. This may also be the only time that the sexual parts of their body are exposed and they have the opportunity to touch themselves sexually.

In Peter's situation, the support worker did the right thing in reporting her observations to the team. Finding out that it happened with the male worker at the day centre suggests it is less about one staff member than how intimate care is given. An idea would be for Peter to have time on his own after intimate care prior to a clean pad being secured, giving him the chance to explore himself sexually and touch his penis. His care plan should set this out and could for example, include what to do if he tries to touch himself when a member of staff is present. It could also set out verbal cues to be used such as 'you can touch now, Peter' (matched to his level of verbal understanding). The guidelines should also be clear about where Peter could be left alone safely and for how long.

Inability to masturbate effectively and inappropriate masturbation

Case study

Julie is a woman with Down's syndrome and moderate learning disabilities who exhibits some challenging behaviours including screaming and occasionally hitting staff. Once or twice a week Julie also displays sexually inappropriate behaviour, usually in the form of rubbing herself against a chair arm in the sitting room or less frequently against the bodies of male staff. When this happens, she is asked to leave the room or pushed away, with a reinforcing verbal cue that this is not allowed.

It is always important to consider the reasons for any challenging behaviour and records such as ABC charts should be kept to see if there are patterns to this, such as to avoid a particular situation, activity or person. It may also be to gain attention or to communicate that something is wrong, such as sexual abuse. Alternatively it might simply be the case that Julie has never received good sex education tailored to her needs and abilities and simply does this when she feels sexy or finds someone sexually attractive.

In Julie's situation the staff did the right thing in treating her sexual behaviour as unacceptable. However, it is also important to help her understand where and when such sexual behaviour is acceptable and this might involve guiding or asking her to go to her own room. Julie would also benefit from individual sex education focusing on appropriate and effective masturbation. Sex educational materials such as line drawings, videos or a model vagina and clitoris might prove helpful.

Masturbation and sexual fetish

Case study

Steve is a young man with autistic spectrum disorder. He collects pictures of babies in nappies and uses nappies and other baby things as part of masturbation. These have always been taken away from him by carers when they have been found in his room. When this happens he gets upset and withdraws and his behaviour can become more challenging.

This example is a reminder of how often carers know more about the private lives of people with learning disabilities than other people – people who are more able to hide their sexual interests. Other examples of sexual fetishes associated with masturbation include cross dressing and foot or shoe fetishes.

A starting point is to identify what the problem is – is it Steve's behaviour or the carers' knowledge or attitude towards it? Many men and women without learning disabilities enjoy sexual fetishes which cause no harm to anyone else and attempting to stop someone having a sexual fetish generally doesn't work. Moreover, it is likely to also be a violation of their rights to private and safe sexual expression. Sex education should instead pay attention to boundaries, responsibilities and consequences. For Steve this could mean finding ways to access nappies which don't involve stealing, having safe and secure storage in his bedroom where his baby things are kept when he is not using them so that carers and other users do not need to see them, how and when he can safely use nappies, how any negative effect of his sexual fetish on other people can be minimised, and what might happen if he discloses this to others. Often when people are given the space to express their sexual fetish appropriately, then its significance in their lives diminishes.

Pornography and masturbation

Many men and some women enjoy pornography whilst masturbating and if used in private by people with learning disabilities it should generally be seen as acceptable. Men with learning disabilities may need to be encouraged to keep it hidden in their rooms and not to show it to other people and may also need to understand that pornography rarely reflects what sex with another person is really like.

The chapter on sexual interests, opportunities and choices (see p81) advises against carers supporting men to obtain pornography, including where it is suggested as a possible solution for a man with learning disabilities who is experiencing problems masturbating. Suggesting the use of pornography is fraught with difficulties including whether someone would be interested in it, what kind of images they might like, whether they might be offended and whether it is likely to address existing problems effectively or cause new problems. The police should be involved if a man with learning disabilities is accessing or is in possession of illegal images of adults or children, for example sexual violence or paedophilia.

Conclusion

Services for people with learning disabilities should ideally have a sexuality policy to advise staff of their responsibilities and what to do in particular circumstances, including:

- ▶ what work they can do and when they need to get specialist advice
- ▶ what to do when they are exposed to a person with learning disabilities masturbating such as during intimate care or in a shared space
- ▶ how masturbation might be related to sexual abuse – either as a potential indicator of abuse or as a form of abuse when being done in front of people (including other people with learning disabilities and staff)
- ▶ the limits to individual work, such as not directly showing or helping someone to masturbate.

Whether or not a policy is available, staff should seek the advice of their line manager or supervisor with responses agreed and recorded in individual plans. This also allows information to be shared within and between teams and is necessary for consistent and considered responses.

The degree of a person's learning disability and their communication needs will affect how support and sex education linked to masturbation can be given. The help of specialists such as sex educators, psychologists or communication therapists will sometimes be needed.

Occasionally staff or family members may oppose advice and education about masturbation in the belief that it will lead to inappropriate sexual behaviour such as exposure. However, there is no evidence to suggest that ignoring difficult situations is more effective than providing information, direction and support.

This all underlines the importance of developing a collective vision and team approach which aims to empower people with learning disabilities to take control and make choices in their lives. Something as common and potentially harmless as masturbation has to be a focus of such work. It is also important to keep things in perspective and to remember that many people with learning disabilities enjoy masturbation as an ordinary part of their sexual lives without any problems. More importantly, everyone should have a right to masturbate as part of their sexual expression.

References

Cambridge P, Carnaby S & McCarthy M (2003) Responding to masturbation in supporting sexuality and challenging behaviour in services for people with learning disabilities. *Journal of Learning Disabilities* 7 (3) 251–266.

Cambridge P, Beadle-Brown J, Milne A, Mansell J & Whelton B (2010) Patterns of risk in adult protection referrals for sexual abuse and people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*. Published online.

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

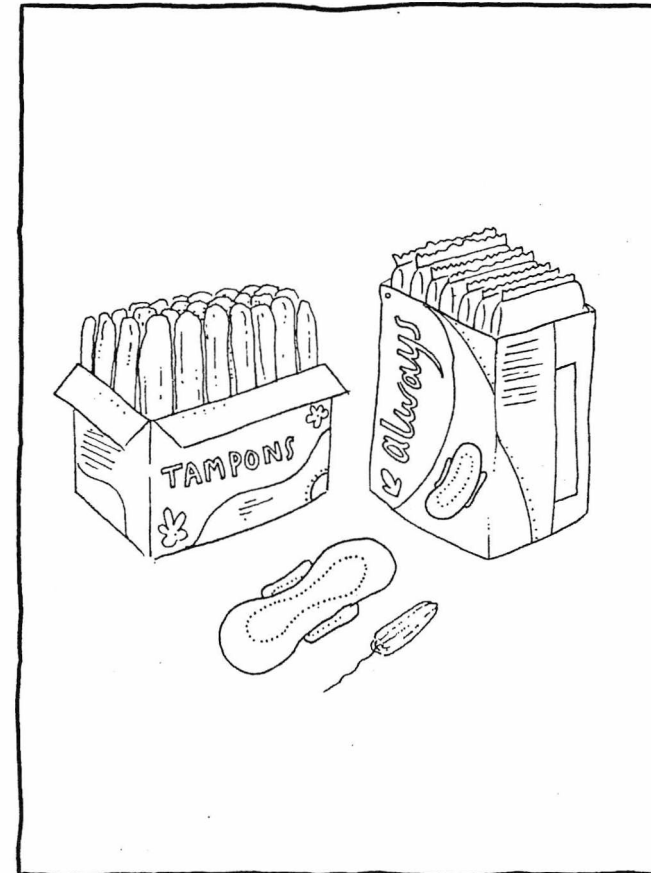
McCarthy M & Thompson D (1997) A prevalence study of sexual abuse of adults with intellectual disabilities referred for sex education. *Journal of Applied Research in Intellectual Disabilities* 10 (2) 105–124.

Murphy G (2007) Intellectual disabilities, sexual abuse and sexual offending. In: A Carr, G O'Reilly, P Noonan Walsh & J McEvoy (Eds) *The Handbook of Intellectual Disability and Clinical Psychology Practice*. London: Routledge.

Chapter 3

Menstruation and menopause

Michelle McCarthy



2.3. Strengthening service management and policy

Ref. 2.3.a.

Cambridge, P. (1997c) At whose risk? priorities and conflicts for policy development in HIV and intellectual disability, *Journal of Applied Research in Intellectual Disabilities*, 10 (2), 83-104.

At Whose Risk? Priorities and Conflicts for Policy Development in HIV and Intellectual Disability

Paul Cambridge

Tizard Centre, University of Kent, Canterbury, Kent CT2 7LZ

Paper accepted June 1997

This paper identifies considerations for HIV policy in services for people with intellectual disabilities and suggests standards for best practice. Evidence from research, policy development and training is examined to inform arguments about the nature, location and management of HIV risk with service and user case studies used to illustrate argument. Priorities for policy are offered and conflicts between the rights and responsibilities of individuals are explored, with discussion centred on the re-homosexualisation of HIV. The paper also identifies key related considerations such as legal and moral questions, policy principles and the need for coordination. The structure of the paper provides a framework for action and pointers are provided for closing the implementation gap between policy and practice.

Targeting HIV Prevention

An emerging body of evidence supports the view that the sexual risk of HIV infection for people with intellectual disabilities mirrors that in the general UK population, in that it is highest for men with intellectual disabilities who have sex with men. Sexual health outreach (Jones, 1993) has made contact with men with intellectual disabilities who cottages (have sex with men in public toilets) and mainstream sexual health needs assessment (Taylor-Laybourn & Aggleton, 1992) has identified HIV risk to young men with intellectual disabilities.

The prevalence of high HIV risk behaviours of men with intellectual disabilities who have sex with men in public places has also been confirmed by specialist needs assessment in work in South East London (Cambridge, 1996a). Sex education work (McCarthy & Thompson, 1994; McCarthy, 1997; Thompson, 1997) has additionally provided a valuable insight into the individual and environmental factors associated with unsafe sexual practices for men and women with intellectual disabilities. Specialist services working with men at risk of sexual exploitation or who sexually abuse (Morris, 1993, 1997) have also identified HIV risk behaviours, as have individual services for people with intellectual disabilities (Davies, 1997) and mainstream health promotion services (Nichol, 1997). There is also wider epidemiological and service-based evidence (Kastner *et al.*, 1989, 1992; Marchetti *et al.*, 1990; Brown, 1991; Dent *et al.*, 1994) of HIV infection and AIDS in the population of people with intellectual disabilities.

The mix of anecdotal, project based, research and practice evidence points to high levels of HIV risk for men with intellectual disabilities who have sex with men and suggests that sex between men with intellectual disabilities and other

men is a relatively common behaviour. There are, however, very real differences in the nature of the sexual experiences and HIV risk for both men and women with intellectual disabilities. These relate to intellectual, social and economic considerations (McCarthy, 1994; Thompson, 1994) and include access to safer sex education, information on HIV and AIDS and to condoms and opportunities to practice safer sex. Relative disadvantage in communication, negotiation and assertiveness skills and the lack of a positive self-image, such as that usually associated with a gay identity, combine to create barriers to HIV prevention work.

In relation to HIV risk in the general UK population, Rooney (1994) reported that 62% of total HIV infections reported since 1984 were accounted for by sex between men and that AIDS cases amongst gay and bisexual men comprised 78% of adult AIDS cases reported since the start of the epidemic. The latest figures from the Communicable Diseases Surveillance Centre (National HIV Prevention Information Service (NHPIS), 1996) indicate that 61% of reported HIV infections were attributed to sex between men. This evidence was recognised by King (1993) in arguing for the re-homosexualisation of AIDS, and a similar argument has been made in relation to targeting HIV prevention work in services for people with intellectual disabilities (Cambridge, 1997a).

Unless services for people with intellectual disabilities invest in effectively targeted HIV prevention work they are indicating that this activity is less important for people with intellectual disabilities than for other members of society who are at similar risk of HIV infection. Without appropriate policy and practice responses, the lives and experiences of people with intellectual disabilities will be further devalued.

Tasks for Policy

Policy has the primary task of ensuring such neglect does not happen, but the risk in any policy is that it will address the requirements of the organisation or managers at the expense of practitioners or the people who use services. McCarthy and Thompson (1996) make the observation that efforts to prevent abuse are usually focused on policy development, with the policy seen as end in itself. Similar effort also needs to be put into policy implementation and maintenance. Policies have the potential to facilitate cultural and behavioural change and the effectiveness of a policy should be judged by its impact on intermediate outcomes (such as the attitudes of staff to homosexuality or knowledge of HIV risk or AIDS) and final outcomes (such as the practice of safer sex or effective use of condoms by service-users). Brown & Cambridge (1997) suggest that the former should include inter-agency relationships, decision-making mechanisms and the process context to learning and discussion. Cambridge & McCarthy (1997) take this point further. As well as working across agencies, policies also need the capacity to interface horizontally between purchaser and provider services and vertically between managers, support staff and other professionals

there are likely to be longer term and more peripheral considerations relating to the impact of the 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 & McCarthy, 1997: 229)

The capacity of a policy located in a single organisation to tackle wider issues of competence in HIV and learning disability, without joint-agency ring-fencing and targeting of HIV prevention resources in localities is seriously in question (Cambridge, 1997a). Moreover, recognition of the findings from intellectual disability research and the wider epidemiological evidence points to a powerful case for dedicated and carefully targeted policy, educational and service interventions which give prominence to the needs of men with intellectual disabilities who have sex with men (Cambridge, 1994, 1996b).

General experience in HIV prevention work can also be used to predict some of the political and ethical conflicts likely to surface as a consequence of policy intervention. Part of the dilemma of gaining funding for HIV prevention activities, including policy development or practice innovation in intellectual disability, extends to acknowledging often invisible and longer-term outcomes or benefits. As Davies *et al.* (1993) have commented:

HIV prevention programs are bedevilled 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: 173)

In addition to helping services recognise where risk is likely to be located, HIV policy also needs to target the case-level processes which ultimately facilitate effective HIV prevention work and individual support. Individual care and service-planning systems cannot be more responsive to sexual health and related needs if they do not explicitly include them (Cambridge, 1996b).

Policies also have to tackle the tendency for services and professionals to focus on the negative consequences, vulnerability and dangerousness of the sexuality of people with intellectual disabilities (see Morris, 1997 in relation to perceived HIV risk). The positive attitudes of residential staff towards the mandatory HIV testing of people with intellectual disabilities reported in a recent study (Murray *et al.*, 1995) suggest a need for policies to moderate staff attitudes, provide consistent responses to HIV risk and establish baseline principles for practice.

Visibility and Recognition

Policies should aim to increase staff competence in recognising and responding to HIV risk and the sexual health needs of service-users and this also impacts on values. By implication, the recognition of homosexuality as a valid and valued sexual behaviour is required. Poor visibility of homosexuality and HIV risk mirrors gaps in competence for recognising sexual abuse (Brown *et al.*, 1994; Turk & Brown, 1993). There are, however, additional disincentives to recognition and disclosure, particularly in relation to men with intellectual disabilities who have sex with men.

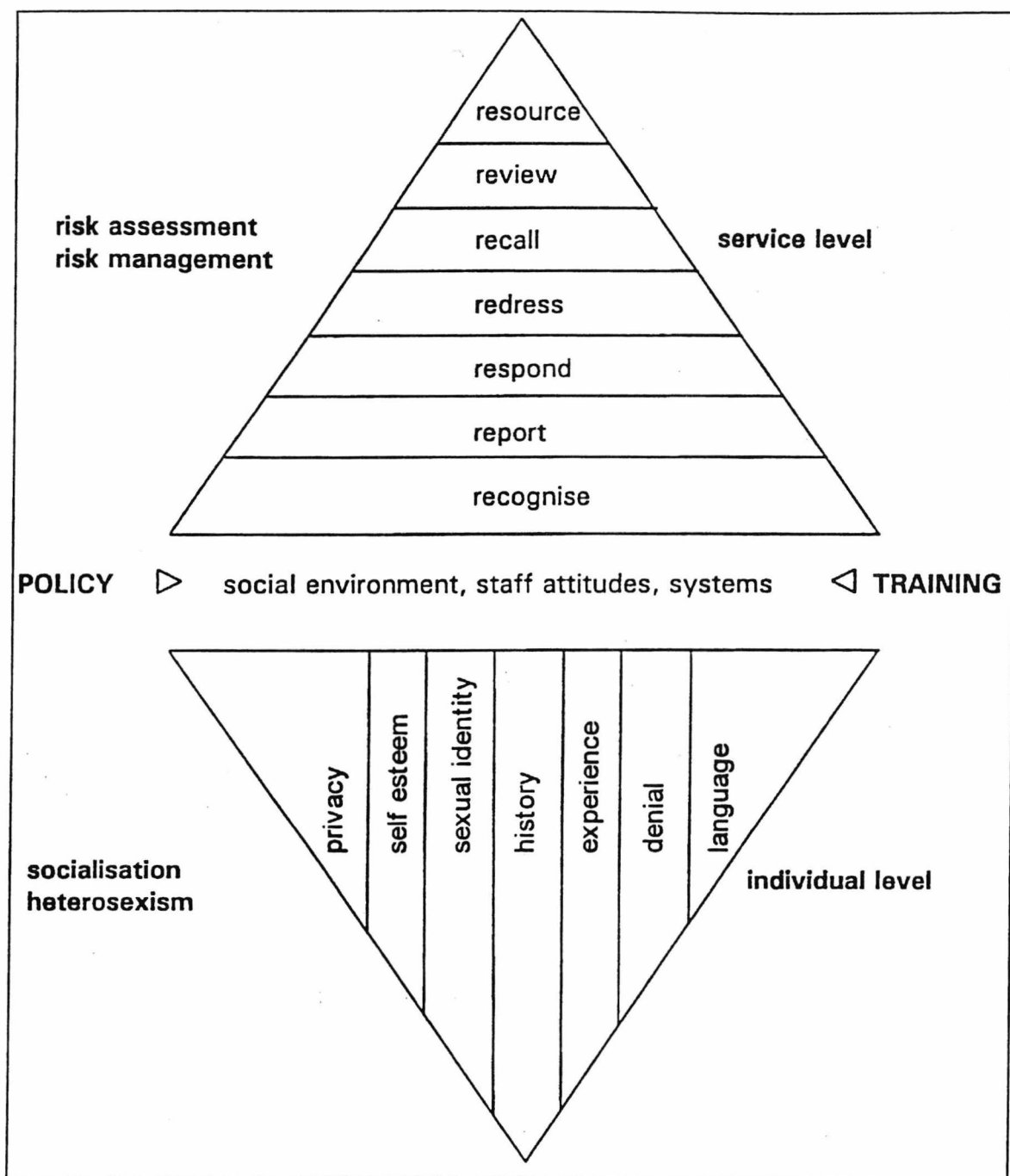


Figure 1 Disincentives to disclosure, recognition and response in HIV and intellectual disability (developed from Turk & Brown, 1993)

Figure 1 illustrates the filtering out of homosexuality and HIV as issues in a society where heterosexism and homophobia are not only present but manifest in service access and provisions (Ross, 1996; Chan, 1996; Kitinger, 1996). Men with intellectual disabilities who have sex with men encounter social disincentives to disclosing their sexuality which can lead to denial and low self-esteem (Thompson, 1997). Even men with intellectual disabilities with a recorded history of homosexuality may have learned to hide their behaviour for fear of censure or punitive intervention. They are also likely to have experienced sex with men as furtive or secretive, reinforcing the socialised belief that such sex is wrong or that men who have sex with men are bad people. It is in the area of individual work

that support workers and specialist practitioners need to reinforce positive messages about homosexuality. Policies are important for setting standards to practice and the values which underpin them.

Men with intellectual disabilities who have sex with men are also likely to lack positive homosexual role models (Thompson, 1994; Cambridge, 1996a). In services which have a strong commitment to equal opportunities, lesbian or gay staff will feel able to share their knowledge and awareness of such issues to inform positive work with users. In other services they too may be silenced or invisible. Policy development should build a map of HIV as an issue in services for people with intellectual disabilities, with the aim of making HIV and high HIV risk behaviours more visible. This will help place HIV and homosexuality on the agendas of staff and individual planning meetings, as well as service commissioners (Cambridge, 1997a, b).

There should also be a two-way link between policy development and service development. The outcomes of innovative sexual health outreach projects or advocacy schemes should inform policy and policy should recommend new service directions. Befriending schemes, where young gay men working in sexual health projects make contact and maintain individual support for men with intellectual disabilities who have sex with men are examples, as are peer education projects or special workshops. Such approaches would benefit more able men with intellectual disabilities by providing positive reinforcement about their sexual identity (Corbett, 1994) and safer sexual behaviours. The increasing number of specialist safer-sex educational and therapeutic services for men with intellectual disabilities run by or involving gay men also offer such opportunities.

Local variations in behaviour and patterns of risk should be explored by commissioners to help predict needs and inform interventions. Factors include the proximity of more able and mobile men with intellectual disabilities to active cottages or cruising areas. Dedicated development projects can be used to map local conditions and understand how to target service interventions. Sexual health outreach for women with intellectual disabilities failed to make contact with women at risk from HIV or exploitation in public places such as pubs and commons in Wandsworth and Tooting in South West London (Cambridge, 1996c). The strategy was successfully changed to inreach into social venues and services used by women with intellectual disabilities.

Sex education should firmly place HIV as an issue and sex between men as a behaviour within mainstream sexuality work. Unless men with intellectual disabilities hear that homosexuality is a valid behaviour, then they are unlikely to talk about their own homosexual behaviours. Unless they can talk about the sex they have in a safe and confidential environment it will be difficult to relate safer sex or condom use to their own sexual experiences. Homosexual behaviour and experience has tended to be marginalised and excluded from sex educational resources and by implication devalued, despite its central importance to targeting HIV prevention. Only recently has it begun to feature at all prominently in sex-education resources and where it does it is often represented less explicitly compared with heterosexual images (Cambridge, 1997a). More representative and inclusive homosexual images of men having safer sex are necessary to take safer sex education work forward. For political and gender reasons the same is needed for lesbian images.

Case study 1

The relative invisibility of homosexuality and HIV was indicated by the difficulties encountered by services in recognising and responding to homosexuality and HIV risk reported in HIV needs assessment work in South East London (Cambridge, 1996a). This covered intellectual disability service-providers in the boroughs of Lewisham, Lambeth and Southwark in 1993. Thirteen of the 26 services responding to a survey reported that they supported men who had sex with men in public places. For the other 13 services the issue was not perceived to apply.

Sixteen men were identified as definitely cottaging (having sex in public toilets), and 18 men as possibly cottaging. Nine services (over a third of respondents) said that they had not discussed the possibility of men with intellectual disabilities having sex with men. Where they had discussed the possibility this was usually a reaction to identified behaviours, although one service did indicate pro-active recognition in relation to developing a sexuality policy. Services were also asked to describe the HIV risk behaviour of the men in the sample. Descriptions ranged from open discussions with users who told staff about their cottaging, where it was known users cottaged, to being seen around public toilets, charging for sex, or less specific responses such as spending long periods outside the service in places such as parks or simply away. A number of very high HIV risk behaviours were identified in this process (see Cambridge, 1996a).

In relation to HIV risk management, services were also asked whether the men had sex with other men or women with intellectual disabilities. Table 1 reports the responses. Nearly 90% of men (30) definitely or possibly had sex with other men with intellectual disabilities (14 and 16 respectively), while a sizeable proportion definitely or possibly had sex with women with intellectual disabilities. This suggests major HIV risk management implications for services and suggests that many women with intellectual disabilities may also be at significant HIV risk from their sexual encounters with men with intellectual disabilities.

Table 1 Men with intellectual disabilities who have sex with men: prevalence of sex with other men or women with intellectual disabilities

| | <i>Number</i> | <i>Percentage</i> |
|----------------|---------------|-------------------|
| Other men | | |
| Definitely | 14 | 41 |
| Possibly | 16 | 47 |
| Definitely not | 3 | 9 |
| No response | 1 | 3 |
| Women | | |
| Definitely | 7 | 21 |
| Possibly | 13 | 38 |
| Definitely not | 7 | 21 |
| No response | 7 | 21 |

When asked whether the user was having sex which put him at risk of HIV infection, responses reflected high levels of uncertainty. Over three-quarters of the sample were reported as possibly having sex which put them at risk of HIV. Four men were said to be definitely having unsafe sex and four men definitely

not having unsafe sex (the research was unable to validate this assessment, such as whether the potential for acquiescence in the non-use of condoms was considered). It was evident from the responses, however, that many providers do not hold a refined understanding of safer sex and HIV risk, are not able to explore such questions with users and hence, have not developed basic risk assessment skills.

For each of the men in the sample, services were also asked how they had responded to his sexuality and sexual behaviour (Table 2). Multiple responses were given in many cases, indicating that a mix of input and support was often provided.

Table 2 Service responses to identified HIV risk behaviours

| | <i>Number</i> | <i>Percentage</i> |
|--------------------------|---------------|-------------------|
| Keeping at home | 4 | 12 |
| Supervision when out | 3 | 9 |
| Assertiveness work | 14 | 41 |
| Check for STD | — | — |
| Counselling for HIV | 8 | 24 |
| HIV antibody test | 1 | 3 |
| Referral to psychologist | 2 | 6 |
| Referral to GP | — | — |
| Other referral | 3 | 9 |

Although this information gives little detail about the quality of response or the resources for which referrals were made, important considerations emerge. Keeping someone at home or supervision when out may be an attractive immediate response, but the longer-term appropriateness of such aversive options should be challenged. Similarly, the possible consequences for the individual and the wider implications of HIV testing, such as confidentiality and anxiety, suggest extreme caution with such a response (Cambridge, 1996b). Overall, the evidence from this research points to the need for the development of more consistent and coordinated local responses to assessing and managing HIV risk. Similar to observations about prevalence work in sexual abuse (Turk & Brown, 1993), poor skills in recognition make it likely that survey results represent a significant under-estimate of need.

Conflicts Between Rights and Responsibilities

Policies have the daunting task of developing management and practice guidelines for HIV which safeguard and promote the individual rights of service-users and address the responsibility of services to promote HIV protection. Moreover, individuals also have a responsibility not to sexually abuse, exploit or expose others to HIV risk, which services also have a duty to promote.

Just as people with learning difficulties have as much right as anyone else to express their sexuality, they also have as much responsibility as anyone else to do it in a way which is not offensive or abusive. (McCarthy & Thompson, 1992: 3)

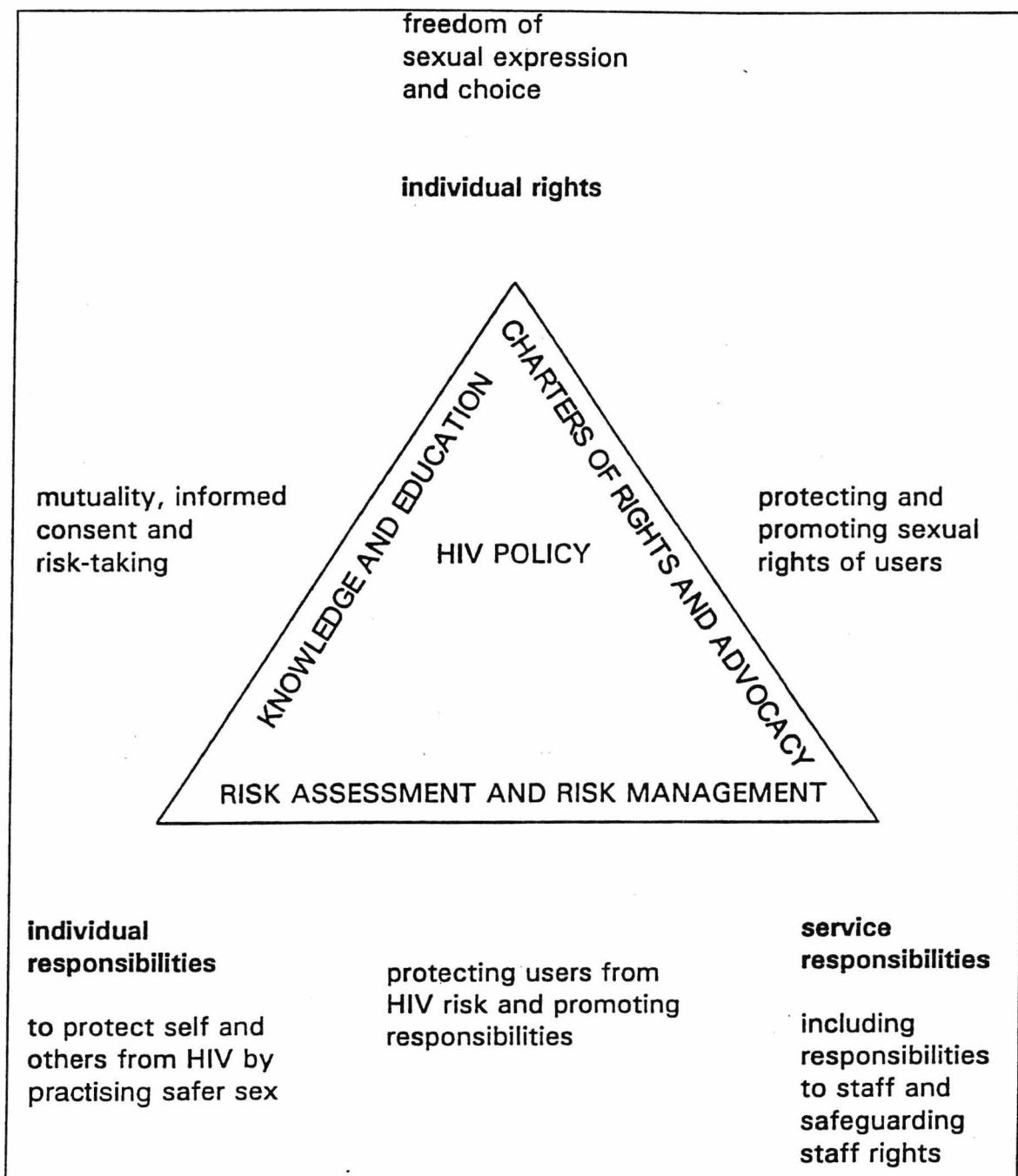


Figure 2 Conflicts between rights and responsibilities in HIV and intellectual disability

Figure 2 illustrates the potential for conflict between rights and responsibilities. The solution has usually been seen as balancing individual rights with responsibilities, the rights of one service-user with another, or the responsibility of services to protect users from undue risk or harm with considerations of freedom and independence.

Services are struggling to find the balance between rights and the need for risk-taking for individuals who perpetrate sexual abuse and the rights and need for safety of the wider group. (McCarthy & Thompson, 1996: 212)

Such an approach has been fundamental to management and practice in sexuality and intellectual disability and policy in HIV should not skirt the imperative to demarcate areas of responsibility. One of the reasons for conflict is that services have been unwilling to draw lines between rights and responsibilities, preferring a dangerous balancing act. Three main foci for articulating rights and responsibilities are evident from Figure 2, and policy needs to address each directly to effectively manage conflict. Boundaries and priorities will vary according to person and place because of unique individual needs and service situations and policy should look to identify such differences. In relation to the use of pornography for instance, some consider services have a responsibility to actively discourage its use while others argue for the individual right to use pornography appropriately (Morris, 1997; Cambridge, 1996d).

Case study 2

Policies bring their own contradictions. As part of training to implement a sexuality policy for an inner North London borough (service A), the policy was examined to identify key user rights and service responsibilities and the conflicts likely to arise (Figure 3).

A number of potential conflicts are immediately apparent on reviewing this list. The right of service-users to freedom to enjoy sexuality and have it recognised by others (Right 1, which would include homosexuality and possibly high HIV risk behaviours) has the potential to conflict with the responsibility of services to be responsive to cultural and religious issues in supporting sexuality (Responsibility 1, which might not accept homosexuality or might forbid the use of condoms) or to take reasonable care of service-users (Responsibility 2, which would include protection from HIV infection).

Policies cannot eradicate such conflicts as they are based on values which may not be shared by all in a culturally diverse society. This question is being explored in relation to sex education (Malhotra & Mellan, 1996; Baxter 1996) but is particularly contentious in relation to HIV because of the use of condoms and homosexuality. However, policies should help resolve such conflicts when they do arise. Guiding principles are one way to help achieve this, although as every situation is unique they will require a different resolution.

An exercise in the sexuality training designed to help implement the policy focused on the rights of users, the responsibilities of users, the rights of staff and the responsibilities of services. Two important issues to surface were staff disclosure of their sexuality and confidentiality about HIV status.

It was generally felt by staff that their sexuality was a private issue, although gay and lesbian staff had the right to be out about their sexuality at work. If they were asked a direct question about their sexuality by a service-user, then their response would depend on the context to the question and their feelings about disclosing personal details, but lesbian and gay identified staff were considered to have the right to appropriate disclosure to service-users (see Thompson [1997] for a rationale in relation to sex education). Homophobic comments were considered totally unacceptable. On the question of HIV status, staff also had the right not to disclose this in the workplace, or if they did for reasons of employment, then they had the right to confidentiality. Similar considerations emerged in relationship to the rights of service-users, with the

Service-users have the right to:

- (1) freedom to enjoy their sexuality and have it recognised by others
- (2) support and counselling from staff in relation to their sexual experiences
- (3) experience sexual relationships with support and without unnecessary intrusion
- (4) professional support, including confidentiality, in relation to a lesbian or gay identity
- (5) have sufficient money to have the choice of buying clothes, toiletries and cosmetics
- (6) not be denied a service or discriminated against because of their HIV status
- (7) information about HIV and AIDS, transmission and safer sex
- (8) education and information about different contraceptive methods
- (9) parenthood and the choice not to have children
- (10) know the limits of acceptable sexual behaviour for their own protection

Services have the responsibility to:

- (1) be responsive to cultural and religious issues in relation to supporting sexuality
- (2) take reasonable care of its service-users, including preventing physical harm and injury
- (3) ensure that pornography is restricted to private use and not promoted within the service
- (4) help ensure sex is consenting and mutual for a person with an intellectual difficulty
- (5) provide formal sex education programmes for all children and young people with intellectual difficulties
- (6) treat sex between two men or between two women with respect and support
- (7) facilitate social opportunities, including the help of an escort
- (8) cater for people's privacy
- (9) support masturbation in an appropriate place through individual care programmes
- (10) provide access to condoms in all residential establishments

Figure 3 User rights and service responsibilities

addition of the right to information about HIV and safer sex and support for homosexuality. Service-users were also seen to have the responsibility not to place other service-users at risk of HIV infection.

HIV Risk Assessment and Management

Policies should also provide guidance on assessing HIV risk and defining consequences for risk management. Figure 4 illustrates the hierarchy of conflict

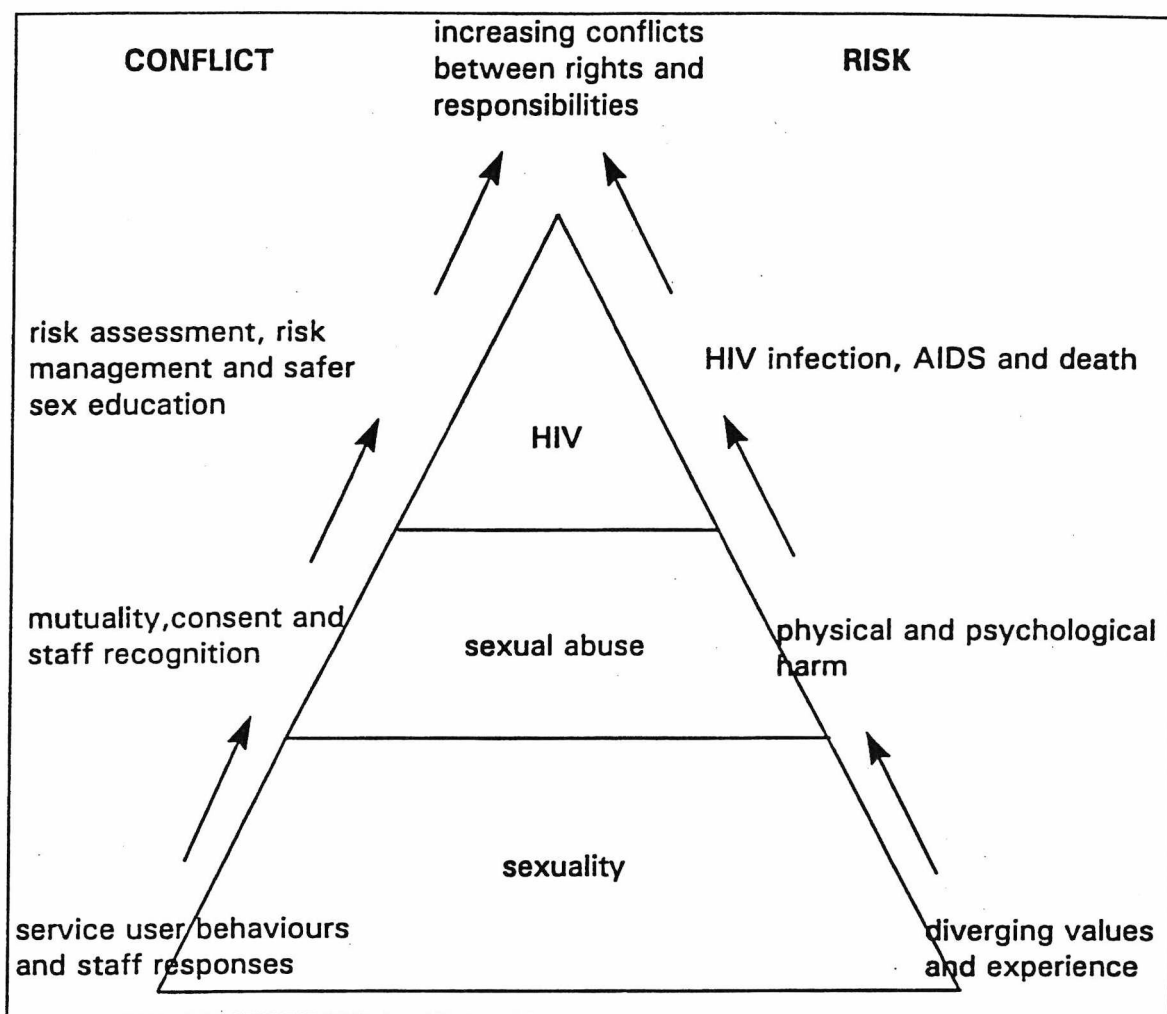


Figure 4 Hierarchy of conflict and risk in sexuality and intellectual disability

and risk for HIV management. Sexuality generates conflict because of diverse individual experiences and attitudes and the gap between socialised attitudes and sexual behaviours. There are ways policy in intellectual disability can be designed to address attitudes and their impact on practice, such as through staff training (Cambridge & McCarthy, 1997). Conflict and risk become more acute when sexual abuse or exploitation is concerned, because physical and psychological harm can come to individuals (Brown *et al.*, 1995). HIV infection is potentially a more extreme risk, because health and life are invariably at stake, placing it at the apex of the sexual risk pyramid. However, risk management can be skewed by the nature of HIV risk, particularly its invisibility and the relatively long time-scales between risk behaviour and the health consequence of HIV infection, such as lowered immunity or AIDS.

Individual rights to sexual activity and opportunities for sexual expression have to be judged in relation to the risks involved for the person and others and lines need to be drawn for prioritising service responses. So far services have mainly developed these skills in relation to recognising and responding to sexual abuse (see Brown *et al.*, 1995). For example, if a man with intellectual disabilities sexually abuses another person with intellectual disabilities, action is taken. The abuse is reported according to procedures and the reporting officer takes the work forward with staff and managers. If necessary, an investigation is

conducted to establish the nature and extent of abuse and whether other people have been abused. The abused person is supported and protected from further abuse and people may be notified on a need to know basis. The abuser may be removed from the service and/or given support concerning his abusive behaviour and staff may be counselled.

HIV policy should articulate similar responses for assessing and managing HIV risk, taking due account of the rights of individuals and their responsibilities to others. Drawing a bold line between acceptable and unacceptable HIV risk is impossible, as people approach personal risk assessment and develop risk management strategies and priorities from very different experiences and emotional circumstances. Work by Davies and colleagues (Davies *et al.*, 1993; Hunt *et al.*, 1993; Hickson *et al.*, 1992) demonstrates a wide variety of sexual and social behavioural responses to HIV risk and changing responses over time. There are complex costs and benefits to sex and sexual encounters which are difficult to elicit, but services *can* ask some basic questions about people's understanding and appreciation of sex, HIV and AIDS, safer sex and HIV risk to help ascertain whether risk-taking is informed and/or the nature of possible HIV preventive or management interventions along the following lines:

- Do they know they are putting themselves at risk of HIV (that they can get HIV from sex)?
- Do they know they can still have sex and reduce their risk of HIV (safer sexual alternatives to penetrative anal or vaginal sex)?
- Do they know about safer sex (when and how to use condoms during penetrative sex)?

If the answer to any of these questions is no, then intervention is needed to provide additional education and support. Moreover, if there are wider disincentives to practising safer sex (such as lack of access to condoms or pressure not to use them from a partner), more complex service responses are likely to be required, sometimes involving more than one service-user. Without such a basic assessment the service cannot assume that users are making an informed choice about having safer or unsafe sex or are knowingly putting their sexual partners at risk. There are further questions that can be used to help fine tune service responses to risk management. These include:

- Do they understand what HIV is and how it is easily transmitted through unprotected anal or vaginal sex?
- Do they know that *they can get* HIV from unprotected anal or vaginal sex, whether they are penetrating or being penetrated?
- Do they know that *they can give* HIV to someone from unprotected anal or vaginal sex, whether they are penetrating or being penetrated?
- Do they know that HIV leads to AIDS and that AIDS is an illness that people die from?

If the answers to one or more of these questions is yes, then this may mean that the person is acting irresponsibly in the knowledge of HIV risk to themselves or others, as they have an understanding of some of the ways to reduce risk. But the explanations for high HIV risk sexual behaviours may be deep and complex (Morris, 1997), and work may be needed with individuals on a number of fronts

for sustained periods of time. Services have a duty of care and that sometimes means protection if the person is unaware or unconcerned about the risks involved to themselves or others.

An argument that short-term measures should be taken to restrict or eliminate the behaviours which lead to high HIV risk can be constructed. If someone was going out on their own and getting beaten up, the service would seek to stop this happening, but like other risks such as smoking, in HIV the nature and consequences of risk are sometimes perceived differently. A number of key questions about the imperative to respond to HIV risk can, however, be asked to help determine the nature of intervention.

- Is the contact mutual or exploitative? If it is exploitative, then there is a clear case for intervening to stop it, regardless of HIV risk.
- Is the behaviour high risk? If they are having unprotected anal or vaginal sex then there is clearly a significant risk to be managed, whereas oral sex or other sexual contact could be assessed as low risk and requiring a lower priority intervention.
- Does the person at risk know about safer sex and are they physically able to practice it? If not, then they should receive intensive safer-sex education, have access to condoms and receive on-going staff support and monitoring.
- Is the person at risk able to insist on safer sex and that they or their partner(s) use condoms for high-HIV-risk activities such as penetrative anal or vaginal sex? If not, then they should receive information on HIV and counselling, safer-sex education and training for negotiating skills and assertiveness.

This reduces to the responsibility of services to take steps to minimise HIV risk to the individuals they support and the ability to demonstrate through intervention and programmes that they have taken reasonable steps to educate people about risk, to assess informed consent, to provide appropriate supports and to minimise opportunities for exploitation. The equation is also about people's rights, however, and service-users should be enabled to express their sexuality and practice the sex they like in rewarding ways whenever this does not conflict with service responsibilities to protect people from undue risk (Cambridge, 1996d). This should be achieved through safer sex education and HIV counselling, rather than policing sexuality or restricting consenting and mutual sexual activities (Cambridge, 1996d: 15).

Legal and moral considerations

Considerations of individual and carer liability help focus policy priorities. With litigation increasingly used as a form of redress by service-users and their relatives, managers should address their responsibilities for minimising the spread of HIV infection. If a person with intellectual disabilities knowingly risks transmitting HIV there is a risk of criminal liability. An example is where an HIV antibody positive status is known or an HIV risk assessment indicates a high probability of HIV infection and the person is known to be having unprotected anal or vaginal sex (which carries a high risk of transmitting HIV) with another person. Although it might be difficult to prove intent or recklessness on the part

of the person with intellectual disabilities, under certain circumstances a carer or service might also be held responsible

a carer, who allowed a person with HIV and with a learning disability to infect a sexual partner with HIV, might also commit the offence committed by the person with intellectual disability. This would follow only if it could be said that the carer had the right to stop the sexual activity which does not follow in all cases. It may be the case that the relationship between the carer and the person with a learning disability is so much one of dependence and inability on the part of the person with a learning disability that the obligation to interfere might arise. (Gunn, 1997: 148)

Whatever the legal risk, an ethical case for intervention exists. A service which knowingly allowed someone to cause physical or sexual harm to another person would be failing in its duty of care. The same principle has to apply to HIV risk and harm. Although the skill, management and resource consequences of responding to HIV risk provide disincentives, the much stronger rationale for responding on both moral and legal grounds has to be firmly embedded in policy.

There are wider legal questions which may produce conflicts of interest and moral dilemmas. There are laws in relation to sexuality, such as rape which apply to everyone, laws in sexuality and intellectual disability which make sex with someone with a severe intellectual disability illegal (Sexual Offences Acts, 1956, 1967; see Gunn, 1996) and laws in relation to HIV which can be applied and interpreted in relation to intellectual disability (Gunn, 1997). There are also laws which discriminate against homosexuality between men, such as the age of consent (which is 18 as opposed to 16 for heterosexual sex) and the circumstances in which sex is considered private. Other homophobic laws have attempted to forbid the public services from representing homosexuality in a positive light (Section 28 of the 1988 Local Government Act), such as in an educational context, but have proved unusable.

All these laws have potential management and practice implications for services for people with intellectual disabilities. The problem facing staff and service managers is that many of these laws are difficult to interpret or case evidence is minimal, some discriminate against people with intellectual disabilities or men who have sex with men and others act as disincentives for best practice, because they may cause anxiety, hesitation or reluctance to respond on the part of support staff or some educators.

Laws in relation to homosexuality and obscenity warrant particular attention. During training staff often assert that they are unable to work with men with intellectual disabilities who have sex with men through fear of breaking the law. There is no law which would make working with someone on issues such as informed consent, the provision of information on HIV or safer sex education, illegal. There have been no prosecutions relating to the use of explicit safer sex educational materials depicting erect penises or anal sex because such materials are not designed to corrupt and there is a 'public good' defence. Staff training should, therefore, make clear that explicit safer sex educational materials representing homosexuality between men are not only justified in relation to rational practice and safer-sex educational criteria but are not illegal in relation

to the obscenity or corruption laws. Best practice would suggest that the educator should feel comfortable using such images and that the intervention would be in response to assessed needs and part of an openly agreed programme (Cambridge, 1997b).

The complex social and medical implications of HIV antibody testing and their implications for informed consent from a person with an intellectual disability have been identified (Tachell, 1994; Cambridge, 1996b). As Gunn (1997) has observed

Two difficult issues associated with having a test for HIV arise. These are concerned with the consequences which might flow from having a test. First, consequences flowing from the simple fact of having the test, and second, the consequences where there is an HIV positive result (Gunn, 1997: 141).

Policies should make it clear that HIV testing is dangerous territory because it is difficult to assess informed consent and if informed consent can be demonstrated, an HIV test amounts to battery and assault. The implications of testing for the individual and the service are difficult to predict, particularly in relation to confidentiality. The person being tested also needs to understand the nature of the test itself, so there are also laws of negligence in relation to the provision of information to consider (Gunn, 1997).

There are clearly potential conflicts of interest in assessing informed consent by the commissioning or providing service and policies should reflect this danger by recommending independent assessment. Although there are issues of competence to consider for GUM (genito-urinary medicine) services, as they may not be skilled at working with people with intellectual disabilities, joint work in tandem with specialist sexuality, educational and therapeutic services for people with intellectual disabilities also provides an effective model.

Principles for Policy

The facility for resolving conflicts and designing individualised service responses are the guiding principles which guarantee standards for practice.

Case study 3

Policy principles were established in work to develop an HIV policy for a major provider of residential, housing and staff support services for people with intellectual disabilities in an inner South London borough (service B). Figure 5 summarises the ten key principles adopted.

What do such principles mean in practice? Promoting the sexual health of service-users means at its simplest, providing information about HIV and AIDS through safer sex education and encouragement and on-going support to practice safer sex. Specialist staff should have the knowledge and competence to deliver sex education on an individual or group basis. Responsibility for assessing and managing HIV risk means that service-users have a right to support to reduce their risk of HIV infection and express their sexuality in safe ways. Service responses to HIV risk should be empowering rather than controlling. Commissioners have a duty to ensure needs assessment at the

- (1) The organisation and its staff have a responsibility to promote the sexual health of service-users
- (2) The organisation and its staff have a responsibility to assess and manage the risk of HIV infection in relation to the sexual and other behaviours of service-users
- (3) The organisation and its staff should not discriminate against service-users on the basis of their known or suspected HIV status.
- (4) The organisation, staff, agents or service-users should not discriminate against staff on the basis of their known or suspected HIV status.
- (5) People receiving the services of the organisation or its employees are entitled to confidentiality and support in relation to their HIV status.
- (6) People employed by the organisation are entitled to confidentiality and support in relation to their HIV status.
- (7) People supported by the organisation should be discouraged from seeking an HIV test until valid consent has been given.
- (8) Service-users should be informed of their rights in relation to sexuality and HIV and also their responsibilities in relation to safer sex.
- (9) Staff should be informed of the policy and its implications for their work and supported in putting the policy into practice.
- (10) A named individual should be skilled and available to help implement the policy and respond to the needs of staff or users.

Figure 5 HIV policy principles

authority level and to specify and purchase specialist sex educational services which can be accessed by provider organisations.

Providing organisations should ensure they promote non-discriminatory practices in relation to the provision of services and other resources such as staff support for the people who use services, regardless of suspected or known HIV status. Infection control precautions should anyway be taken during personal care and day-to-day support and procedures guarding against Hepatitis B are more than adequate in relation to HIV. There should similarly be non-discriminatory employment practices and support for staff. Employees should not have to put up with discrimination in relation to their sexuality or known or suspected HIV status.

Service-users who disclose their HIV positive status to managers or staff should have this treated confidentially. Other staff should only be informed of the HIV status of service-users on a *need to know* basis or with the expressed and informed consent of the service-user according to criteria laid down in a policy. Users who are HIV positive or at risk of HIV have the right to respect and dignity. This means that they are entitled to receive counselling in relation to their HIV status or HIV risk. Staff who disclose their HIV positive status to colleagues should also have this treated confidentially and support should be made available.

Staff should not encourage a service-user to have an HIV antibody test and informed consent should be assessed independently of the service if a service-

user expresses a wish to have an HIV test. People have a right to full information about the advantages and disadvantages of HIV antibody testing, including the possible consequences and implications of testing positive. They are likely to need to understand the differences between HIV and AIDS before consent is informed. More widely this means that service-users should have straightforward information in the form of words and pictures which explain their rights to them or which staff can use with them to help structure and convey their rights and responsibilities.

To help policy implementation, staff should receive training to understand the policy, its values and what it aims to achieve. They should have a basic knowledge of HIV and AIDS and safer sex and their implications for supporting people with intellectual disabilities. To this end, staff have a right to access to information and support from managers in relation to how HIV and AIDS impinges on their work and practice. One solution is to train a key service coordinator or contact outside the service with the necessary skills who can be accessed or consulted about the policy and who can give advice on how to respond and what action to take in particular situations. However, it is important that dialogue is also developed with line management, supervision and teamwork to prevent workers and issues from becoming isolated.

Coordinating Policy and Practice

Respect for the individual, privacy and confidentiality are valued in western society and are frequently articulated into rights (McCarthy & Cambridge, 1996; Cambridge, 1996d). There are ethical and legal obligations of confidentiality, particularly in relation to HIV positive status. It is, therefore, essential that considerations of confidentiality, disclosure and need to know are addressed by HIV policies. A useful mechanism is an HIV coordinator, whether issues concern help with risk assessment, professional advocacy or confidentiality. This approach can be modelled on the investigating officer role in sexual abuse (Brown *et al.*, 1995). Staff with information or concerns about HIV risk or risk behaviour could approach the HIV coordinator without disclosure to colleagues. It may be decided that there are good reasons to inform line managers or other staff, for example in situations where

- someone working with the sexual partner of a person who is suspected or found to be HIV positive would need this information to help with risk assessment, risk management or providing safer-sex education to the partner;
- a designated support worker might need to help a service-user who is HIV positive with their diet, medical check ups or attending outpatients clinics;
- A service or line manager might be accountable for possible consequences or implications of particular risk situations and need to know about the legal implications of different interventions;
- it would be the job of a service manager, care manager or broker to help with securing appropriate services for the person and coordinating appropriate social and health care inputs if made aware of the situation.

Responsibility for making such decisions and deciding on *need to know* should lie with the HIV coordinator and line managers. In some cases, the HIV coordinator may also need to consult with outside advisors. Indeed, an alternative model is for the provider to commission coordinated input from a specialist worker in a local HIV, sexual health or advocacy service for people with intellectual disabilities. An ideal scenario would be a joint local appointment across health and social services with the brief to pump-prime new specialist local services, staff training and policy development.

It is evident from the above that service-users have a right to information and safer sex education and services have a responsibility to protect people from HIV risk, partly through group and individual educational strategies (McCarthy & Thompson, 1992). There are examples of how information on HIV and AIDS can be disseminated to service-users and staff (Cambridge, 1996e, f) and policies can establish such rights to information. The following case example illustrates a considered response to managing rights and responsibilities through clear prioritisation. It is also important to acknowledge that decisions are sometimes made on the basis of only partial information and that service responses will often need to be flexible and priorities change to adapt to emerging knowledge:

Case study 4

- *Part 1* A young man with intellectual disabilities is known to regularly cottage in a local park. He discloses to his keyworker that he often has receptive oral and anal sex with different men but rarely do those men use condoms. The service response should initially aim to reduce the risk of HIV infection by safer sex education and counselling about HIV risk and transmission. Condoms would be made available or he would be helped to buy them. He would demonstrate his intention to use them and the reasons for this and there would be an attempt to monitor his success in practising safer sex. If this did not work then there would need to be more intensive therapeutic or psychological interventions. At some point the other risks of his behaviour, such as the legal situation and risk of getting beaten up would also need to be explained. Intervention would also need to explore issues of sexual identity and self-image and alternative opportunities to express his sexuality or socialise in less isolating situations.
- *Part 2* It is subsequently found this man occasionally has sex with an older man with intellectual disabilities in the service who he penetrates anally. If this was found to be consenting on the part of the other man, if the other man could confirm extra strong condoms and water-based lubricants were used and was aware of the importance and reasons for practising safer sex and if the sex was in an appropriate place then there would be no need to intervene. If it was found to be exploitative of the older man then there is clearly a case to intervene to stop it. If the younger man refused to use condoms and the older man was unaware of the risk, then there would be a case to intervene to provide intensive safer sex education and support for the older man and counselling for the younger man about his responsibilities to practice safer sex.
- *Part 3* It is also subsequently disclosed that this man has regular vaginal sex with a young woman with intellectual disabilities. She considers him to be

her boyfriend and has had minimal sex education and does not know about HIV or safer sex. She wants the relationship to continue. He considers the relationship to be casual. There would need to be intensive counselling work with the man on issues relating to his responsibilities to practice safer sex and on personal and emotional relationships. His responsibility towards others for HIV and emotional risks would need to be addressed. The young woman would need intensive individual work on safer sex and contraception and on-going support in relation to her emotions and feelings. She should be helped to become more assertive and independent of him and make informed decisions about continuing the relationship based on the different risks involved for her, as she is unlikely to have given informed consent knowing his behaviour and HIV risk. She should demonstrate her intentions and ability to insist on protected vaginal (and other high-risk) sex.

Conclusions

Despite lead agencies, commissioning and care management, providers often find themselves in situations where their practice demands that they take the initiative in key areas of policy development and the implementation of new procedures and guidelines. (Cambridge & McCarthy, 1997)

HIV policy is still embryonic in services for people with intellectual disabilities and commissioners and providers still have much to learn about developing and implementing such policies. In many cases the initiative is coming from providers who see at first hand the emerging demands HIV is creating for management and practice and who anticipate the consequences of doing nothing or responding in an *ad hoc* or reactive fashion.

Policies in HIV and intellectual disability cannot and should not attempt to list answers to all possibilities, situations and scenarios. Experience is accumulated by individuals and organisations and policies should enable staff to use their experience effectively, facilitate the acquisition of new skills and competencies and develop foresight and flexibility to changing circumstances.

Policies should set a floor to standards and principles for practice, which should aim to help people enjoy healthy and safe sexual lives. These are ambitious aims for services and staff, but policies should provide the procedures, guidelines and management conditions to enable a start to be made. In summary, the following priority guidelines for managing individual rights and service responsibilities are offered

- (1) People with intellectual disabilities have the right to sexual expression, including homosexuality. They have a right to staff support for sexuality and to sex and safer sex education. *Where a person with an intellectual disability is at risk of HIV, the priority concern should be for sexual health and access to condoms, education, assertiveness and other resources to help the person express their sexuality in ways which are safe to them and others.* This should over-ride other considerations such as culture or religion which may conflict with homosexuality or the use of condoms.
- (2) The right to sexual expression ultimately includes informed risk taking in relation to HIV infection when this has been assessed. *It would need to be*

demonstrated that educational and other interventions have been made and that risk management has been addressed in individual programmes. Ultimately, however, the practice of safer sex is a decision for individuals and if able to understand the potential implications of unsafe sex then there is limited scope for intervention considering the priority of (1) above.

- (3) The responsibility of protection would take priority when the person is not in a position to understand the potential implications of high-HIV-risk sexual behaviours and/or is not able to give informed consent to sex in the first place. *Services have a responsibility to intervene to stop high HIV risk sexual behaviour when this puts the person or another person with intellectual disabilities, who is unable to take informed risks in relation to HIV, in a position of vulnerability.*

Correspondence

Any correspondence should be directed to P. Cambridge, Tizard Centre, University of Kent at Canterbury, Kent CT2 7LZ, UK. E-mail: P.Cambridge@tizard.ukc.ac.uk

References

- Baxter, C. (1996) Sex education: Ethnically sensitive services to people with intellectual disabilities. *Tizard Learning Disability Review* 1 (4), 13–16.
- Brown, D. (1991) HIV infection in persons with prior mental retardation. *AIDS Care* 3 (2), 165–73.
- Brown, H. and Cambridge, P. (1997) Policies and their contribution to coherent decisionmaking. In P. Cambridge and H. Brown (eds) *HIV and Learning Disability*. Kidderminster: British Institute of Learning Disabilities.
- Brown, H., Hunt, H. and Stein, J. (1994) Alarming but very necessary: Working with staff groups around the sexual abuse of adults with learning disabilities. *Journal of Intellectual Disability Research* 38, 393–412.
- Brown, H., Stein, J. and Turk, V. (1995) The sexual abuse of adults with learning disabilities: Report of a second two year incidence survey. *Mental Handicap Research* 8 (1), 1–22.
- Cambridge, P. (1994) A practice and policy agenda for HIV and learning difficulties. *British Journal of Learning Disabilities* 22 (4), 134–9.
- Cambridge, P. (1996a) 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 (3).
- Cambridge, P. (1996b) Assessing and meeting needs in HIV and learning disability. *British Journal of Learning Disabilities* 24 (2), 52–7.
- Cambridge, P. (1996c) Evaluating sexual health outreach work for women with learning disabilities. National Association for the Protection from Sexual Abuse of Adults and Children with Learning Disabilities, Bulletin 15, March 1996.
- Cambridge, P. (1996d) *The Sexuality and Sexual Rights of People with Learning Disabilities: Considerations for Staff and Carers*. Kidderminster: British Institute of Learning Disabilities.
- Cambridge, P. (1996e) *HIV and AIDS and People with Learning Disabilities: What You Need to Know about HIV and AIDS*. Kidderminster: British Institute of Learning Disabilities.
- Cambridge, P. (1996f) *HIV and AIDS and People with Learning Disabilities: Guidelines for Staff and Carers*. Kidderminster: British Institute of Learning Disabilities.
- Cambridge, P. (1997a) How far to gay? The politics of HIV in learning disability. *Disability and Society* 12 (3), 427–53.
- Cambridge, P. (1997b) *HIV, Sex and Learning Disability: A Staff Training and Safer Sex Educational Resource for Working on HIV and with Men with Learning Disabilities who have Sex with Men*. Brighton: Pavilion.

- Cambridge, P. and McCarthy, M. (1997) Developing and implementing sexuality policy for a learning disability provider service. *Health and Social Care in the Community* 5 (3), 227-36.
- Chan, C. (1996) Combatting heterosexism in educational institutions: Structural changes and strategies, In D. Rothblum and L. Bond (eds) *Preventing Heterosexism and Homophobia*. London: Sage.
- Corbett, J. (1994) A proud label: Exploring the relationship between disability politics and gay pride. *Disability and Society* 9 (3).
- Davies, P., Hickson, F., Weatherburn, P. and Hunt, A. (1993) *Sex, Gay Men and AIDS*. London: Falmer Press.
- Davies, S. (1997) A provider perspective. In P. Cambridge and H. Brown (eds) *HIV and Learning Disability*. Kidderminster: British Institute of Learning Disabilities.
- Dent, J., Vergnaud, S. and Piachaud, J. (1994) HIV infection and people with learning disabilities. *The Lancet* 343, 919.
- Gunn, M. (1996) *Sex and the Law: A Brief Guide for Staff Working with People with Learning Difficulties*. London: Family Planning Association.
- Gunn, M. (1997) The law, HIV and people with learning disabilities. In P. Cambridge and H. Brown (eds) *HIV and Learning Disability*. Kidderminster: British Institute of Learning Disabilities.
- Hickson, F., Davies, P., Hunt, A., Weatherburn, P., McManus, T. and Coxon, A. (1992) Maintenance of open gay relationships: Strategies for protection against HIV infection. *AIDS Care* 4 (4), 409-19.
- Hunt, A., Weatherburn, P., Hickson, F., Davies, P., McManus, T. and Coxon, A. (1993) Changes in condom use by gay men. *AIDS Care* 4 (4), 439-48.
- Jones, J. (1993) Men with learning difficulties and cottaging, Saturday seminars. London: North West Thames Regional Health Authority.
- Kastner, T., Hickman, M. and Bellehumeur, D. (1989) The provision of services to persons with mental retardation and subsequent infection with HIV. *American Journal of Public Health* 79, 1-4.
- Kastner, T., Nathanson, R. and Marchetti, A. (1992) Epidemiology of HIV infection in adults with developmental disabilities. In A. Crocker, H. Cohen. and T. Kastner (eds) *HIV Infection and Developmental Disabilities*. London: Brookes.
- King, E. (1993) *Safety in Numbers*. London: Cassell.
- Kitzinger, C. (1996) Speaking of oppression: Psychology, politics and the language of power. In D. Rothblum and L. Bond (eds) *Preventing Heterosexism and Homophobia*. London: Sage.
- Malhotra, S. and Mellan, B. (1996) Cultural and race issues in sexuality work with people with learning disabilities. *Tizard Learning Disability Review* 1 (4), 7-12.
- Marchetti, A., Nathanson, R., Kastner, R. and Owens, R. (1990) AIDS and state developmental disabilities agencies: A national survey. *American Journal of Public Health* 80, 54-6.
- McCarthy, M. (1994) Against all odds: HIV and safer sex education for women with learning difficulties. In L. Doyal., J. Naidooi. and T. Wilton (eds) *AIDS: Setting a Feminist Agenda*. London: Taylor and Francis.
- McCarthy, M. (1997) HIV and heterosexual sex. In P. Cambridge and H. Brown (eds) *HIV and Learning Disability*. Kidderminster: British Institute of Learning Disabilities.
- McCarthy, M. and Thompson, D. (1992) *Sex and the 3 Rs: Rights, Responsibilities and Risks*. Brighton: Pavilion Publishing.
- McCarthy, M. and Thompson, D. (1994) HIV/AIDS and safer sex work with people with learning disabilities. In A. Craft (ed.) *Practice Issues in Sexuality and Learning Disabilities*. London: Routledge.
- McCarthy, M. and Thompson, D. (1996) Sexual abuse by design: An examination of the issues in learning disability services. *Disability and Society* 11 (2), 205-17.
- McCarthy, M. and Cambridge, P. (1996) *Your Rights about Sex: A Booklet for People with Learning Disabilities*. Kidderminster: British Institute of Learning Disabilities.
- Morris, S. (1993) Protect and survive. *Community Care* 30 December, 12-13.
- Morris, S. (1997) Experiences of risk: The role of therapy in sexual health. In P. Cambridge

- and H. Brown (eds) *HIV and Learning Disability*. Kidderminster: British Institute of Learning Disabilities.
- Murray, J., MacDonald, R. and Minnes, P. (1995) Staff attitudes towards individuals with learning disabilities and AIDS: The role of attitudes towards client sexuality and the issue of mandatory testing for HIV infection. *Mental Handicap Research* 8 (4), 321–32.
- NHPIS (1996) London: Health Education Authority, National HIV Prevention Information Service.
- Nichol, J. (1997) HIV prevention and health promotion. In P. Cambridge and H. Brown (eds) *HIV and Learning Disability*. Kidderminster: British Institute of Learning Disabilities.
- Rooney, M. (1994) *Information File*. London: HIV Project, North Thames Regional Health Authority.
- Ross, M. (1996) Societal reaction to homosexuality: Culture, acculturation, life events and social supports as mediators of response to homonegative attitudes. In D. Rothblum and L. Bond (eds) *Preventing Heterosexism and Homophobia*. London: Sage.
- Tachell, P. (1994) *Safer Sexy*. London: Freedom Editions.
- Taylor-Laybourn, A. and Aggleton, P. (1992) *HIV Health Promotion Needs Assessment for Men who have Sex with Men in Camberwell: Final Report*. London: King's Healthcare.
- Thompson, D. (1994) Sexual experience and sexual identity for men with learning disabilities who have sex with men. *Changes* 12 (4).
- Thompson, D. (1997) Safer sex work with men with learning disabilities who have sex with men. In P. Cambridge and H. Brown (eds), *HIV and Learning Disability*. Kidderminster: British Institute of Learning Disabilities.
- Turk, V. and Brown, H. (1993) The sexual abuse of adults with learning disabilities: Results of a two year incidence survey. *Mental Handicap Research* 6 (3), 193–216.

Ref. 2.3.b.

Brown, H. and Cambridge, P. (1997) Policies and their contribution to coherent decisionmaking, In P. Cambridge and H. Brown (Eds.) *HIV and Learning Disability*. (pp.159-181), Kidderminster, British Institute of Learning Disabilities.

Chapter 11

Policies and Their Contribution to Coherent Decision Making

by Hilary Brown and Paul Cambridge

The aim of this chapter is to outline the contribution which policies can make in the area of HIV and learning disability and also to set out the pitfalls and limitations of written guidance. Policy needs to be enshrined in a number of documents and reflected in day to day practice and management decisions. In this chapter we look at the function of such guidance for developing coherent strategies and setting out how, and by whom, decisions should be made. These statements of intent and structure aim to influence implications for the values and attitudes of staff in services and the opportunities for safer sex education which are made available to service users. Lastly we look at the need for agreed measures for managing HIV risk in services, offering a model set of service principles.

Not Just a Piece of Paper

The term policies is used in the plural as this indicates that we need a many faceted approach. A policy on HIV which is a single document often filed in the bottom drawer of a dusty cabinet, is not going to be enough. A series of interlocking statements are needed which address process, action and outcomes. These will need to include inter-agency relationships, decision-making mechanisms and other forums for learning and discussion. They will also need to address different audiences and target appropriate guidance to people at different levels in the organisation and the other agencies concerned. The audiences should explicitly span the range of interests in the learning disability community and certainly include users, direct care staff, carers, provider managers, workers in specialist HIV and sexuality services, commissioners and care managers. Some sexuality policies have been developed by explicitly drawing on such a range of interests (Cambridge & McCarthy, 1996).

Later sections of this chapter examine detailed considerations for policy in relation to underlying principles, confidentiality and safer sex education.

Specific issues to be covered are likely to include:

1. principles
2. how to use the policy
3. background information on HIV and AIDS
4. housing and support needs
5. confidentiality
6. HIV antibody testing and informed consent
7. assessing and managing risks
8. housing and support rights
9. safer sex education
10. training
11. inter-agency working.

The function of policies should be to structure the way the plans and situations of individual users are approached. They should therefore set the parameters within which staff, both in their individual work and collective discussions make professional judgements and implement shared decisions. In a contentious area, such as sexuality, they also serve to protect individual workers when they make potentially unpopular but principled decisions and to protect the rights of users to sexual expression as well as to protection from exploitation or undue HIV risk.

By creating a structure which establishes general principles *and* sets out how and by whom decisions should be made, the service will effectively own decisions and take shared responsibility for them. This is a vital outcome in any area which demands risk-taking and supportive, rational and coherent management. Individual members of staff would otherwise feel burdened by the weight of decisions or individual service users would be at risk of capricious or inconsistent decisions if each individual member of staff acted according to his or her own values and judgements.

The ideal would be for very specific individual guidance to be given to staff regarding a particular user or circumstance, where responses have been worked out collectively and to the greatest possible extent, in partnership with the user whose life it concerns. Such guidance should clearly reflect the overall philosophy of the service and therefore appear rational to staff, even if they disagree with particular aspects of a decision.

Policies which fail usually attempt to be all things for all people, by trying to anticipate every scenario in which choices might need to be made and setting out detailed prescriptions or instructions for responding. Sometimes situations

arise often enough for a generic statement to be useful, for example the first formal guidelines on sexuality published by Hounslow Social Services (1981), made a general 'rule' that if an adult with learning disabilities wanted to be included in a sex education programme and, after consultation, their parents disagreed, then the person's own decision would stand and be supported by the service. A floor to practice was therefore set which would apply in all such cases. Few issues are however, so clear cut or so easily foreseen. The risk with an over-prescriptive policy is that it ties staff into decisions which are overly standardised, blunt and which fail to acknowledge individual needs and circumstances. Similarly, there will be unique cultural aspects and nuances such as religion or ethnicity which need to inform service responses.

Conversely, under-prescriptive policies risk devolving ambiguity and delegating anxiety to those with least power in the system. One staff member interviewed about sexual abuse policies characterised her agency's policy as:

'an uncomfortable fence-sitting exercise, neither addressing the rights of the individual well or fully addressing issues relating to staff protection.' (Brown, Hunt & Stein 1994, p.401).

Such a policy may set lofty ideals but leave people with too much leeway to resolve the issues and conflicting interests in practice. Where there is no *right way*, if policies and procedures are seen or used as a way of covering manager's backs rather than supporting front-line staff, they soon fall into disrepute and disuse.

It is therefore sensible that when individual decisions are the focus of written policy it is more important to set out how to go about making them than to catalogue rules to cover every eventuality. The aim must be to set very clear parameters and channels for communication in order that responsibility is referred upwards as specific guidance and support is passed back down (or across from other agencies). This does not mean that decisions should be taken at a distance from users and direct carers, but that they should be supported and put into practice by those who have the most expertise and resources.

The Function of Policies

Good practice is reflected in individual decisions and planning, the resourcing of relevant options and the development and deployment of staff awareness and expertise. Enabling all staff to tap into a shared pool of information is a vital starting point. Staff may well hold information in different compartments. They may not consider people with learning disabilities to be sexual and hence not sense the risk to them of unsafe sex (Cambridge, 1994). They may be ill-

informed about homosexuality or hold homophobic attitudes. They may be unaware of users individual rights in relation to their sexual lives (see Cambridge 1996a). They may not know about the transmission of HIV, the difference between HIV and AIDS or basic information about safer sex (see Cambridge, 1996b). They may not know about local GUM services (special clinics or genito-urinary medicine clinics where people go for advice about or treatment for, sexually transmitted diseases, including HIV counselling and testing). This need for information is particularly acute in relation to sexuality which is still often treated on a *laissez-faire* basis, as if no intervention from staff would of itself guarantee maximum autonomy for service users. But as the literature demonstrates, without coherent and well planned interventions, people with learning disabilities face their sexual lives with no preparation or support, they risk becoming victims of sexual abuse (see Brown, Stein & Turk, 1995), of having one sided and unpleasurable relationships (see McCarthy, 1994), abusing others (see Charman & Clare, 1992) or having unsafe sex (see Cambridge, 1996c). Therefore the goals of any policies in this area need to include the co-ordination of specialist and generic agencies to create and support opportunities for people to learn about sexual relationships and health in a respectful and explicit way.

A first task, in the new complex web of service agencies which have developed since the introduction of the market in social care, is to identify where expertise currently lies and how it can be accessed. As Paul Cambridge argues in Chapter 1, a bridge needs to be created between specialist HIV agencies and specialist learning disability agencies. Models of joint-work and mutual consultation need to be piloted and developed, as James Nichol has explored in Chapter 3. A balance needs to be maintained between strategic commissioning of service options which require pump-priming and more flexible spot contracts which can be put in place in response to particular needs or situations. Joint commissioning should be explored where a specialist service is likely to be needed by too few users within any one area to be viable or in relation to those services which have both health and social care elements within them.

Accessing specialist advice or services for individuals can be complex and policies should set out at what level such decisions should be taken. Where there are several possible routes into a service, for example, via a GP or a care manager, local guidelines should be developed and collaborative relationships established. Often the critical issue is not only *who pays* but *who knows* about the service and its appropriateness.

Levels of Decision-Making

Good practice in this area involves several distinct elements:

- the creation of a positive sexual culture especially one which redresses discrimination and the frequent *invisibility* of same sex activities and relationships;
- the provision of specialist, explicit sex education and safer sex education for individuals and groups, which is adapted to their needs for information and sensitive to their ways of understanding (particularly important for men with learning disabilities who have sex with men because of the relative lack of such images);
- the capacity to work *with* some individuals to help them to manage risk and on *behalf* of others (such as those who cannot consent or who do not have the capacity to protect themselves) and to protect more vulnerable people from abuse;
- the provision of counselling and HIV testing services to people who may have HIV, which support them emotionally and empower them to access medical services and continue to have safer sex, both for their own and other peoples' health;
- the co-ordination of services to people who have HIV related illnesses, who are ill with AIDS, who need domiciliary or buddy services or who have to receive hospital or hospice based treatment or care.

Mainstream services for people with learning disabilities have tended to address only the first two elements and even then in a patchy way. Although many gay identified men work in sexual health and HIV prevention, including self help and voluntary services and although many bring their experiences of working on HIV and AIDS and their knowledge and commitment into their particular specialisms in the learning disability community, there remains a need for befriending, peer safer sex education and other support links between the learning disability and the gay communities.

Values and Action

Many policies attempt to influence the *culture* of services and to safeguard civil liberties in relation to sexual rights, but the reality is that values are contested within services as much as they are within society at large. Moreover, users themselves may hold conservative views even when these are in conflict with their experiences or behaviours. Heyman and Huckle (1995) document the pervasive disapproval of sex and sexuality by parents and carers which characterises the backgrounds of many people with learning

disabilities and which may well be the source of these attitudes; and Thompson (1994) relates the reluctance of men with learning disabilities to talk about sex with men during sex education.

Moreover there are few consistent ethical frameworks to draw on. Normalisation presents a very muddled view of sexual options (see Brown 1994): men who have sex with men need to challenge and seek to reframe ordinarily *valued options* so as not to adapt to society's devaluation or stereotypical views of their sexuality nor to simply replicate heterosexual norms by wrapping them in a *lesbian or gay* cloak.

Different formulations of the principle (see Emerson 1992) place varying emphases on conformity and difference: the North American model argued that people who were already at risk of being devalued because of their disability, should court normalising or status enhancing activities and possessions according to a *conservative corollary*, whereas the Scandinavian model was framed more in terms of rights but within a more segregated context.

The law also provides a contradictory backdrop in that it discriminates against homosexuality between men in relation to the age of consent (18 as opposed to 21) and the provision of what amounts to a private place (the circumstances under which sex is legal), as well as a host of other social and economic irregularities that without general anti-discriminatory legislation, apply to lesbian and gay lifestyles and access to a range of services and resources. It is also at risk of being discriminatory in relation to people with severe learning disabilities who are deemed not to be able to give their consent. The aim of this legislation was to protect people from abuse and exploitation, but it is a blunt instrument when it comes to determining capacity to consent to specific acts within specific circumstances or relationships. Services find the legislation difficult to interpret and to work within, as has been demonstrated by Simon Davies in Chapter 4. The *blanket prohibition* which is effectively established by the law is one which many service workers would challenge, although it provides the only legal protection against abuse or exploitation to some very vulnerable people (see Brown & Turk 1992). A citizenship model would recognise people with learning disabilities as adults with rights which they exercise from a position of multiple inequalities and might include poverty, ethnicity *and* sexuality. But this kind of framework could only work if services develop competence in assessing the functional capacity of individuals to make decisions and take risks. Until services can do this on behalf of individuals there are grave risks in abandoning the safety net provided by current legislation (see also

Michael Gunn's account in Chapter 10).

The extent to which the sexual attitudes of staff towards people with learning disabilities (and specifically towards men with learning difficulties who have sex with men) can be modified through policies is questionable. Rose and Holmes (1991) reported that training was effective to some extent, but Brown, Hunt and Stein (1994) report that within the gendered (and one might also argue by extrapolation *heterosexist*) hierarchies of staff teams, attitudes are more likely to be shaped by real experience than by written guidance. Where staff had passed on concerns to management for these to be dismissed out of hand, they developed a kind of siege mentality which led them to conceal concerns about sexual behaviour and/or to act alone and from personal conviction in seeking to encourage or suppress particular behaviours. It is for this reason that policy development work in sexuality has sought to elicit staff views and experiences at an early stage (see Cambridge & McCarthy, 1996). Positive policy-making needs to be backed up by the explicit sharing of responsibility to assure openness and consistency. Box 1 identifies the main reasons why some policies tend to fail.

Box I REASONS SOME POLICIES FAIL

- not disseminated
- too vague or long winded
- contain contradictions between rights and responsibilities
- not backed up with individual planning
- staff lack skills or support
- not implemented with training
- few or no guidelines for practice
- divorce front line staff from managers
- pass the buck to direct care staff
- actual contingencies work against policy
- lack of agreement or ratification
- perpetuate inter-agency confusion
- lost in the new contract culture
- do not reflect the reality of users' experiences and needs
- have no internal co-ordination or focus for responsibility
- do not acknowledge what they cannot achieve
- are not reviewed or updated with experience
- do not help resolve the problems faced by staff

Safer Sex Education

There is an increasing choice of well grounded materials and models of service delivery for sex education and counselling in schools (see David Stewart, Chapter 9), hospital settings (see McCarthy & Thompson, 1992) and specialist counselling services (see Stephen Morris, Chapter 7). Policy and written guidance has the task of ensuring staff know *who* can refer people to these services and *how* to go about it. Moreover many services provide sex education in-house or in the context of self advocacy or other group work. When this is done a proper supervision process should be in place and clear operational boundaries set up with regard to time, place and confidentiality. One obvious area for innovation is to include safer sex education in all such interventions. Where information is offered by care staff within the context of an ordinary caring relationship this should also be discussed in supervision sessions and referenced in individual planning records, as should any sexual behaviour directed towards care staff which is experienced as abusive or inappropriate. We need to remember that such behaviour may be an indication of sexual activity, consenting or non-consenting elsewhere.

Sex educators also need clear guidance about the limits to their role and expertise. They should understand under what circumstances they might need to break confidentiality, for example if a disclosure of abuse, abusing or of high HIV risk behaviour, were offered by an individual in a one to one session or by a group member. They should also be clear about when to refer an individual to more specialist support or assessment (for example to a psychologist). Moreover they should be able to access support and input for themselves, for example through formal supervision or external consultation, such as from a speech therapist who might advise on communication or the choice of appropriate materials or an advisor from a specialist organisation if they need guidance or support about a specific issue, such as challenging sexual behaviour.

Identifying people who need support and/or who are sexually active is a prerequisite for facilitating appropriate access to safer sex education. Staff often assume people with learning disabilities are asexual because they do not have the confidence to develop relationships but they also persist in this view even when faced with evidence to the contrary, by minimising or trivialising sexual relationships or even sexually abusive acts when these are witnessed. Men who have sex with men are particularly likely to hide their sexuality or to lack positive role models (Thompson, 1994 & Cambridge, 1996c). In services which have a strong commitment to equal opportunities, lesbian or gay staff

will feel able to share their knowledge and awareness of same sex relationships and sexuality to inform positive work with users. In other services they may be silent and invisible.

Who Manages Risk?

By the time an issue becomes framed in terms of risk management it is almost inevitable that decisions should be shared across professional and agency lines. Where individuals are able to benefit from information and support to help them limit risks to themselves or others, that judgement will need to rest on a psychological assessment and be supported by representatives of the purchasing agency responsible for the person's care (such as the care manager or commissioner). Services which fail to *notify* risk, lay themselves open to allegations of negligence in the event that someone is harmed. Managed and acknowledged risk is an essential alternative to *post hoc* justifications and excuses: it ensures that ongoing risk can be reassessed and intervention considered again if individuals are unable to protect themselves or continue to behave in ways which poses a risk to others (Simon Davies in Chapter 4 presents a worked example of this kind of power sharing). Action can be taken informally or under Mental Health Legislation if unacceptable risk levels continue from the point of view of an individual's own or another person's behaviour.

People with significant intellectual impairments may not be able to manage high risk situations for themselves, or to consent to participation in sexual activities, medical testing or treatment. A service which fails to note this, hiding behind *empowering* rhetoric allows the reality to allude them. There is nothing empowering about being either out of control or in the grip of other more powerful individuals. The risk manager should draw up a clear contract with the provider agency and through the management line, with direct carers. This should stipulate the degree of supervision or intervention deemed necessary and what signals are to act as a trigger for re-evaluation of the situation and a re-design of the risk management strategy. It is in such situations that advocacy and representation for the individual becomes especially important, as it can help to ensure that any measures taken are in the person's best interests, balanced and regularly reviewed.

Professional judgements may need to take precedence over legal options here and shared planning is the only context within which these can be developed. Supervision or chaperoning of individual men should not take place without clear evidence that it is necessary and a clear rationale as to how it will be

implemented. A service instituting such interventions must be prepared to justify its decision on the grounds that it is in the man's best interest, or in the interests of others (see Brown & Thompson, in press). But what do we need to know to help to take such decisions forward?

Competence in HIV risk assessment is a pre-requisite to informed HIV risk management. Individual rights to sexual activity and opportunities for sexual expression have to be balanced against the risks involved for the person and other people, as much for HIV as for sexual abuse or lower order risks such as crossing the road on the way to the Post Office, which can be equally life threatening. Although people with learning disabilities do not live in a different moral or ethical world, we have a responsibility to acknowledge and respond to their social economic and emotional marginalisation, which makes them particularly vulnerable to these sorts of risk. So far services have developed these skills mainly in relation to recognising and responding to sexual abuse, largely as a result of the work of Brown and colleagues (Brown, Turk & Stein, 1995). For instance, if a man with learning disabilities sexually abuses another person with learning disabilities this is not ignored. Action is taken:

- The abuse is reported according to procedures.
- The reporting officer takes the work forward with staff and managers.
- If necessary an investigation is conducted to establish the nature and extent of abuse and whether other people have been abused.
- The abused person is supported and protected from further abuse.
- People may be notified on a *need to know* basis.
- The abuser may be removed from the service and/or given support concerning his abusive behaviour.
- Staff may be counselled, and so on.

We need the competence to articulate similar responses to managing HIV risk, taking due account of the rights of individuals, the responsibilities of services and the responsibilities of individuals towards others. Service responses will also need to vary according to the nature of HIV risk. The responses to managing HIV risk for men with learning disabilities who have unsafe sex in public toilets (Cambridge, 1996c), varied from keeping people at home or supervising people when out (and in one case included an HIV test for the person) to assertiveness work and HIV counselling. The former would clearly reduce HIV risk by restricting high risk behaviours or limiting opportunities, but would also directly affect the right to sexual expression and opportunities to meet people, move independently and interact in the wider community.

Services therefore need to decide on appropriate responses when they discover someone they support is putting themselves at risk of HIV. But it will be almost impossible to assess what level of risk is reasonable by extrapolating from our own personal responses, as people approach risk assessment and risk management very differently at an individual level. Priorities depend on the various circumstances, demands and preferences in their lives, as there are complex costs and benefits to sex and sexual encounters and the assessment of associated risks. What services *can* do however, is ask some basic questions about peoples' understanding and appreciation of sex, safer sex and risk.

- do they know they are putting themselves at risk of HIV (that they can get HIV from sex)?
- do they know they can still have sex and reduce their risk of HIV (safer sexual alternatives to penetrative anal or vaginal sex)?
- do they know about safer sex (when and how to use condoms during penetrative sex)?

If the answer to any of these questions is no, then the service clearly needs to intervene to provide additional education and support. Moreover, if there are wider disincentives to practicing safer sex (such as access to condoms or pressure from a partner), more complex service responses are likely to be required. Without such a basic assessment the service cannot assume that the user is making an informed choice about having unsafe sex. There are further questions that can be used to help fine tune service responses to risk management. These include:

- do they understand what HIV is and how it is easily transmitted through unprotected anal or vaginal sex?
- do they know that they *can get* HIV from unprotected anal or vaginal sex, whether they are penetrating or being penetrated?
- do they know that they *can give* HIV to someone from unprotected anal or vaginal sex, whether they are penetrating or being penetrated?
- do they know that HIV leads to AIDS and that AIDS is an illness that people die from?

If the answers to one or more of these questions is yes, then this may mean that the person is acting irresponsibly in the knowledge of risk as well as some of the possible ways to respond to reduce risk. But as we have heard from Stephen Morris in Chapter 7, the explanations for risk behaviours may be deep and complex and work may be needed with individuals on a number

of fronts and this work may need to be sustained for long periods of time. We have seen similar messages from Michelle McCarthy and David Thompson (Chapters 6 and 5) that a long term approach is similarly desirable for sex education. But services have a duty of care and that sometimes means protection if the person is unaware or unconcerned about the risks involved. An argument could be constructed that short term measures should be taken to restrict or eliminate the behaviours that lead to high HIV risk. If someone was going out on their own and getting beaten up, the service would seek to stop this happening, but like other risks such as smoking, the nature and consequences of the risk are sometimes perceived differently, in that they are seen not to demand an immediate response.

A service which knowingly allowed someone to cause physical or sexual harm to another person would be failing in its duty of care. The same principle has to apply to HIV risk and harm. Although the management difficulties and resource consequences of responding to HIV risk need to be acknowledged to help to remove disincentives to recognition, the much stronger rationale for responding on both moral and legal grounds (as Michael Gunn has demonstrated in Chapter 10) has to be firmly embedded in policy, hence the imperative to respond to HIV risk and to determine the nature of the person's risk-taking and an appropriate response or intervention.

In an ideal world people would respond to knowledge about whether they might have HIV and how they can avoid giving it to someone else if they do have it. This knowledge would need to be based on a reasonable understanding of the nature of their own risk and risk behaviours, both past and present and the potential consequences of unsafe sex for themselves or others. They would also need to demonstrate an understanding of AIDS, illness and death and the links between unsafe sex and HIV transmission. This is a complex chain of inter-connections and possibilities, and can be more simply approached by asking:

- is the contact mutual or exploitative? If it is exploitative, then there is a clear case for intervening to stop it, regardless of HIV risk.
- is the behaviour high risk? If they are having unprotected anal or vaginal sex then there is clearly a significant risk to be managed, whereas oral sex or other sexual contact could be assessed as low risk and requiring a lower priority intervention.
- does the person at risk know about safer sex and is she or he physically able to practise it? If not, then they should receive intensive safer sex

education, have access to condoms and receive ongoing staff support and monitoring.

- Is the person at risk able to insist on safer sex and that they or their partner(s) use condoms for high HIV risk activities such as penetrative anal or vaginal sex. If not, they should receive counselling and education for negotiating skills, assertiveness and HIV.

This relies on services taking steps to minimise HIV risk to the individuals they support and having the ability to demonstrate through intervention and programmes that they have taken reasonable steps to educate people to risk, assess informed consent, provide appropriate supports and minimise opportunities for exploitation. The equation is also about peoples' rights, however, and people should be enabled to express their sexuality and practice the sex they like in rewarding ways whenever this does not conflict with service responsibilities to protect people from undue risk. Safety should be assured whenever possible through safer sex education and HIV counselling, rather than policing sexuality or restricting consenting and mutual sexual activities (see case study below).

Principles for Policy

We have identified ten key principles which we believe should underpin and inform policy in HIV in learning disability services and which can be used to help map the more detailed content of policies. These are presented below in the form of statements of principle, followed by a brief exploration of the implications for practice.

1. Services have a responsibility to promote the sexual health of service users. This means providing information about HIV and AIDS, safer sex education and support and advice in practising safer sex and/or reducing high HIV risk behaviours. Staff and service users should have access to appropriate safer sex education resources and use them as identified and laid out in the policy. Service users who are sexually active, at risk of HIV infection or worried about HIV or AIDS have a right to safer sex education and information about the transmission of HIV.

2. Services and staff have a responsibility to assess and manage the risk of HIV infection in relation to individual service users. This means that staff should have broad skills in recognising and assessing risk of HIV infection and be able to respond and manage risk in appropriate ways to protect vulnerable users from unacceptable risk. Specialist staff should

have the knowledge and competence to practice this principle. Service users have a right to support in reducing their risk of HIV infection and in helping them to manage risk, without compromising their rights to sexual expression. Service responses to HIV risk should, wherever possible, be empowering rather than controlling.

3. Services and staff should not discriminate against service users on the basis of their known or suspected HIV status. This means that there should be non-discriminatory policies and practices in relation to HIV, the provision of services, and other resources (such as staff support) for service users. For instance, no service user should be excluded from appropriate services or have staff support withdrawn on account of their HIV status. Service users have a right to appropriate and equivalent services and support regardless of their HIV status or of the unfounded opinions of staff about people with HIV or the risk of HIV transmission.

4. Staff should not be discriminated against on the basis of their known or suspected HIV status. This means that there should be non-discriminatory employment practices and staff support. Employees should not have to put up with inequitable treatment or disadvantage in relation to their known or suspected HIV status and have the right to be treated equally and fairly. They should not be subject to insult or abuse, whether from other staff or service users and should have access to management support and counselling services.

5. People receiving services are entitled to confidentiality and support in relation to their HIV status. This means that service users who disclose their HIV positive status to managers or staff should have this treated confidentially. Staff should only be informed of the HIV status of service users on a need to know basis according to criteria laid down in the policy. Users who are HIV positive have the right to respect and dignity, including privacy and confidentiality. They are also entitled to receive counselling in relation to their HIV status.

6. People employed by services are entitled to confidentiality and support in relation to their HIV status. This means staff who disclose their HIV positive status to colleagues or managers should have this treated confidentially and under no circumstances should such information be disclosed to service users. Staff who are HIV positive have the right to respect and dignity, including privacy and confidentiality. They are also entitled to receive counselling and specialist support in relation to their HIV status.

7. People supported by services should be discouraged from seeking an HIV test unless informed consent can be independently validated. This means that staff and managers should not persuade or encourage a service user to have an HIV antibody test unless they are satisfied that the individual is prepared for this and both able and willing to consent. Informed consent should be assessed independently of the service and people have a right to full information about the advantages and disadvantages of HIV testing, including the possible consequences and implications of testing positive.

8. Service users should be informed of their rights in relation to sexuality and HIV and also their responsibilities in relation to safer sex. This means that service users should have straightforward information in the form of words and pictures which explain their rights directly or as part of a programme introduced by staff which conveys their rights and responsibilities. These include the right to have safer sex and the responsibility to practice safer sex.

9. Staff should be informed of the policies and their implications for practice and supported to implement relevant guidance. This means staff should receive training to understand the implications of policy statements, setting out service values and how these can be achieved. They should have a basic knowledge of HIV and AIDS and its implications for people with learning disabilities. Staff have a right to access information and support from managers in relation to how HIV and AIDS impinges on their work and practice.

10. There should be a named service contact competent at providing advice and support and implementing policy. This means a key service contact or outside practitioner available to all staff who is able to explain policy and offer advice about interpretation. This would include risk assessment, risk management, confidentiality and guidance about what to do in specific situations. They would have the competence and knowledge to respond in line with the agency's policy and its aims and procedures.

Addressing Confidentiality

Every person has a right to privacy and respect about their lifestyles and sexuality including people with learning disabilities supported by community based services (McCarthy & Cambridge, 1996). Written guidance on sexuality should outline the details and reasons for this. Not everyone chooses to talk about their sexual lives with others. Some people only tell close or trusted

friends who they know will be able to help them with difficulties or advise them what to do if they have worries or concerns. Others feel comfortable telling lots of people about their sex and relationships. Some people would prefer not to be told things about someone else's sexuality. It is therefore not easy to establish any hard or fast rules about this.

People with learning disabilities are no different. Sometimes service users ask staff about their private lives or about the sex they have. Staff may not feel comfortable disclosing such information or may judge it inappropriate to tell someone else. Alternatively they might feel able to respond in an open and appropriate way, feeling that the question was a natural thing to ask and that their closeness with the person as a keyworker or support worker warranted an honest response. Conversely when staff are in the position of seeking information they also need to acknowledge boundaries. Answering a question or concern a service user may have may mean asking additional questions to clarify things. If someone is embarrassed, then this should be obvious and a useful point for drawing the line of privacy. Although information shared between two individuals should be regarded as confidential unless there are clear reasons to the contrary, when one person is a service worker and the other a service user, the former has a duty to share relevant information with managers in order to ensure that a consistent approach is formulated. Information belongs to the agency rather than to individual members of staff and should be noted properly in records to ensure continuity when staff leave or their responsibilities change. The detail and type of information recorded should be subject to scrutiny, with due regard to confidentiality and access.

If someone discloses an abusive incident or unsafe sex during ordinary conversation or sex education, this will have potential implications for service responsibilities and may need to be taken further. For example, a male user discloses unsafe sex in public toilets or a woman service user sexual abuse by a member of staff or a more able service user. It is in such situations that rights and responsibilities conflict and decisions have to be made in relation to confidentiality. It is also in such situations that the support and guidance of co-ordinators in the service should be sought, not necessarily by disclosing names or breaking confidentiality. Whatever happens, the person's views should be sought and the situation explained to them.

This may not necessarily be such a dilemma as many suppose, because the keyworker or sex educator should anyway have agreed the *rules* with the

person before starting the work. There is also a big difference between telling a colleague and telling someone in the service who is also aware of the importance of confidentiality and guidelines for handling sensitive situations.

Considerations of confidentiality are particularly important in relation to sexuality and HIV, because some people have been verbally and physically abused or discriminated against on the basis of their suspected or known HIV status, or simply because of their sexuality. Not all men who have sex with men are gay identified. Some are in heterosexual relationships and identify as straight and we know that many men with learning disabilities have sex with men and that very few identify as gay (Thompson, 1994). It is therefore important that considerations about confidentiality in relation to HIV are also linked with confidentiality in relation to sexuality. This discussion can be condensed to four key points in relation to confidentiality and HIV:

1. Service users who are thought to be practising unsafe sex, sex with people from high risk groups, or other HIV risk behaviours such as injecting drug use with shared needles or dirty works (drug injecting equipment) are entitled to confidentiality.
2. Service users who have expressed a wish to take an HIV antibody test and/or for whom informed consent has been assessed as valid are also entitled to confidentiality.
3. Service users who are tested for HIV, whether the result is negative or positive, are entitled to confidentiality in relation to the test and its result.
4. Service users who have HIV or AIDS and are under the supervision of their GP or consultant at a GUM clinic for monitoring or regular check ups, are entitled to confidentiality in relation to their HIV status or related illnesses.

Staff with such information or concerns should approach the key service contact without disclosing their concerns to other people. It may be decided that there are good reasons to inform other staff, for example in situations where

- someone working with the sexual partner of a person who is suspected or found to be HIV positive would need this information to help with risk assessment, risk management or providing safer sex education to them or their partner;
- a designated support worker might need to help a service user who is HIV positive with their diet, medical check ups or attending outpatient clinics;

- it would be the job of a service manager, care manager or broker to help secure appropriate services for the person and to co-ordinate appropriate social and health care inputs.

Similarly, a service user's suspected or known HIV status should not be disclosed to another service user, as there are other ways of addressing issues of risk, protection and support. The responsibility for making these decisions and deciding on *need to know* lie with the HIV co-ordinator who should be an experienced senior practitioner and/or manager. In some cases, the HIV co-ordinator may need to consult with service managers or outside specialists/consultants.

Training Needs

There is a wide choice of sex-education and staff training resources available for addressing sexuality and HIV issues in learning disability. Training managers are usually responsible for developing training programmes and purchasing training for provider organisations and this needs to be matched to the policy, competence of staff and changing needs of service users. As with training initiatives on sexual abuse at agency and inter-agency levels (Stein & Brown, 1995) evaluation of such interventions can identify effectiveness but also any gaps in implementation. In HIV, the specialist competencies of managers and the HIV co-ordinator will need to be met, in addition to the general staff training needed to develop mainstream competence and to help implement and maintain the effectiveness of policy. Induction training for new staff should similarly reference HIV. It is often the case that staff simply need basic information and reassurance about HIV and AIDS which challenges some of the myths associated with infection and transmission (see Cambridge, 1996b).

Support staff and keyworkers who are interested in, and competent at, working on sexuality and HIV should be available to provide ongoing support and reinforce the messages from formal education, although policies will need to acknowledge that no person within the service should be expected to provide advice and support on sexuality or HIV if they do not have the motivation, or find the subject difficult or embarrassing. There are also likely to be religious or cultural reasons why some people will not wish to become involved in this activity.

The education of service users about sexuality, HIV and AIDS is an important component of policies and underpins implementation by fostering empowerment. A wide range of sex education and safer sex education resources

are available, including booklets, teaching packs, drawings and other written or pictorial materials. There is also a selection of videos, mainly designed for groupwork and sex education groups. Such resources vary in coverage, detail, key messages, social context, role models, attention to equal opportunities and the values which drive them. It is therefore important to agree on a range of resources to use for specific purposes which are in line with the principles and philosophies of the service. Some HIV and safer sex educational materials fail to represent homosexuality or safer sex in accurate ways, marginalising sex between men, despite this being a priority for HIV prevention. Those resources for sex and safer sex education considered most appropriate in terms of their usability, effectiveness and suitability should be referenced in policies and made available for training and education.

There are five key aims in relation to providing sex and safer sex education which policies and guidelines will need to address.

1. Safer sex education should be provided as an integral part of all sex education programmes designed at the individual or group levels.
2. Sex and safer sex education should be provided to all service users as part of an ongoing programme of education and support for sexuality and HIV.
3. Specialist sex and safer sex educators should be responsible for designing, delivering and reviewing the HIV elements of the programme, whether specially trained key educators from within the service or specialist educators from outside.
4. Sex and safer sex education should be provided in accordance with individual programmes agreed as part of the individual planning systems in response to assessed needs.
5. Staff involved in delivering sex and safer sex education should receive supervision and support from managers.

Case studies provide a useful device for trainers and managers who wish to examine the robustness of a policy or the competence of staff to navigate what amount to complex moral dilemmas and conflicting rights and responsibilities at the individual and service levels. It is also important to acknowledge that decisions are sometimes made on the basis of only partial information and that service responses will often need to be flexible and adapt to changing circumstances or knowledge, viz.

- A young man with learning disabilities is known to cottage regularly in a local park. He discloses to his keyworker that he often has receptive oral and anal sex with different men but rarely do those men use condoms. The service response would initially aim to reduce the risk of HIV infection by safer sex education and counselling about HIV risk and transmission. Condoms would be made available or he would be helped to buy them. He would demonstrate his intention to use them and the reasons for this, and there would be an attempt to monitor his success in practising safer sex. If this did not work then there would need to be more intensive therapeutic or psychological interventions. At some point the other risks of his behaviour, such as the legal situation and risk of getting beaten up would also need to be explained. Intervention would also need to explore issues of sexual identity, self image and so on and alternative opportunities to express his sexuality or socialise identified and discussed.
- It is subsequently found that this man occasionally has sex with an older man with learning disabilities in the service whom he penetrates anally. If this was found to be consenting on the part of the other man and if the other man could confirm extra strong condoms were used and was aware of the importance and reasons for practising safer sex and if the sex was in an appropriate place then there would be no need to intervene. If it was found to be exploitative of the older man then there is clearly a case to intervene to stop it. If the younger man refused to use condoms and the older man was unaware of the risk, then there would be a case to intervene to provide intensive safer sex education and support for the older man and counselling for the younger man about his responsibilities to practice safer sex.
- It is also subsequently disclosed that this man has regular vaginal sex with a young woman with learning disabilities. She considers him to be her boyfriend and has had minimal sex education and does not know about HIV or safer sex. She wants the relationship to continue. He considers the relationship to be casual. There would need to be intensive counselling work with the man on issues relating to his responsibilities to practice safer sex and on personal and emotional relationships. His responsibility towards others for HIV and emotional risks would need to be addressed. The young woman would need intensive individual work on safer sex and contraception and ongoing support in relation to her emotions and feelings. She should be helped to become more assertive and independent of him and make informed decisions about continuing the relationship based on the

different risks involved for her. She should demonstrate her intentions and ability to insist on protected vaginal sex.

New Partnerships

Services for people who are HIV positive, and/or have become ill with HIV related illnesses or AIDS, need to be provided in partnership with other specialist agencies with the aim of *bridging* rather than duplicating skills. Sexual health is acknowledged as a priority within the Health of the Nation strategy (1995), but work will be needed to ensure that mainstream services do not marginalise people with learning disabilities in meeting their wider targets or aims. Complex negotiations already take place in relation to health and social care needs and responsibilities and these will need to be adapted to reflect the involvement of various health and social services input to people with learning disabilities. Simpson (1994) recently reviewed access to sexual counselling services and did not find them equipped or committed to offering services to people with learning disabilities. Disability awareness may need to be built into their contracts and supported by training and appropriate consultation.

It is clear that if people with learning disabilities who are at risk of HIV, and more specifically men with learning disabilities who have sex with other men, are to have appropriate access to preventative education, support, treatment options and health services, prejudices must be dispelled. Explicit policies can provide a framework for good practice: safeguarding the civil liberties of users and setting up channels through which staff can access information, professional expertise and appropriate services. Policies fail when they try to stipulate *what* rather than *how* decisions are to be made. But they also fail if they are not clearly enshrined in contracts, job specifications and quality standards, or if the pressures of the work in new devolved and deregulated service structures militate against the sharing of responsibility. When that happens people with learning disabilities who are at risk from HIV are likely to get too little help too late. They should be helped to get the best advice, support and services, and to get them in time.

References

- Brown, H. (1994) *An ordinary sexual life?: A review of the normalisation principle as it applies to the sexual options of people with learning disabilities*, Disability and Society, 9(2), 123-144.
- Brown, H., Hunt, N., & Stein, J. (1994) *Alarming but very necessary: Working with staff groups around the sexual abuse of adults with learning disabilities*, Journal of Intellectual Disability Research, 38, 393-412.
- Brown, H., Stein, J. & Turk, V. (1995) *Report of a second two year incidence survey on the reported sexual abuse of adults with learning disabilities, 1991 and 1992*, Mental Handicap Research, 8(1)1-22.
- Brown, H. & Thompson, D. (in press) *A minefield in a vacuum: the ethics of working with men with learning disabilities who have unacceptable or abusive sexual behaviours*, Disability and Society.
- Brown, H. & Turk, V. (1992) *Defining sexual abuse as it affects adults with learning disabilities*, Mental Handicap, 20(2), 44-55.
- Charman, T. & Clare, I. (1992) *Education about the laws and social rules relating to sexual behaviour*, Mental Handicap, 20, 74-80.
- Cambridge, P. (1994) *A Practice and Policy Agenda for HIV and Learning Difficulties*, British Journal of Learning Disabilities, Vol.22, No.4.
- Cambridge, P. (1996a) *The Sexuality and Sexual Rights of People with Learning Disabilities: Considerations for Staff and Carers*, BILD, Kidderminster.
- Cambridge, P. (1996b) *HIV and AIDS and People with Learning Disabilities: Guidelines for Staff and Carers*, BILD, Kidderminster.
- Cambridge, P. (1996c) *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, Vol.40(3), June.
- Cambridge, P. & McCarthy, M. (1996) *Developing and implementing sexuality policy for a learning disability provider service*, Health and Social Care in the Community.
- Emerson, E. (1992) *What is normalisation*, in (Eds.) H. Brown & H. Smith, Normalisation: A Reader for the Nineties, Routledge, London.
- Health of the Nation (1995) *A Strategy for People with Learning Disabilities*, Department of Health, London.
- Heyman, B. &

- Huckle, S. (1995) *Learning Difficulties*, Vol.10, No.2, p.139-157.
- Hounslow Social Services (1981) *Guidelines on Personal Relationships, Sexuality and Mentally Handicapped People*, Hounslow Social Services Department, London.
- McCarthy, M. (1994) *Against All Odds: HIV and Safer Sex Education for Women with Learning Difficulties*, in (Eds.), L. Doyal, J. Naidoo & T. Wilton, AIDS: Setting a Feminist Agenda, Taylor and Francis, London.
- McCarthy, M. & Cambridge, P. (1996) *Your Rights about Sex: a Booklet for People with Learning Disabilities*, BILD, Kidderminster.
- McCarthy, M. & Thompson, D. (199) *Sex and the 3 Rs: Rights, responsibilities and Risks*, Pavilion, Brighton.
- Rose, J. & Holmes, S. (1991) *Changing staff attitudes to the sexuality of people with mental handicaps: an evaluative comparison of one and three day work shops*, Mental Handicap Research, Vol.4, No.1, pp.67-80.
- Simpson, D. (1994) *Sexual Abuse and People with Learning Difficulties: Developing Access to Community Services*, Family Planning Association, London.
- Stein, J. & Brown, H. (1995) *All in this together: an evaluation of joint training on the abuse of adults with learning disabilities*, Health and Social Care in the Community, Vol.3, No.4.
- Thompson, D. (1994) *Sexual experience and sexual identity for men with learning disabilities who have sex with men*, Changes, Vol.12, No.4.

Hilary Brown is Professor of Social Work and Community Care at the Open University. Prior to her appointment she was senior lecturer in learning disability at the Tizard Centre, University of Kent at Canterbury, where she directed a programme of research and consultancy on sexual, and other, abuse of vulnerable adults, including joint input to the first nationally funded incidence study of reported sexual abuse of adults with learning disabilities.

Ref. 2.3.c.

Cambridge, P. and McCarthy, M (1997) Developing and implementing sexuality policy for a learning disability provider service, *Health and Social Care in the Community*, 5 (4), 227-236.

Developing and implementing sexuality policy for a learning disability provider service

Paul Cambridge BA and Michelle McCarthy BA BPhil CQSW MA

Tizard Centre, University of Kent, Canterbury

Correspondence

Paul Cambridge or
Michelle McCarthy
Tizard Centre
University of Kent
Canterbury
Kent CT2 7LZ
UK

Abstract

This paper discusses a case study of the development of a sexuality policy for a learning disability service, identifies key considerations for the development process and examines the wider implications for the service. The intervention was based on a consultancy model, with external consultants who were commissioned to manage the policy development task: the stages in this process are discussed. The operational, management and practice issues that emerged as a result of the intervention and the ways in which they were resolved are described. These issues include the different interests at stake and the incorporation of the views and experiences of users, parents and direct support staff. A model for policy development, including pointers for the management of sexuality and for practice intervention is provided.

Keywords: consultancy, learning disability, organizations, policy, sexuality, training

Accepted for publication: 17 April 1996

Introduction

The Tizard Centre at the University of Kent at Canterbury was commissioned by a large provider of residential and staff support services for people with learning disabilities to develop a sexuality policy for the service. The provider had made an executive decision to develop a sexuality policy in the absence of policy guidance from the social services commissioner. Neither the social services department or the health authority had policies for the management of issues relating to sexuality (including sexual abuse and HIV) for the learning disability services, despite emerging evidence of the prevalence of sexual abuse in services. They are, however, responsible for purchasing and reviewing (Brown *et al.* 1995).

Most of the people supported by the service had experienced long periods of institutionalized living in large mental handicap hospitals before they were resettled into the community in the late 1980s. The local re-provision services were originally provided by social services and were based on an Ordinary Life (King's Fund Centre 1982), with case management

from within the service. People were supported in small group homes and home care placements. The providing arm of the service became an independent agency when the consultancy began in 1995.

As their histories might suggest, most service users are very dependent on staff for self-care and daily living, including social skills. For instance, those who attend the workshops are the most able service users, yet they need considerable staff support (emotionally, physically and intellectually) to attend.

The case study fits the purchase model of consultancy (Schein 1969), and brings with it particular demands. These include questions about the diagnosis, or rationale for the policy, the effective communication of these to the consultant and the consequences of this communication. In this case the influences of the consultants on the behaviour of individuals in the organization and the effects of the policy intervention itself. These difficulties were partly overcome by negotiations over the contract and initial task identification work with the service managers and included the essential points for agreement between the client and the change agent (Bunning *et al.* 1990).

Sexuality and people with learning disabilities

One of the reasons work in sexuality is formalized through policies and guidelines is that service providers for people with learning disabilities find sexuality a difficult issue. This is the case at the cultural level within services and in relation to individual sexual behaviours. For example, sexually inappropriate or challenging behaviour and sexual abuse are often seen as problems to be managed. However, many of these problems are themselves products of the social and physical environments constructed by services, as well as the wider ways in which sexuality is a social construct of a society that dislikes diversity, both in relation to sexuality and people with learning disabilities. Historically, people with learning disabilities have been seen, either as perpetual children who do not need to know about sex, or as sexually dangerous because they are unable to control their sexual feelings appropriately. Although work on sexuality has broken such stereotypes, the continued economic and social marginalization of people with learning disabilities, reinforced by the formalization of dependency through services, segregation and social exclusion, all act as disincentives to view and respond to their sexuality in ordinary ways. Examples are failure to recognize the needs of men with learning disabilities who have sex with men, and responding in positive ways to the management of HIV risk (Cambridge 1996a) or recognizing the rights of women with learning disabilities to have the sex they like and enjoy in emotionally and physically safe ways (McCarthy 1994). Outreach work has indicated that women with learning disabilities are likely to be vulnerable within services and segregated environments (Cambridge 1996b), whereas sex education work (Thompson 1994) and research (Cambridge 1996a) has shown that men with learning disabilities do have sex with men in public places.

Commissioners and providers therefore tend to view sexuality and sexual abuse as problems to be managed. However, the long-term answer is to empower people with learning disabilities in order that they participate more widely in society and community life, make informed and safe sexual choices and learn from their sexual experiences. Exclusion and powerlessness perpetuate the conditions which make people with learning disabilities vulnerable to sexual abuse and more generally open to exploitation. Despite an Ordinary Life (King's Fund 1982) and the Five Accomplishments (O'Brien 1987), obstacles still exist in transition to adulthood, such as lack of sex education or education for community living.

Identifying interests and stakeholders

The development of a sexuality policy for a service does not mean coming in, writing a policy, showing it to staff and managers and setting up systems for implementation. Nor does it mean listening to the views of managers, staff and service users and simply resolving differences of opinion. Part of the role of a consultant is to bring ideas and experience to help direct the work informatively. This should provide an element of objectivity, and as in the case study, include lessons transferred from research and practice.

We undertook an informal exercise designed to ensure the consultancy input could be utilized (see Patton 1986 in relation to a utilization-focused approach to evaluation) and was relevant to the needs of a range of service users and providers.

Service users

Service users comprised those people receiving the services who were not an organized or vocal group. Most were very dependent on the service and staff, although a small minority were known to have been sexually active in the past (for instance in hospital) or were currently sexually active on their own or with other people. It was decided that, if the policy were to have relevance to their lives and experiences, then their interests required to be formally acknowledged and represented in the policy development process. Involvement was fostered through sexuality workshops for users. These were conducted by the consultants with the involvement of a link member of staff.

Relatives of users

Not many users had close or regular contact with relatives, as most had lived for long periods in mental handicap hospitals before moving to the community service. However, some had parents or siblings who were socially and emotionally part of their lives, and there was an established parents' group that could be used to link into the interests of relatives. The group already met the managers of the service regularly. The consultants met the parent's group and offered a special training day on sexuality. Most parents were unavailable for a day because of work commitments or because they were elderly and unable to get out of the house for long periods. Alternative approaches were made, including the setting up of a special telephone line to receive any enquiries, questions or feedback about any concerns as a result of the regular parents' group meetings.

Service managers

The policy intervention resulted from a recognition by the managers of the service that there was a need for both structure and procedures to help manage issues relating to the sexuality of users, and to help develop consistent and valued service responses. In the past, management had tackled such issues on an individual basis and there were no procedures for reporting, managing or responding nor was it clear who was responsible for taking such action. The effective management of sexuality within the service therefore depended on available management space and the level of priority given to sexuality.

Direct support staff

Staff were in a similar position to managers, in that they had to provide support for sexually active clients and respond to the day-to-day sexual behaviours and needs of people outside practice guidelines or consistent management support. Only a handful of staff had received any previous training on sexuality and there had been no comprehensive or integrated staff training on the subject. Staff had not had the opportunity as individuals or teams to present concerns or formulate appropriate practice responses. Much, therefore, depended on the attitudes and competence of individual members of staff and their line management support.

Costs and benefits

In addition to the direct economic costs of the time of two consultants, there were additional costs, some of which can be priced and some which relate to the capacity to develop competence in dealing with sexuality. The development of a sexuality policy for a service will affect human resources in five main areas.

(1) Releasing support staff, preferably in teams, for training associated with the development and implementation of policy requires cover to be arranged for the houses or teams in question, at additional organizational and resource costs to the service.

(2) Management and administrative time is required to arrange and attend meetings with the consultants, to review progress and implementation, and solve any difficulties. There are also the additional demands placed on the agendas of ethical committees and consultation groups, such as the parents' groups.

(3) Management and practice information systems associated with introducing the policy and maintaining its effectiveness must be developed. These include risk assessment and risk management procedures,

protocols for reporting, recording and responding and practice guidelines. There may also be consequences for assessment and individual planning systems.

(4) The newly identified needs of service users must be met. These are likely to surface as a result of staff training and sex education, and relate both to additional user support needs from keyworkers, and to specialist input such as sex education or counselling services.

In addition, there are likely to be longer term and more peripheral considerations relating to the impact of the 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.

The benefits of any policy initiative will not be immediate. However, there was a broad consensus that the initiative was required, not only to respond to emerging management and practice issues in the service, but also in terms of the competence of the service in the eyes of the purchasers and its profile with other local agencies.

Staff needs

The training components of the consultancy were provided in two phases. The first phase comprised half-day training sessions designed to draw on staff experience in order to identify the topics to be covered by the policy and to provide information on the required content. This work started by exploring the influences on sexuality and finding out what staff knew about the sexual and the other relationships in which clients were involved. The identification of issues and dilemmas raised for the staff and service, including lessons and support needed, enabled the consultants to keep the work relevant to real management and practice needs, and to build in the capacity to respond to likely future needs. Case studies of staff roles and responsibilities were followed by investigation of the areas the policy needed to cover and the stance to be taken. This phase was successful in identifying a number of issues of concern. These are given below in rank order of the frequency with which they are mentioned by staff: public masturbation by male clients, sexual abuse by male clients, sex between male clients, public masturbation by female clients, sexually offensive behaviour by male clients, male clients experiencing difficulty masturbating, stripping in public, female clients being attracted to male staff, and not respecting clients privacy or dignity.

A male client cross-dressing, sexual abuse by a female client, moving victims of sexual abuse and the propositioning of staff by clients were also mentioned. The most common problem regarding sexual behaviour concerns inappropriate masturbation by male service users. Issues concerning sexual abuse, and differential power in sexual relationships are also commonly mentioned. Normally, it is predominantly male clients who are reported to present difficult or inappropriate sexual behaviour.

User needs and experiences

Sex-education groups for service users were organized, with separate men's and women's workshops. Sex education groups are a useful starting point for exploring the sexual experiences and needs of users as well as providing general information on sex. They can be organized in various different ways depending on their purpose and objectives (McCarthy & Thompson 1992). Each workshop lasted one and a half hours, with a half hour break for tea and biscuits, and was held on the same afternoon each week to establish continuity and familiarity. The workshops were held in a venue outside the service, and were designed to meet two linked objectives.

The first objective was to provide an opportunity for service users to learn about and discuss the body and sex. Space and safety was also provided to allow users to talk about their own sexual experiences and preferences, and to introduce the concepts of good and bad sex, and sex and relationships. The second objective was to identify those views, opinions and needs of service users which were relevant to the content and development of the sexuality policy. The immediate priority was to invest time in getting to know each other, gain confidence and agree ground rules and ways of working. The ground rules included the following:

- talking about anything we wanted to if it had some connection with sex education;
- arriving on time and not coming and going from the workshops;
- not telling other people at home or work people's names or what they said;
- not making fun of anyone, or laughing at them;
- letting one person talk at a time;
- letting everyone have a say;
- no shouting, swearing or hitting each other.

The sex education groups identified differences between women and men, starting with women's and men's names, the sorts of clothes women and men wear, and eventually women's and men's bodies.

When asked about the differences between men and women, one person in the men's group responded in relation to the club he used to attend,

... the men sit on that side of the room ([pointing] and the women sit on the other.

The groups went on to draw, identify and label body parts, finally talking about genitalia and the sexual differences between men and women. These discussions demonstrated that some male service users had acquired considerable sexual knowledge, including medical and common names for sexual organs and sexual acts.

The groups also confirmed that some male service users had been sexually active with women or other men, with two disclosing possibly abusive sexual contact. Discussions about good and bad sex continued amongst the men and the group considered that:

- bad sex was when you didn't want to have sex and a person said 'no', or when sex hurt;
- good sex was when both people wanted to have sex and liked it;
- you could have sex with someone without them being your girlfriend or boyfriend if you both wanted to;
- if you had a boyfriend or girlfriend you didn't have to have sex with each other if you didn't want to;
- not everyone has sex and it was OK not to have sex if you didn't want to;
- two men, two women or a man and a woman can have sex with each other.

When discussing sex and types of sex, the men's group agreed that another difference between men and women was that only women had babies and that women become pregnant when a man got on top – also called 'making a baby'. The men's group also discussed how babies develop and where they come out, as well as different ways to have sex, agreeing that it was 'OK' for a woman to get on top of a man or to have sex in other ways as well. This included masturbation on your own, or with someone else and oral sex. In particular, the groups felt that there are some private places like bedrooms or places where other people can't see you where it is 'OK' to have sex. There are also some places like living rooms, that are shared with other people, where it is not 'OK' to have sex.

The women's group had a much lower level of experience than the men's group, and there were more difficulties with communication and participation. As a consequence, topics were discussed in the women's group at a more basic and less overtly sexual level.

Overall, the workshops proved a useful way to undertake a basic assessment of where additional

work needed to be targeted, identifying gaps in knowledge or understanding. Some points are also likely to emerge in other services for people with learning disabilities. These include:

- the need for individual work with possible victims or perpetrators of sexual abuse;
- the need for ongoing work with individual users on contraception and conception;
- risk assessment and risk management for individuals in relation to HIV and safer-sex education;
- privacy and gender issues in relation to keyworking and support for personal care;
- issues relating to the procurement, availability and use of pornography;
- issues in relation to same sex relationships, as some users did not think these were right.

One of the lessons that emerged from the workshops was that there is a need for clear individual lead responsibility for addressing and resolving sexuality within the service. There is a case for involving staff, on the grounds that they may have a good knowledge of individuals and their past and present lives, and may be able to help in areas like expressive communication and signing. Conversely, the presence of staff may inhibit openness and compromise confidentiality, or the interests of users, as opposed to the service. However, precautions can be taken such as briefing and training selected members of staff.

One of the most important factors to consider is enthusiasm for the subject and the objectives of sex education and the willingness of staff to become involved. They can help co-facilitate work, and bring helpful knowledge of individual clients and local service conditions. Alternatively, independent resources such as specialist communicators or peer educators can be used, but careful thought should be given, as in any sex education context, to matching the competence of the educator with the needs of clients.

Another consideration is continuity, as many of the issues outlined above may need to be addressed on a one-to-one basis with individuals or developed through groupwork in response to the identified needs of the group. Input on assertiveness, saying no, personal relationships and emotions are likely to be high on the list of needs for both men's and women's groups, although the emphasis is likely to be different because of the ways men and women are socialized to behave sexually and emotionally.

The workshops proved both interesting and productive. Most users grasped the opportunity to participate and express interest in the work, although the less able often did not participate actively. Although

participation partly depends on demonstrating respect and confidentiality, it also hinges on individual skills and motivation. Not all people will be willing or able to participate in the same ways and it is therefore important to aim for groups of people with relatively similar skills and experiences (McCarthy & Thompson 1992).

User rights

As a consequence of direct work with service users and staff training, we decided it was important not just to talk about user rights in the policy, but to make sure these were available in a form easily referenced by staff in their day to day support work and for service users themselves. Finding ways to help close the gap between the principles behind the policy and the practice of the policy was felt to be important. A booklet was designed to cover sexual rights in plain easy to follow language. There were illustrations in the following key areas:

- touching yourself sexually is a good and normal thing to do in private (with a picture of a young man masturbating in bed under a sheet);
- explaining the difference between mutual and non-consenting sex (with pictures of good and bad touch);
- explaining that you can have sex with a man or woman and you should not feel bad about choosing someone the same sex as yourself (with a picture of two men with their arms around each other);
- explaining your right to sex education and some of the consequences of having sex (with a picture of a education session);
- saying that you should be given privacy by other people (with a picture of a member of staff knocking on a bedroom door with the person inside dressing);
- explaining that you have a right to ask for someone of your own sex to help with personal care (with a picture of a woman helping a woman to dress after a bath);
- saying that you have the right to feel safe and happy about sex and that you do not have to put up with touching you do not like (with a picture of a person in a wheelchair rejecting unwanted contact); and
- explaining how to say no to sex or touching you don't want, and whom to tell about it (with a picture of a person in a wheelchair telling a member of staff).

The themes and accompanying illustrations were selected by the consultants as reflecting the realities of sexual experience for people with learning disabilities,

as they were unable to cover every possibility. For instance, abusers were shown as men, as over 95% of known perpetrators of sexual abuse of people with learning disabilities are men (Turk & Brown 1993, Brown *et al.* 1995), and two men were portrayed in same sex situations, as this is much more common than lesbian relationships between women with learning disabilities, which (McCarthy 1993) is known to be uncommon behaviour (Cambridge 1996a).

The sexual rights of people with learning disabilities have become relatively neglected as a result of the priority given to sexual abuse and the focus on protection. People with learning disabilities have rights to sexual expression and information about bodies and sex. The need to protect people from sexual abuse and exploitation, therefore, has to be balanced with the need to protect people's other sexual rights, such as the right to information. The two aims go hand in hand, as information and language about sex can help empower people to say no or to tell someone about abuse.

The booklet has since been adapted for more general use by services and staff (McCarthy & Cambridge 1996), and can be used by services, educators and people with learning disabilities. It also compliments information on related issues for people with learning disabilities, such as on HIV and AIDS (Cambridge 1996c), the law (Hollins *et al.* 1996 a, b) and sexual abuse (Hollins & Sinason 1992, 1993). It also provides a good example of how the products of consultancy work can cross over to help mainstream competence.

Parent's needs

Workshops were organized for parents with two aims in mind: first, to explain the main aspects of the policy and their rationale; and second, to provide an opportunity for parents and relatives to express any concerns, or ask questions, about the policy as it might affect them or their relative. It would have been easy to introduce the policy without consultation, as the relatives are a small and relatively powerless group and the service held resources and responsibility for care. However, to ignore the anxieties or concerns of relatives would not have fitted with the culture of the service nor the values of the consultants. The exclusion of parents could have had implications for the future effectiveness of the policy. It would also not accord with practice which aims to include education on potentially diverse interests for the learning disability community, a strategy which has been tested in relation to information on HIV and AIDS (Cambridge 1996 d, e).

The sexuality policy was included on the agenda of the regular consultation meetings between parents and managers initiated by the service itself. The

responses of parents were almost all positive. The consultants briefly outlined the policy aims and the different aspects. Most parents welcomed the policy, expressing their experience that such a policy was required. They were often aware of the sexuality of their relatives and had difficulty knowing how to respond and what to do for the best. They expressed their strong agreement with the policy aims in each aspect. In order to give parents useful information about the policy a leaflet was also produced. This outlined the key policy aims and contacts for enquiries about concerns or complaints and included:

- an explanation as to why a sexuality policy was needed, and what it aimed to achieve;
- the values, principles and assumptions underlying the policy;
- reference to the common issues and difficulties experienced with sexuality, such as masturbation, inappropriate touching and sex education;
- information on things parents and relatives can themselves do to help; and
- mention of other policies and resources the service has to help.

Consultation

Within large organizations innovation faces special problems. As size increases there is a tendency towards greater depersonalization coupled with a decrease in lateral and vertical communication. Many employees feel like faceless numbers... (Rosenfeld & Servo 1990).

In many respects, consultation with managers and staff about the policy proved the most difficult part of the work. It was highly political in that such interventions highlight poor systems of communication between people outside provider organizations and those working within them, as well as between staff working at different levels and in different areas within organizations. The timing of the consultancy in relation to other changes was unfortunate in that the service had recently become independent from the purchaser and was relocating to new offices. These factors made it difficult for managers to give the consultancy immediate priority. We have identified three areas critical to facilitating effective consultancy input.

(1) Free channels of communication between consultants, managers and administrative staff are important. These are required to help both the service and consultants respond to changing demands.

(2) The interest and commitment of executive managers and senior managers in the service reinforces the consultancy process, as they have the potential to

sabotage or support the intervention, individually, or through service management, or committees.

(3) Working relationships between managers and support staff can affect the work of consultants, as an organizational culture characterized by lack of trust and suspicion inhibits the identification and achievement of collective goals.

There is an array of factors which are potentially relevant to managing change in organizations (Beckhard & Harris 1987) including the commitment and degree of choice for change, conflicting perceptions about the necessity of change and management control over change. All of these were encountered by the consultants. Consultants from outside the organization are in a relatively weak position to negotiate responsive support, although they can have more power in helping define the future desired state, and in managing the transition as long as they have the support of the director, or influential senior managers. We had to play by the rules of the game and the rules varied. Although while we were clearly 'followers' at the management level it was possible, partly by nature of our independence, to be enactors in training and contact with support staff:

The players usually include enactors, those who play a key role in the development of rules, enforcers, those who play an important role in the process of rule compliance, and followers, those who are primarily charged with complying with the rules (Mills & Murgatroyd 1991).

There was some argument amongst staff about whether there was a need for the policy. The more motivated staff adopted the role of enforcers. One of the lessons from the case study is that consultants should give greater thought to setting up the rules for their involvement, in terms of administrative support and the cooperation of managers. Making such expectations explicit, and having penalties in contracts, might prove an incentive for an efficient approach to achieving change and reaching desired goals.

Policy elements

The policy was drafted to reflect the different interests and views expressed, with the consultants providing an independent perspective for resolving conflicting opinions and setting best practice for dealing with sexuality issues. The initial framework was built on the opinions of staff and the experiences of service users. The following key issues were covered:

- masturbation, including how individual teaching programs should be developed, specialist teaching resources made available and guidance on the circumstances and process for teaching masturbation;
- sexual abuse and exploitation, with clear definitions of abuse and informed consent, explicit reporting procedures, protection of victims and the development of sexual and personal relationships;
- personal care and respect, such as encouraging independence, the minimum exposure of body parts, privacy, gender and intimate care, and confidentiality within the team;
- involving relatives, including what parents should and should not be told, managing requests for information from parents, support to parents on sexuality issues and informing parents if abuse has occurred;
- people with severe learning disabilities, including guidelines for determining consent, staff action, referral to other staff or services, the law on sexuality and learning disability and the responsibilities of the service;
- same sex relationships and acceptance of equality by staff support, facilitating partners to live together if they wish and responding to the expression of homophobic views by service users or colleagues;
- pornography, referencing staff roles and responsibilities, the purchasing of pornographic materials, rights of use in clarity about the use of explicit materials in sex education;
- contraception, explaining the right to choose contraception, guidelines on the use of oral contraceptives and responding to users who express a wish not to use contraception or to become pregnant;
- sex education, including access to comprehensive sex education, responding to assessed needs, training for staff and the availability and use of different sex education resources;
- privacy and confidentiality, such as staff access to information on user's sexuality, conduct when interacting with users, procedures for respecting confidentiality and privacy and providing;
- HIV and sexual health, explaining HIV and safer sex in relation to staff training and safer sex education for users, and non-discrimination on the basis of known or suspected HIV status, availability of condoms and safeguards for HIV testing.

Policy implementation

The implementation training for staff was designed as a 2-day block which could be repeated until all staff had attended the programme. Training was provided for each of six localities, within which support to people in their own homes was organized and deployed. Staff therefore had some working familiar-

ity with each other and could take their shared experiences forward in their work at the house and at local level. The trainers sought to limit numbers to about 20. Some training blocks had parallel sessions conducted in separate groups, with integrated discussion at feedback.

Introductions and ground rules are vital when giving training on sexuality. These should cover confidentiality relating to users (for instance, a client might be recognized from talking about their sexually challenging behaviour), and to staff themselves (some people will offer personal experience or preferences to illustrate points they are making). It is also vital that staff realise that there are likely to be occasions when sexually explicit language or materials are used and that they are able to safely opt out of any work or situations they find embarrassing or difficult. People with learning disabilities are not the only people who have been sexually abused or who are at risk of HIV infection. In addition, some staff will have same sex relationships or practice sexual behaviours which others find unacceptable, so it is important to respect difference, diversity and minority lifestyles.

The training was designed to provide detailed input on the main policy areas, and also to equip staff with the competence to take work on sexuality forward as the service developed in the future. The programme was designed to encompass the following issues:

- staff values in relation to different kinds of sex and relationships;
- masturbation and related issues;
- the reality of sex and relationships for people with learning disabilities;
- the sexual knowledge of people with learning disabilities (including lessons for sex education);
- assessing and using sex-education resources (including videos);
- the relative merits of different sex-education videos;
- different types of sex and relationships and the support required;
- defining sexual abuse and what makes people with learning disabilities vulnerable;
- the patterns and occurrence of sexual abuse in learning disability;
- implications of and responses to sexual abuse;
- assessing mutuality and exploitation;
- service responsibilities and user rights.

The training package was designed for the service by the consultants who delivered it. This helped to ensure consistency in the values underpinning the training and the messages the training conveyed, continuity in theme in relation to issues raised elsewhere in the consultancy, and relevance to the policy itself.

The training used a combination of paired discussion, groupwork using case studies and resolving problems, led discussion, presentations, and responses to video programs. In addition, the materials developed for existing (McCarthy & Thompson 1992, 1994) sex education and staff training packs proved particularly useful, as did a comparison of two very different safer sex videos for people with learning disabilities (SELHPS 1992, WLHPA 1994).

Emerging issues

Following the training described above we sought staff views about ways to reduce the gap between the policy and its implementation. We posed two specific questions.

(1) What does the service need to do to help implement the sexuality policy?

The responses were that the service should:

- develop guidelines and procedures for risk taking;
- listen to house staff more;
- include house staff representative(s) on the ethics committee;
- provide training for home carers;
- get to know individual clients more;
- provide sexuality and education resources for teams;
- improve staffing levels;
- encourage better team working;
- develop advocacy resources for clients.

Direct support staff recognized that just having a policy on its own without also investing in information and support systems for staff is unlikely to significantly change attitudes and behaviour. To make policies work effectively, services need to address issues relating to autonomy, line management and staff support and to the deployment of staff resources through leadership, teamworking and keyworking arrangements. Furthermore, the need for help to redress imbalances of power between services and staff on the one hand, and service users on the other was recognized, with better knowledge of users and professional advocacy and the independence self advocacy resources can promote.

(2) What training or support do staff need to help them implement the sexuality policy?

The responses were that the policy should result in:

- specialist educators or therapists being available;
- ongoing training for staff;

- the availability of nominated link personnel to coordinate work on sexuality at the service, locality and house level;
- the inclusion of sexuality and relationships in individual care, programme and service planning systems;
- the nomination and training of someone to work on sex education within the service;
- the provision of workshops for clients;
- the provision of sex and safer-sex education materials for nominated staff to use.

The staff responses and suggestions reflect how marginalized sexuality is an issue for practice in most community services for people with learning disabilities. Few services have reporting officers or specialist sex educators to respond to the demands that work on sexuality brings. Identification and recognition of need remains low because interventions at the staff and user levels such as staff training and individual planning, lack the capacity to incorporate or respond to sexuality and related issues.

There are cultural and political disincentives to meeting the sexual needs of people with learning disabilities within services and the care market (Cambridge 1996f). Contract specification rarely refers to sexuality because contracts are primarily designed to navigate the purchaser-provider divide, and usually exclude service users themselves (Brown & Cambridge 1995). The slow development of joint commissioning in learning disability (Cambridge *et al.* 1996g) also means that the commissioning cycle (Department of Health 1995, Knapp & Wistow 1992) is incomplete or fragmented. As many commissioners are without policies or purchasing guidance on sexuality, sexual abuse or HIV, it is frequently left to providers to develop the necessary competence. This requires a significant investment of time and resources as in this case study. There have also been inter-agency policy initiatives, which aim to develop competence across a whole service system. An example is the collaborative work on sexual abuse in Greenwich (Greenwich SSD 1993).

Conclusion

While sexuality is more than just an issue to be managed as part of service audit and the contract culture, we need to acknowledge that, as a medium term response, services and users will improve if good sexuality policies are implemented well. In the longer term, we need to focus our efforts on empowerment, our own attitudes as individuals to sexuality and sexual diversity, how we view people with learning disabilities and our work with people with learning

disabilities. This might involve taking practice risks, providing radical responses and challenging inequalities in economic, social-political or legal spheres. This will enable a shift from a culture of protection, of both service interests and people with learning disabilities themselves, to one of inclusion and empowerment.

Despite the existence of lead agencies, commissioning and care management, providers often find themselves in situations where their practice demands that they take the initiative in key areas of policy development and the implementation of new procedures and guidelines. This imposes additional costs and resource demands. Each member of staff is likely to require release for training, which has implications for the organization of rotas and the cost of replacement staff cover. Managers also have additional demands made of their time and on their energy, through liaison with house managers and trainers and through ongoing discussion with consultants (or in-house developers).

The practical difficulties associated with arranging sex education for service users are also considerable, and include rearranging day support services and transport to workshops. Staff support may need to be provided as concerns and anxieties often arise from users receiving confidential sex education through workshops or on a one to one basis. The training of sex educators within staff teams, and their ongoing responsibilities for liaison with staff, reporting and programme planning and direct work with users also affect team resources and relationships.

The service that formed the basis for this case study and discussion was conscious, of some, but not all, of the demands being placed on it in managing and supporting sexuality. The demand system as a trigger for organizational change (in this case policy development leading to changes in practice) is well acknowledged:

Anyone in a leadership position in a complex organization knows viscerally that the formal organization or hierarchy only partially represents it ... the true picture includes formal outside domains such as competitors, regulators and suppliers; and societal issues... (Beckhard & Harris 1987).

Increasingly, providers of services for people with learning disabilities will need to demonstrate their capacity and competence to recognize and respond to sexual abuse, assess and manage risk in relation to HIV and support users in sexual activities and personal relationships in constructive ways. These will be some of the quality audit and outcome criteria for the future evaluation of service performance and for the specification of individual contracts. Without these complex skills, providers will not be in a position of strength in relation to the demands and expectations commissioners are likely to place on them.

References

- Beckhard R. & Harris R. (1987) *Organisational Transitions: Managing Complex Change*. Addison-Wesley, MA.
- Brown H., Stein J. & Turk V. (1995) The sexual abuse of adults with learning disabilities: report of a second two year incidence survey. *Mental Handicap Research* 8 (1), 3-24.
- Brown H. & Cambridge P. (1995) Contracting for change: making contracts work for people with learning difficulties. In T. Philpot and L. Ward (Eds) *Values and Visions: Changing Ideas in Services for People with Learning Difficulties*. Butterworth-Heinemann, Oxford.
- Brunning H., Cole C. & Huffington C. (1990) *The Change Directory: key issues in organisational development and the management of change*, British Psychological Society, Leicester.
- Cambridge P. (1996a) 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 (3), 241-251.
- Cambridge P. (1996b) *Evaluating Sexual Health Outreach Work for Women with Learning Disabilities*, Bulletin No. 15. National Association for the Protection from Sexual Abuse of Adults and Children with Learning Disabilities, University of Nottingham, Nottingham.
- Cambridge P. (1996c) *HIV and AIDS and People with Learning Disabilities: What You Need to Know About HIV and AIDS*. British Institute of Learning Disabilities, Kidderminster.
- Cambridge P. (1996d) *HIV and AIDS and People with Learning Disabilities: a Guide for Parents*. British Institute of Learning Disabilities, Kidderminster.
- Cambridge P. (1996e) *HIV and AIDS and People with Learning Disabilities: Guidelines for Staff and Carers*. British Institute of Learning Disabilities, Kidderminster.
- Cambridge P. (1996f) Assessing and meeting needs in HIV and learning disability. *British Journal of Learning Disabilities* 24 (4), 52-57.
- Cambridge P., Greig R. & Rucker L. (1996g) *Care Management and Joint Commissioning in Purchasing Services for People with Learning Disabilities and Challenging Behaviour*. British Institute of Learning Disabilities, Kidderminster.
- Department of Health (1995) *Practical Guidance on Joint Commissioning for Project Leaders*. Department of Health, London.
- Greenwich Social Services Department (1993) *Recognising and Responding to the Sexual Abuse of Adults with Learning Disabilities*. Greenwich Social Services and Greenwich Health Authority.
- Hollins S. & Sinason V. (1992) *Jenny Speaks Out*. St George's Mental Health Library, London.
- Hollins S. & Sinason V. (1993) *Bob Tells All*. St George's Mental Health Library, London.
- Hollins S., Clare I. & Murphy G. (1996a) *You're Under Arrest*. St George's Mental Health Library, London.
- Hollins S., Clare I. & Murphy G. (1996b) *You're On Trial*. St George's Mental Health Library, London.
- King's Fund Centre (1982) *An Ordinary Life*. King's Fund, London.
- Knapp M. & Wistow G. (1992) *Joint Commissioning for Community Care*. PSSRU/Nuffield Institute paper, University of Kent, Canterbury.
- McCarthy M. (1993) Sexual Experiences of Women with Learning Difficulties in Long Stay Hospitals. *Sexuality and Disability*, 11 (4), 227-285.
- McCarthy (1994) Against all odds: HIV and safer sex education for women with learning difficulties. In L. Doyal et al. (eds) *AIDS: Setting a Feminist Agenda*. Taylor and Francis, London.
- McCarthy M. & Cambridge P. (1996) *Your Rights About Sex: a Booklet for People with Learning Disabilities*. British Institute of Learning Disabilities, Kidderminster.
- McCarthy M. & Thompson D. (1992) *Sex and the 3Rs: Rights, Responsibilities and Risks*. Pavilion, Brighton.
- McCarthy M. & Thompson D. (1994) *Sex and Staff Training: Sexuality, Sexual Abuse and Safer Sex*. Pavilion, Brighton.
- Mills A. & Murgatroyd S. (1991) *Organisational Rules: a Framework for Understanding Organisational Action*. Open University, Milton Keynes.
- O'Brien J. (1987) A guide to lifestyle planning. In B. Willcox and G. Bellamy (Eds). *The Activities Catalogue*. Brookes, Baltimore, MD.
- Patton M. (1986) *Utilisation Focused Evaluation*. SAGE, London.
- Rosenfeld R. & Servo J. (1990) Facilitating innovation in large organisations. In M. West and J. Farr (Eds) *Innovation and Creativity at Work: Psychological and Organisational Strategies*. Wiley, Chichester.
- Schein E. (1969) *Process Consultation: its Role in Organisation Development*. Addison-Wesley, MA.
- SELHPS (1992) *My Choice, My Own Choice*. South East London Health Promotion Service/Pavilion, Brighton.
- Thompson D. (1994) Sexual experience and sexual identity for men with learning disabilities who have sex with men, *Changes* 12 (4), 254-263.
- Turk V. & Brown H. (1993) The sexual abuse of adults with learning disabilities: results of a two year incidence survey. *Mental Handicap Research* 6 (3), 193-216.
- WLHPA (1994) *Piece by Piece*. West London Health Promotion Agency, London.

Ref. 2.3.d.

Cambridge, P., Carnaby, S., and McCarthy, M. (2003) Responding to masturbation in supporting sexuality and challenging behaviour in services for people with learning disabilities, *Journal of Learning Disabilities*, 7 (3), 251-266.

Responding to masturbation in supporting sexuality and challenging behaviour in services for people with learning disabilities

A practice and research overview

PAUL CAMBRIDGE University of Kent at Canterbury, UK

STEVEN CARNABY University of Kent at Canterbury, UK

MICHELLE MCCARTHY University of Kent at Canterbury, UK



Journal of
Learning Disabilities

© 2003

SAGE PUBLICATIONS

London, Thousand Oaks

and New Delhi

VOL 7(3) 251-266

035566

ISSN 1469-0047(200309)7:3

Abstract Masturbation is frequently referenced as a key issue for supporting the sexuality of people with learning disabilities, yet the subject has received little attention in the professional and academic literature. This article provides an overview of masturbation in relation to service responses and user support in sexuality work in learning disability more widely, drawing in evidence and experience from sex education, clinical work and staff training. Issues such as gender, sexuality, culture and consent are addressed and some of the commonly held myths and assumptions about sexuality and masturbation are challenged. The discussion and related suggestions are designed to be of value to service managers and practitioners, particularly those involved in sexuality work and one-to-one support.

Keywords challenging behaviour; masturbation; rights; sex education; sexuality policy

Introduction

There is a long discourse on the sexuality of people with learning disabilities and the development of protective and empowering support and education based on an increased awareness of sexual abuse and risks (e.g. Brown and Thompson, 1997; Brown et al., 1995; McCarthy and Thompson, 1996) and the articulation of rights and education agendas (e.g. Brown,

1980; Craft, 1983; 1987). The related research and practice debates have focused on emerging themes including HIV and homosexuality (Cambridge, 1997; 2001a); the sexuality of men (Cambridge and Mellan, 2000; Thompson, 2001); capacity to consent and consent to touch (Brown and Turk, 1992; Murphy and Clare, 1995); and the sexuality and sexual health of women with learning disabilities (McCarthy, 1998; 2001), including menstruation (Rogers, 2001) and the menopause (McCarthy, 2002a). These and related literatures in sexuality have shifted the agenda for sexuality in learning disability from one characterized by pathology and suppression to one centred on rights and empowerment, despite a continuing recognition of the prevalence of sexual abuse.

Despite this paradigm shift, relatively little attention has been paid to one of the commonest sexual behaviours, namely masturbation. This is particularly surprising as it is also the most frequently referenced presenting issue for referral to sex education for men (much less frequently, women) with learning disabilities (McCarthy, 1996) and repeatedly surfaces in staff training and clinical work (Cambridge, 2001b; Cambridge and McCarthy, 1997). Concerns are seen to centre primarily on five key and sometimes interrelated themes:

- 1 The person is considered to be unable to masturbate properly, usually meaning that it is thought they are unable to reach orgasm/ejaculate.
- 2 The person does not know how to masturbate, usually meaning that they have been observed rubbing their penis or vagina, generally through their clothes, against people or objects.
- 3 The person is doing it too much, usually meaning that the duration or frequency of the masturbation is such that staff consider that the person is losing out on social opportunities at home or in the community.
- 4 The person is inappropriately masturbating, usually meaning that they are masturbating in public or shared spaces in services, causing difficulties for staff or other service users.
- 5 The person is using inappropriate objects or means to help them masturbate, usually meaning that they are using objects not intended to aid masturbation which could hurt them.

Commonly, staff relate explanations or hypotheses they have developed to help them understand the behaviours they observe. An example is linking unsuccessful masturbation with frustration, leading to challenging behaviour (e.g. Sheppard, 1991). Challenging behaviour may also be directly linked to masturbation, such as inappropriate sexual behaviour, which may include masturbation in a public place, self-stimulation through sexual rubbing against another person or the inappropriate use of pornography

to aid masturbation. Self-injury may be linked to the use of inappropriate or dangerous objects by the person to aid sexual self-stimulation or masturbation. In such situations it may be hypothesized that their removal may lead to aggression or other challenging behaviours. Complex causal linkages may therefore be constructed between masturbation, as it presents itself or is perceived to be a problem, and challenging behaviour, so it remains important to ensure that masturbation and sexuality *per se* are not pathologized in any debate.

Overlying such considerations are issues of gender and sexuality. Masturbation is generally reported to be much more of an issue for men with learning disabilities than for women (McCarthy, 2002b). More widely it has been observed that the sexuality of men with learning disabilities is seen as relatively pathological, with a range of sexual behaviours such as homosexuality having historically reinforced such perceptions owing to homophobia (Cambridge, 1997; Cambridge and Mellan, 2000). Conversely, it has been observed that the sexuality and sexual experiences of women with learning disabilities have remained relatively hidden (McCarthy, 1999; McCarthy and Thompson, 1998). Lesbian sex, for example, is virtually invisible in services for people with learning disabilities, particularly compared with the relative visibility of homosexuality between men. Such observations are mirrored in relation to referrals to sex education in services for people with learning disabilities (McCarthy, 1996) and discussions in staff training in sexuality and learning disability (Cambridge and McCarthy, 1997).

The remainder of this article examines these issues and offers interpretations and explanations for the commonly reported difficulties associated with masturbation, with suggestions for supporting service users in masturbation and supporting staff to respond effectively.

Why masturbation is often seen as a problem

One of the main explanations for this is that masturbation is a common and frequently occurring sexual behaviour, regardless of intellectual ability. It is therefore not surprising it is often visible in services for people with learning disabilities and is consequently perceived to be a problem, regardless of related considerations such as the neglect of sex education, lack of privacy in services themselves or failure to recognize differences in culture or ethnicity (Baxter, 1996; Malhotra and Mellan, 1996; Senker, 1997). We construct and organize social and physical space and support in services for people with learning disabilities in ways where communal and collective spaces such as living rooms, bathrooms and toilets often merge along the public-private continuum with shared or individual spaces such as

bedrooms (Parkin, 1989) or in ways which are fundamentally ethnocentric. By and large, private space and culturally appropriate space are at a premium. In residential services someone may have their own bedroom, but its use may be discouraged during the day, there may be no locks on bedroom doors, and staff and other service users may not respect privacy. This is why simple messages such as a right to privacy and respect and the importance of gender in some intimate care interaction have received prominence in some educational materials (e.g. Cambridge, 1996; Cambridge and Carnaby, 2000a; McCarthy and Cambridge, 1996). Private spaces in day services or services for people with profound and multiple learning disabilities are even scarcer, and the only places available for someone to masturbate may be the toilets, which may sometimes not even have private cubicles or locks on doors.

In addition to the tendency to disrespect or disregard privacy in services for people with learning disabilities, there is also a tendency to desexualize and to deindividualize people with learning disabilities (Carnaby, 1997; 1999). This can mean that ordinary sexual behaviours, when they do surface, are interpreted as inappropriate. Masturbation, exposure of the body and homosexual tendencies were, for example, crudely referenced as behaviour problems on the Adaptive Behaviour Scale (Nihira et al., 1974, referenced and discussed in Felce et al., 1994).

How best to respond

The first steps are to clarify and accurately describe the actual behaviour and its social and physical context. Five key sets of questions can be asked about the actual behaviour, evidence and context (McCarthy and Thompson, 1998), the answers to which can be formulated into an agenda for individual work:

- 1 What is the actual behaviour or form of sexual self-stimulation? For example, is the person rubbing themselves against objects or touching their vagina or penis directly?
- 2 How do staff respond to the behaviour, and are responses consistent? For example, do some staff or staff responses seem to be more effective than others?
- 3 Does the behaviour (masturbation) vary between places or settings? If so, what factors might explain this variation?
- 4 Is there a daily or temporal pattern to the person's masturbation? If so, what might this suggest? Are there times when this does not appear to be a problem? If so, is there a ready explanation for this which might help formulate an intervention?

- 5 Is this is a new behaviour which has recently surfaced or been observed, or has it been going on for some time? If it seems durable, what interventions have already been tried out and how successful have they been in modifying the behaviour?

Depending on the individual situation or behaviour, more detailed questions may also be helpful to ask and seek to answer, for example:

- For a woman, does she directly stimulate her clitoris, vagina or breasts, and is this done above or beneath clothing?
- Does she seem to achieve satisfaction, whether through orgasm or not?
- For a man, does he get an erection, does he get his penis out and use his hand, and does he ever ejaculate?

Answers will provide precision about describing different forms of self-stimulation and masturbation which may have only been loosely described or labelled in the past and consequently aid the design and planning of interventions.

For both women and men, a series of secondary questions are also likely to prove useful, in particular:

- 1 Does there seem to be a particular stimulus or co-factor, for example a particular place, contact with a particular person or association with a particular care activity, such as changing a continence pad? If so, such associations may need to be mapped and understood in more detail in terms of their cause or function.
- 2 Is the masturbation part of a wider repertoire of attention seeking behaviours or other challenging behaviours such as self-injury? If there appear to be links, then the underlying functions of the masturbation and other challenging behaviours will need to be clearly articulated and understood.
- 3 Is there any suspicion or evidence that the person may have experienced sexual abuse in the past or is currently at risk of sexual abuse or exploitation? If so, and especially for people with very limited verbal communication, touching their genital area may be their only way of drawing attention to something having happened to that part of their body.

Answers to these questions will help place the behaviour on a continuum between sexual arousal, self-stimulation and masturbation, which will inform the response. They will also help develop and test hypotheses about the link between masturbation and other stimuli or challenging behaviours or the function of the behaviour itself which may be more than self-stimulation. In some cases, it may be necessary to collect additional

information to help decide on the function of the masturbation and clarify the attribution if it is a challenging behaviour, for example using a simple but widely recognized ABC (antecedent, behaviour, consequence) approach to understanding setting conditions and triggers as part of behaviour analysis (e.g. Murphy, 1994).

In many cases it will also be important to check out some even more basic but often overlooked possibilities, particularly in relation to situations where the woman or man is considered to be unable to masturbate effectively. For example:

- Does the person have a vaginal, penile or urinary tract infection?
- Are there any signs of a skin irritation or condition, such as thrush or eczema?
- Could having an erection cause pain for the man, as with a very tight foreskin?
- Is the person on any form of medication which could reduce their ability to masturbate or their libido, such as anti-psychotic medication?

Whilst we may not always be able to understand why a person behaves in a certain way, if we accept the premise that the person will usually have a reason for what they are doing, the challenge for carers and support workers lies in working out the reason. The importance of such a response has been clearly stated:

addressing inappropriate masturbation successfully relies on an understanding of what the behaviour communicates about that person, or what purpose the inappropriate masturbation may be serving for them. If this understanding is lacking, approaches tend to be oppressive and punitive. (Walsh, 2000, p. 29)

In trying to understand a person's sexual behaviour, staff need to be encouraged to reflect on their own beliefs and values about sexuality. We draw on a range of models and sources for this, including our cultural backgrounds, subjective feelings ('gut reactions'), beliefs about how common or uncommon a certain type of sexual behaviour is, our understanding of the law, and so on. The models of 'normality' people hold can be influential in determining our responses and staff need to be helped to recognize that many of us make distinctions about what we think is 'normal' or 'abnormal' on an instinctive and subconscious level, rather than as a result of considered reflection.

Finding out more about a person's motivations and purposes will obviously require careful and respectful observation. Intimate and personal care or help with washing or bathing can sometimes provide such opportunities (Cambridge and Carnaby, 2000a). If a person is able to discuss such

matters, then private and respectful conversations can help. However, in many cases if staff already consider someone is unable to masturbate effectively, then they are likely to hold similar information or observations to support their concerns or will have collected evidence indirectly. It will remain important to check such evidence at staff meetings or case reviews in order to validate any assumptions or interpretations as a first step to planning responses or deciding on what additional information may be needed to inform any intervention. Considerations likely to surface from such work include links with activities and levels of meaningful engagement. If people lack meaning in their lives they are more likely to engage in self-involved behaviours which serve the purpose of relieving boredom or frustration, than in interesting and enjoyable activities. Similarly, if they have been denied structured sex education they are more likely not to have been given clear messages about masturbation being a normal and enjoyable activity, either on your own or with a consenting partner, or about the importance of privacy.

Policy and practice guidelines

Two caveats need to be referenced at this point in the discussion. The first relates to the role of sexuality policies in services for people with learning disabilities (Cambridge and McCarthy, 1997). Most such policies make a point of referencing service users' rights to information about sexuality, and services' responsibilities for providing sex education and support for sexuality, including masturbation. The second concerns the ways individual or group sex education work is organized.

Individual educational interventions need to be agreed and referenced in the person's individual plan (Carnaby, 2002). This may need to involve the multi-disciplinary or community team, care manager and service manager, depending on supervision and line management arrangements and the nature of outside support being provided for the service user. This has obvious implications for an individual's confidentiality and rights to privacy and these need to be weighed against the benefits of sharing such sensitive information about an individual (Downs and Farrell, 1996). It will also be important to identify the aims of the work, how these relate to the teaching, how the teaching will be undertaken, who will conduct the work and where it will take place. Similarly, group educational interventions, such as women's or men's sex education groups, require careful planning, supervision and management (Cambridge and McCarthy, 1997; McCarthy and Thompson, 1998). In short, both forms of sex education require the unambiguous allocation of worker led responsibility, within an individual or service-level action plan and outcomes.

Commonly reported problem areas

Attempts to masturbate during intimate or personal care are frequently reported, especially in services for people with profound and multiple learning disabilities, for whom a discourse on sexuality has been initiated (Downs and Craft, 1997). Such situations may be the only time someone has access to the sexual parts of their bodies (Cambridge and Carnaby, 2000a) and so are easily understandable, but they do raise particular adult protection concerns (Cambridge and Carnaby, 2000b). However, there are a number of ways staff can respond, such as leaving someone in a safe and comfortable place to allow them to explore their own bodies in private and giving them a positive response verbally or through other forms of communication (Ware, 1996) that the behaviour is allowed and valued.

Where an individual is masturbating in a communal area and it is not thought that they are doing it deliberately to offend others, the role of staff would be to sensitively guide the person to his or her own private space (usually a bedroom). If this behaviour occurs in a day service setting, then strictly private space is unlikely to be available and the best option available (such as the toilets) may have to be used. Clearly, there are other instances where consideration must be given to the possibility, or likelihood, that the person knows what they are doing is wrong and indeed that they are doing it deliberately to offend others or gain attention. Good guidance on working with men with learning disabilities with unacceptable and difficult sexual behaviours now exists (Thompson and Brown, 1998) and such materials can help formulate service responses.

If a man is deemed to be masturbating too much or ineffectively, it is sometimes suggested that chemical responses using medication designed to suppress the male sex drive (such as Androcur) will help the situation. However, without the person's informed consent, which in the case of someone with a profound or severe learning disability would be very unlikely, then this is not a realistic or ethical option to consider. In addition to the ethical problems, there is the question of effectiveness, as experience suggests that men who take this medication may still experience sexual feelings and attempt sexual activity (either alone or with a partner), but are unable to reach orgasm. This can then exacerbate the problem it was trying to solve. Rather, support staff need to be asking whether the individual concerned is having enough 'private' time. For example, if appropriate and safe, is he being given time to relax alone in the bath or shower, or have time to rest in bed when not actually sleeping, without wearing pads or restrictive clothing?

Similar dilemmas occur, for example, with managing the risk to people who use inappropriate or dangerous objects to masturbate. Vaginal or anal

insertions of certain objects pose a clear risk and necessitate action on the part of staff. There will clearly be a strong case in terms of risk management to protect the person by removing the dangerous object. However, in terms of the person's rights and in interests of providing a supportive response, there would also be a case for replacing the object with a safe alternative, such as a specially designed sex aid or similarly shaped object.

Taking sex education forward

A range of possible educational responses for helping teach someone to masturbate effectively or in an appropriate place can be considered (McCarthy and Thompson, 1998):

- talking to the person, using unambiguous terms
- discussion using photographs or line drawings (for example Cambridge, 1997; McCarthy and Thompson, 1998)
- using a sex education video, where actors or puppets demonstrate masturbation (for example FPANSW, 1993; WLHPA, 1994)
- demonstrating on a model vagina or penis
- directing them or taking them to an appropriate place when they start to masturbate
- introducing modification, such as lubrication or a sexual aid if an inappropriate object is being used
- physically directing a person's hand when they are trying to masturbate (for example Shelton, 1992).

Two overriding principles are relevant here. The first is informed consent, and the second is that the least intrusive methods should always be tried first. The most important practical consideration will therefore be to tailor the educational response to the person's cognitive capacity and known sexual experience. Issues of consent for and the design and targeting of educational interventions underline why it is important to have these agreed in the person centred plan (Department of Health, 2001) and to adhere to basic principles of consent (mirroring those developed for sexual activity itself by Brown and Turk, 1992, and others). These would need to take account of the person's sexual experience and their understanding of the planned intervention. However, consent can be more difficult to put first when service responsibilities for care and the protection of vulnerable adults (Department of Health, 2000), possible legal constraints (Gunn, 1996; 1997) or the risk of negligent practice or assault (Cambridge, 2001a) are part of decision making.

Some of the difficulties of matching resources to needs are reflected in

the range of off-the-shelf educational resources available. For example, videos which use puppets to demonstrate masturbation (WLHPA, 1994) are sometimes considered to create an additional conceptual barrier, namely the difficulty of the person relating the puppet on the video to self. Conversely, there may be a reluctance on the part of the educator to use sexually explicit educational material or images (such as those on masturbation using actors in FPANSW, 1993), on the basis that the service user might misinterpret these or simply because the educator finds using such material difficult.

When considering options, concern within services often returns to whether such interventions, if successful, will then lead to the person spending too much time masturbating, as they may have learnt how to do it well and effectively. Although there is little evidence that this happens in reality, if such outcomes occur, then it will be necessary to revisit considerations of engagement in activities more widely.

Another important reference issue at this stage is often the practice and adult protection boundary between education and what has been euphemistically coined 'hands-on' intervention. Providing information and education in response to an assessed need is clearly the right thing to do, but the question of how to do this effectively may present a challenge. Whilst it might be rational to suggest, in a particular agreed case or situation, that staff should guide a person's hand, this is not the same as, for example, placing a man's hand on his penis or a woman's fingers on her clitoris, and simulating masturbation for the person. The latter interventions will rarely or ever be appropriate, owing to confounding issues of consent and experience on the part of the service user and the feelings, motives and rights of staff. Indeed, these interventions are highly likely to be defined as abusive under adult protection procedures. For similar reasons intimate and personal care interventions are informed by considerations of consent to touch (Cambridge and Carnaby, 2000b) where hand over hand contact and indirect cues to consent such as body language and non-verbal forms of communication are utilized. However, it also needs to be recognized that there are often no absolute boundaries on issues such as 'hands-on' interventions (Shelton, 1992), a reality mirrored in sexuality work more widely, where previously 'taboo' issues such as access to paid sex by men with learning disabilities have recently been discussed (Cambridge, 2001b).

The cultural appropriateness of educational method, image or message is also an important consideration. For example, it has been observed in safer sex education that images which may be culturally appropriate to a gay identified man may not be culturally appropriate to a man with learning disabilities who has sex with men (Cambridge, 1997). Cultural

appropriateness in relation to race and ethnicity has also been discussed in relation to sexuality work and sex education in learning disability (Baxter, 1996; Malhotra and Mellan, 1996; Senker, 1997) and is also relevant to anti-oppressive practice more widely (Baxter et al., 1990; Karmi, 1996; Shah, 1998). However, it is worth noting that few, if any, of the major world religions take a positive view of masturbation (Thomson, 1993). That is not to say that there is no value in consulting specialist advisers on cultural matters relating to the education of people with learning disabilities about masturbation. Experience suggests that this may be very useful and sometimes a very pragmatic and helpful approach may be taken, but there may also sometimes be conflicts with user rights as articulated in law or in sexuality policies.

Considerations for working with men with learning disabilities

An issue which often emerges when undertaking sexuality work with more able men with learning disabilities concerns the use of pornography, which is often used as part of masturbation or an aid to masturbation. Difficult political and practice arguments surround the use of pornography, such as situations where the man may have bought this himself or been given it by other men he has met (Cambridge and Mellan, 2000). Staff may object to its presence in bedrooms and the man has responsibilities to use it appropriately and in private. However, in situations where it is used in shared spaces or for masturbation in non-private places, the man will need to be given clear messages that this is unacceptable.

For more able men with learning disabilities who may be having sex with men outside their service (Cambridge, 1997), it will be particularly important to present consenting masturbation and mutual masturbation as positive sexual behaviour in the context of safer sex education, counselling about HIV or assertiveness work. Men with learning disabilities who engage in masturbation in public sex environments will be less vulnerable to exploitation or sexual abuse and more able to escape assault or arrest than those engaging in other, more involved forms of sexual contact. However, the reality of sexual encounters in such situations will often mean that masturbation is the initial stage of a sequence of sexual behaviours which may lead to very unsafe sex, and safer sex education will need to acknowledge such connections and risks (Cambridge, 1999).

Masturbation is popularly considered to be almost a preoccupation for adolescent boys in the general population and clearly the enormous physical and hormonal changes that take place during this time in a young person's life can lead to a very strong interest in masturbation and indeed

other sexual activities, for girls as well as boys. Yet the needs and feelings of adolescents with learning disabilities are often overlooked (Rowitz, 1988), despite the fact that they will largely be undergoing the same physical changes, with the disadvantage of less formal and informal sources of sex education and support than other young people.

Considerations for working with women with learning disabilities

One of the main considerations for working with women with learning disabilities on masturbation issues is how little we know about women's experiences and their feelings and needs related to this sexual activity. There are few avenues for women with learning disabilities to talk about masturbation and, even when provided with respectful opportunities to do so, most women with learning disabilities find it extremely difficult and embarrassing (McCarthy, 1999). This is not surprising given the double standards and strong social taboos which still exist for all women in talking about the sexual pleasure they can give themselves (McNeil, 1992). This issue is made more complex for women with learning disabilities given the negative feelings and lack of pleasure and pride they often take in their bodies (McCarthy, 1998).

However, if appropriate opportunities can be made to discuss masturbation (and experience suggests that for many women with learning disabilities, this will be need to be on an individual basis, owing to the embarrassment factor in group settings), then there is much that could be gained from it. If women with learning disabilities can be helped to understand that masturbation is normal and widely practised amongst most women (Hite, 1976), then they may feel less embarrassed and negative about their own experience of it. In turn, they may learn what kinds of sexual touch they do and do not enjoy and this can only help in any subsequent sexual activity they have with a partner. As evidence suggests that many women with learning disabilities do not get much, if any, pleasure from the sexual activity they engage in (McCarthy, 1999), then this would clearly be of benefit.

Concluding remarks

Masturbation is one of the commonest and potentially most harmless forms of sexual behaviour, enjoyed by women and men alike, sometimes solely, but more often as part of a wider sexual repertoire. Most people also masturbate throughout the majority of their lives. Considering this reality, services for people with learning disabilities have been slow to empower

service users to enjoy masturbation and to support them to masturbate effectively and in appropriate ways and places. This is sadly often reflected in the responses of service users themselves to masturbation, reported from individual and group sex education (Cambridge and McCarthy, 1997; McCarthy and Thompson, 1998), where it attracts negative interpretations and associations with guilt and shame.

This inheritance reflects decades of neglect in relation to sexuality, rooted in a values system in which people with learning disabilities are socially and culturally marginalized and economically excluded, and where services are still largely segregated and fail to acknowledge the heterogeneity in the population of people with learning disabilities. Recent policy initiatives (Department of Health, 2001) have stressed the importance of individualized and person-centred services and of social inclusion, and almost two decades on from the influential work of Craft (1987) and Brown (1980) we are now in a service culture where adult protection policy (Department of Health, 2000) and management and practice in sexuality can move forward in more empowering as well as protecting ways. A starting point is how we respond to masturbation in productive and empowering ways.

References

- BAXTER, C. (1996) 'Sex Education: Ethnically Sensitive Services to People with Learning Disabilities', *Tizard Learning Disability Review* 1 (4): 13-16.
- BAXTER, C., POONIA, K., WARD, L. & NADIRSHAW, Z. (1990) *Double Discrimination*. London: King's Fund.
- BROWN, H. (1980) 'Sexual Knowledge and Education of ESN Students in Centres of Further Education', *Sexuality and Disability* 3 (3): 215-20.
- BROWN, H. & THOMPSON, D. (1997) 'Service Responses to Men with Intellectual Disabilities Who Have Unacceptable or Abusive Sexual Behaviours: The Case against Inaction', *Journal of Applied Research in Intellectual Disabilities* 10 (2): 176-97.
- BROWN, H. & TURK, V. (1992) 'Defining Sexual Abuse as It Affects Adults with Learning Disabilities', *Mental Handicap Research* 20 (2): 44-54.
- BROWN, H., STEIN, J. & TURK, V. (1995) 'The Sexual Abuse of Adults with Learning Disabilities: Report of a Second Two Year Incidence Survey', *Mental Handicap Research* 8 (1): 1-22.
- CAMBRIDGE, P. (1996) *The Sexuality and Sexual Rights of People with Learning Disabilities: Considerations for Staff and Carers*. Kidderminster: British Institute of Learning Disabilities.
- CAMBRIDGE, P. (1997) 'How Far to Gay? The Politics of HIV in Learning Disability', *Disability and Society* 12 (3): 427-53.
- CAMBRIDGE, P. (1999) 'Considerations for Informing Safer Sex Education Work with Men with Learning Disabilities', *British Journal of Learning Disabilities* 27: 123-6.
- CAMBRIDGE, P. (2001a) 'The HIV Testing of a Man with Learning Disabilities: Informed Consent, Confidentiality and Policy', *Journal of Adult Protection* 3 (4): 23-8.
- CAMBRIDGE, P. (2001b) 'Editorial: Sexuality under Scrutiny', *Tizard Learning Disability Review* 6 (1): 2-3.

- CAMBRIDGE, P. & CARNABY, S. (2000a) 'A Personal Touch: Managing the Risks of Abuse during Intimate and Personal Care for People with Learning Disabilities', *Journal of Adult Protection* 2 (4): 4-16.
- CAMBRIDGE, P. & CARNABY, S. (2000b) *Making It Personal: Providing Intimate and Personal Care for People with Learning Disabilities*. Brighton: Pavilion.
- CAMBRIDGE, P. & MCCARTHY, M. (1997) 'Developing and Implementing Sexuality Policy for a Learning Disability Provider Service', *Health and Social Care in the Community* 5 (4): 227-36.
- 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.
- CARNABY, S. (1997) 'What Do You Think? A Qualitative Approach to Evaluating Individual Planning Services', *Journal of Intellectual Disability Research* 41 (3): 225-31.
- CARNABY, S. (1999) 'Individual Programme Planning: Where Is the Individual?', *Tizard Learning Disability Review* 4 (3): 4-9.
- CARNABY, S. (2002) 'Making Plans: Undertaking Assessment and Care Planning', in S. CARNABY (ed.) *Learning Disability Today*. Brighton: Pavilion.
- CRAFT, A. (1983) *Sex Education and Counselling for Mentally Handicapped People*. Tunbridge Wells: Costello.
- CRAFT, A. (ed.) (1987) *Mental Handicap and Sexuality: Issues and Perspectives*. Tunbridge Wells: Costello.
- DEPARTMENT OF HEALTH (2000) *No Secrets: Guidance on Developing and Implementing Multi-Agency Policies and Procedures to Protect Vulnerable Adults from Abuse*. London: Department of Health.
- DEPARTMENT OF HEALTH (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*. London: Department of Health.
- DOWNS, C. & CRAFT, A. (1997) *Sex in Context: A Personal and Social Development Programme for Children and Adults with Profound and Multiple Impairments*. Brighton: Pavilion.
- DOWNS, C. & FARRELL, S. (1996) 'A Practical Response to Masturbation: Working with People with Profound and Multiple Disabilities', *Tizard Learning Disability Review* 1 (4): 23-6.
- FELCE, D., LOWE, K. & DE PAIVA, S. (1994) 'Ordinary Housing for People with Severe Learning Disabilities and Challenging Behaviours', in E. EMERSON, P. MCGILL & J. MANSELL (eds) *Severe Learning Disabilities and Challenging Behaviours*. London: Chapman and Hall.
- FPANSW (1993) *Feeling Sexy, Feeling Safe*. Family Planning Association of New South Wales.
- GUNN, M. (1996) *Sex and the Law: A Brief Guide for Staff Working with People with Learning Difficulties*. London: Family Planning Association.
- GUNN, M. (1997) 'The Law, HIV and People with Learning Disabilities', in P. CAMBRIDGE & H. BROWN (eds) *HIV and Learning Disability*. Kidderminster: British Institute of Learning Disabilities.
- HITE, S. (1976) *The Hite Report*. London: Pandora.
- KARMI, G. (1996) *The Ethnic Health Handbook*. London: Blackwell.
- MALHOTRA, S. & MELLAN, B. (1996) 'Cultural and Race Issues in Sexuality Work with People with Learning Disabilities', *Tizard Learning Disability Review* 1 (4): 7-12.
- MCCARTHY, M. (1996) 'The Sexual Support Needs of People with Learning Disabilities: A Profile of Those Referred for Sex Education', *Sexuality and Disability* 14 (4): 265-79.

- MCCARTHY, M. (1998) 'Whose Body Is It Anyway? Pressures and Control for Women with Learning Disabilities', *Disability and Society* 13 (4): 557-74.
- MCCARTHY, M. (1999) *Sexuality and Women with Learning Disabilities*. London: Jessica Kingsley.
- MCCARTHY, M. (2001) 'Women with Learning Disabilities: Experiencing their Sexuality in a Healthy Way', *Tizard Learning Disability Review* 6 (1): 16-21.
- MCCARTHY, M. (2002a) 'Responses to Women with Learning Disabilities as They Go through the Menopause', *Tizard Learning Disability Review* 7 (1): 4-12.
- MCCARTHY, M. (2002b) 'Sexuality', in P. NOONAN WALSH & T. HELLER (eds) *Health of Women with Intellectual Disabilities*. Oxford: Blackwell.
- MCCARTHY, M. & CAMBRIDGE, P. (1996) *Your Rights about Sex: A Booklet for People with Learning Disabilities*. Kidderminster: British Institute of Learning Disabilities.
- MCCARTHY, M. & THOMPSON, D. (1996) 'Sexual Abuse by Design: An Examination of the Issues in Learning Disability Services', *Disability & Society* 11 (2): 205-17.
- MCCARTHY, M. & THOMPSON, D. (1998) *Sex and the 3Rs: Rights, Responsibilities and Risks*. Brighton: Pavilion.
- MCNEIL, P. (1992) 'Doing It On My Own', in P. MCNEIL, B. FREEMAN & J. NEWMAN (eds) *Women Talk Sex*. London: Scarlett.
- MURPHY, G. (1994) 'Understanding Challenging Behaviour', in E. EMERSON, P. MCGILL & J. MANSELL (eds) *Severe Learning Disabilities and Challenging Behaviours: Designing High Quality Services*. London: Chapman & Hall.
- MURPHY, G. & CLARE, I. (1995) 'Adults' Capacity to Make Decisions Affecting the Person: Psychologists' Contribution', in R. BULL & D. CARSON (eds) *Handbook of Psychology in Legal Contexts*. Chichester: Wiley.
- NIHIRA, K., FOSTER, R., SHELLHAAS, M. & LELAND, H. (1974) *AAMD Adaptive Behaviour Scale*. Washington, DC: American Association on Mental Deficiency.
- PARKIN, W. (1989) 'Private Experiences in the Public Domain: Sexuality and Residential Care Organisations', in J. HEARN ET AL. (eds) *The Sexuality of Organizations*. London: Sage.
- ROGERS, J. (2001) 'The Experiences and Management of Menstruation for Women with Learning Disabilities', *Tizard Learning Disability Review* 6 (1): 36-44.
- ROWITZ, L. (1988) 'The Forgotten Ones: Adolescence and Mental Retardation', *Mental Retardation* June: 115-17.
- SECKER, J. (1997) 'Gender, Race and Sexual Behaviour: Issues in Service Responses', *British Journal of Learning Disabilities* 25 (2): 58-63.
- SHAH, R. (1998) 'Addressing Equality in the Provision of Services to Black People with PMLD', in P. LACEY & C. OUVRAY (eds) *People with Profound and Multiple Learning Disabilities: A Collaborative Approach to Meeting Complex Needs*. London: David Fulton.
- SHELTON, D. (1992) 'Client Sexual Behaviour and Staff Attitudes: Shaping Masturbation in an Individual with a Profound Mental and Secondary Sensory Handicap', *Mental Handicap* 20 June: 81-7.
- SHEPPARD, R. (1991) 'Sex Therapy and People with Learning Difficulties', *Sexual and Marital Therapy* 6 (3): 307-16.
- THOMPSON, D. (2001) 'Is Sex a Good Thing for Men with Learning Disabilities?', *Tizard Learning Disability Review* 6 (1): 4-12.
- THOMPSON, D. & BROWN, H. (1998) *Response-Ability: Working with Men with Learning Disabilities Who Have Difficult or Abusive Sexual Behaviour*. Brighton: Pavilion.
- THOMSON, R. (1993) *Religion, Ethnicity and Sex Education: Exploring the Issues*. London: National Children's Bureau.

- WALSH, A. (2000) 'IMPROVE and CARE: Responding to Inappropriate Masturbation in People with Severe Intellectual Disabilities', *Sexuality and Disability* 18 (1): 27-39.
- WARE, J. (1996) *Creating a Responsive Environment for People with Profound and Multiple Learning Difficulties*. London: David Fulton.
- WLHPA (1994) *Piece by Piece*. West London Health Promotion Agency. Brighton: Pavilion.

Correspondence should be addressed to:

PAUL CAMBRIDGE, Tizard Centre, University of Kent at Canterbury, Canterbury, UK.
e-mail: P.Cambridge@ukc.ac.uk.

Date accepted 24/02/03

Ref. 2.3.e.

Cambridge, P. (2006b) Developing policies, procedures and guidelines for intimate and personal care in services for people with learning disabilities, in (Eds.) S. Carnaby and P. Cambridge, in *Intimate and Personal Care for People with Learning Disabilities*, Jessica Kingsley, London.

Developing Policies, Procedures and Guidelines for Intimate and Personal Care in Services for People with Learning Disabilities

Paul Cambridge

INTRODUCTION

Social care services seem increasingly inundated with various policies and procedures for just about every aspect of management and practice: sexuality, adult protection, risk management, the use of physical interventions, infection control, and so on. It is hoped that the provision of intimate and personal care will also be included as policy and that it will be effective. It is, however, easy to perceive of such policies as protecting agencies and sometimes staff, at the expense of what we might claim to be intuitive best practice. Although policies tend to set floors to practice in the hope of eliminating bad practices while raising expectations and standards, they may sometimes unwittingly also set ceilings and stifle innovation and best practice. They can be defensive in as much as they place boundaries on management and support in services for people with learning disabilities, but should also be empowering and enabling, in as much as they should promote best practice. Policies and procedures are also caught in a conceptual dilemma in relation to 'whose' best practices and best interests dominate – much work in social care is based on experience, judgement and responding appropriately to the unexpected as much as it is on reflective management and practice, learning from past experience and being grounded in an interpretative consensus.

Policies therefore clearly have their limits as well as their advantages. The limits are perhaps most obvious when policies relate to the often 'invisible'

aspects of social care, such as how to manage risk such as abuse (Lee-Treweek 1994), as opposed to how we execute physical interventions, for example. Even in the latter, where there are tangible things happening that can be observed, there has been a difficult and long-running discourse and debate about the pros and cons of different approaches and the rights, wrongs and moralities of different interventions (Harris 2002).

Less 'visible' policy realms include sexuality and adult protection. Arguably, intimate and personal care is relatively visible as it concerns physical aspects of care and physical tasks. However, it also includes invisible aspects such as the feelings and responses of those providing and receiving intimate and personal care, which is often where things go wrong, or staff develop a perspective skewed towards task completion at the expense of the quality of care provided (Carnaby and Cambridge 2002). Moreover, while it may be visible to the carer, there may be a gap between how it is intended and how it is experienced by the care receiver. Further, although it may be visible to those involved in the actual care interaction, it may be invisible to other carers, staff and service users for reasons of privacy. Intimate and personal care is consequently closer to policy areas such as sexuality, where policy helps identify rights and responsibilities and important principles and values in guiding management and practice.

In adult protection, policy has become important because of national priorities (Department of Health 2001). However, it remains the task of local managers and practitioners to articulate the process of investigations and decision-making in adult protection (Cambridge and Parkes 2004), addressing issues of risk in the degree of autonomy in decision-making. The same demands are present in other policy areas such as intimate and personal care. Indeed, risk management has itself become an important policy domain impacting on management and practice across health and social care services (Alaszewski *et al.* 1998, 1999, 2000; Cambridge 2002).

In areas of policy and practice such as sexuality and intimate and personal care, decision-making and monitoring of effectiveness get more difficult because most situations are unique, varying according to those involved in the care interaction and the nature of their relationship, the particular care task involved and where and when the interaction takes place. Rules and guidelines might not always be informative or very helpful, but are needed to inform the interaction or the decision-making surrounding it. The nature of caring relationships and care interventions also compound policy and guidelines as the phenomenological nature of practice becomes even more evident and stark, exacerbating the challenges for policy formulation and implementation. Here the gap between policy and practice is potentially widened further by the physical isolation of those involved in the care interaction as well as its invisibility – rules surrounding best practice suggest this should be conducted in private to

respect the dignity of the person receiving the care. How then, we might ask, can policy in this area ever be properly implemented and monitored for its effectiveness?

This difficulty can be responded to in a number of ways. For example, Kent Social Services Department has led the development of multi-agency policies, procedures and protocols in adult protection (Kent Social Services Department 2000). Each 'policy' level has a function. The broad policy provides a framework in which more detailed procedures and protocols help guide staff action, responses and decision-making. In intimate and personal care we can similarly differentiate across a number of policy levels. For example, the intimate and personal care policy can set expectations such as same-gender care and the circumstances under which cross-gender care is allowed. It can stipulate how care relationships are decided upon and how person-centred decisions about intimate and personal care are made. What it cannot do is specify individual intimate and personal care responsibilities of particular staff for particular service users and how particular intimate and personal care tasks are conducted. In short, policy cannot particularise to individuals from the general level.

Individual intimate and personal care guidelines, on the other hand, can help construct care interactions, based on policy, around the needs of individuals, but again limits are evident. Experience suggests that the ways particular care tasks are conducted between the care giver and care receiver are often the most difficult to define and articulate (Cambridge and Carnaby 2000a; Carnaby and Cambridge 2002).

DEVELOPING AND IMPLEMENTING INTIMATE AND PERSONAL CARE POLICY

The reasons policies often fail have been identified (Brown and Cambridge 1997). These include poor dissemination, being too vague or long winded, containing contradictions between rights and responsibilities (of staff as well as between staff and service users), and the absence of supportive individual planning. The last factor is a particularly important consideration for policies on intimate and personal care, where person-centred approaches are essential for helping ensure good quality and productive care interactions. Other reasons cited for the failure of policies include lack of skills or support on the part of staff and a failure to implement thorough training, which is why priority needs to be given to developing staff training and support materials in intimate and personal care (Cambridge and Carnaby 2000a).

Policies are unlikely to succeed if they do not help resolve the problems faced by staff in their day-to-day work, which is why policy implementation needs to go hand in hand with needs assessment as well as staff training, and why policies should be reviewed and updated in the light of experience.

Experience of policy implementation in adult protection (Brown and Stein 1998) suggests complex organisational, management and practice considerations, supporting some level of policy coordination. This could be achieved by having a manager or practitioner leading in organisations providing intimate and personal care – someone to bounce ideas off or with whom to share concerns, or to take responsibility for developing the policy in light of experience. In some policy areas such as adult protection, the importance of specialist coordinators has been demonstrated (Cambridge and Parkes 2004). Experience in intimate and personal care (Cambridge and Carnaby 2000a) also suggests the need for lead responsibilities and that time will need to be protected to discuss and reflect effectively on practice in intimate and personal care and to feed this through to the development and review of policies and individual guidelines. Often, regular discussion or information-exchange mechanisms such as staff meetings, peer review or supervision do not have the capacity in time or space required to discuss intimate and personal care practice adequately. Having a dedicated lead person can help close this policy–practice gap.

Policies cannot answer all questions or provide guidance on every individual case or difficulty that is likely to arise in providing intimate and personal care. They can, however, provide a framework for establishing general principles, setting out how and by whom decisions should be made and defining associated responsibilities. However, under-prescriptive policies lose practice relevance and can lead to ambiguity, so it is important to achieve a balance between general principles and specific guidance. Having case studies of particular situations or dilemmas and how these might be resolved satisfactorily can help close the policy–practice implementation gap.

A model for policy implementation exists from work in sexuality policy development that could be used to help develop and review intimate and personal care policy in services for people with learning disabilities (Cambridge and McCarthy 1997). Policy development and implementation should not be an abstract exercise, divorced from the experiences of staff, service users or managers. In their case study of sexuality policy development, Cambridge and McCarthy initiated preliminary staff training, men's and women's sex education groups and meetings with relatives in order to include the views of different stakeholders and identify the range of issues which policy needed to acknowledge and respond to as well as potential conflicts.

The policy was then implemented through a consultation and training process with staff and relatives. User consultation groups also proved a helpful mechanism for identifying what was important to service users in best value reviews (Cambridge and McCarthy 2001); although people with profound and multiple disabilities are likely to be unable to participate in such mechanisms, some people with learning disabilities receiving intimate care are able to be

consulted. Indeed, insights and transferable lessons can also be provided by discussions with others receiving intimate and personal care, such as people with physical disabilities. More directly, for those individuals receiving intimate and personal care, a working group (Cambridge and Carnaby 2000a) could be constructed, comprising family members, staff or advocates who know the individual well and who could help develop individual care guidelines and advise on the provision of intimate and personal care. Similar consultation groups could be developed at the policy level.

OPERATIONAL POLICIES FOR INTIMATE AND PERSONAL CARE

Figure 6.1 illustrates how policies on intimate and personal care in services for people with learning disabilities are open to influence from a range of sources within and outside services. Similarly the issues covered by policy will be wide, applying not only to how intimate and personal care is organised and delivered and the values that underpin the provision of intimate and personal care, but also how intimate and personal care fits with other policies. These include policies on sexuality, adult protection, risk management and infection control, as well as government policy on social inclusion and the development of learning disability services as articulated in *Valuing People* (Department of Health 2001).

Choice and inclusion at the social policy level will need to be translated to choice in such matters as the provision of intimate and personal care and how this fits with initiatives such as person centred planning. Policies will also need to address how intimate and personal care fits with practice issues such as key-working arrangements, supervision, the use of communication, support of people with profound and multiple learning disabilities and other complex needs, person centred planning, and so on. Policies, procedures and guidelines on intimate and personal care, like those in other areas of practice, will consequently need to work on a number of issues.

The following sections of this chapter examine the main issues that have an impact on how intimate and personal care is provided and that policy will likely need to address.

Abuse and neglect

There are a number of areas where the law should potentially inform the planning and delivery of intimate and personal care for people with learning disabilities. If intimate and personal care is conducted in careless or thoughtless ways that physically hurt the person receiving it, or results in injury, then this

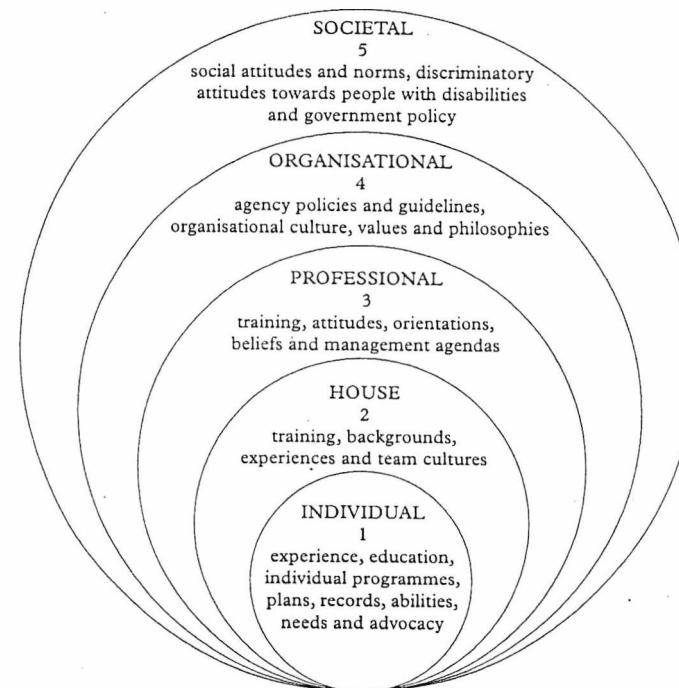


Figure 6.1 Influences on policy and practice

would not only be seen as reckless but, under adult protection policy, would be defined as physical abuse. It might also be seen as assault under criminal law.

Similarly, if a person's intimate care needs, such as those recognised in individual guidelines or through service planning meetings or care plans, are neglected, then this would also constitute abuse under adult protection policy. However, it might also be seen as a failure in duty of care, which might have common law or criminal consequences. Even aspects of care not referenced in guidelines would potentially apply. If someone clearly needed help to use the toilet, or if their continence pad required changing and nothing was done, then this would be irresponsible and could result in pain, injury or other health consequences. Neglect is not doing a care task appropriately with due regard to the person's welfare, as well as not doing it when it would be reasonable to expect it to be done. Leaving someone on the toilet or in a bath unattended, resulting in injury, suffering or distress to the person, are examples of how this might happen.

Policies on intimate and personal care clearly need to spell out that a failure to provide intimate and personal care according to agreed procedures outlined in individual guidelines or according to general policy principles could, depending on the circumstances, be experienced by the person receiving care or

be judged by others as abusive, neglectful or even constituting a criminal offence. Most vulnerable adult policies include neglect and mistreatment and, more centrally for intimate and personal care, failure to keep to care guidelines, as categories of abuse, according to the intention of *No Secrets* (Department of Health 2000). Indeed, there are frequent examples where the breaching of care guidelines has been the main characteristic of abusive cultures in residential care (Buckinghamshire County Council 1998; Cambridge 1999a; Macintyre 1999).

Sexuality

Sexuality is another area where the law as well as good practice drivers influence how intimate and personal care is provided. It is in intimate care provision that the sexual parts of people's bodies are exposed during washing and drying or the application of medication, and it is such interactions that can potentially create legal as well as social or cultural dilemmas. Clearly touching someone else's sexual parts such as penis, vagina, anus or breasts during intimate and personal care can be justified when this is part of the care plan and there is a specific reason for this, such as personal hygiene. However, even in such circumstances, other considerations apply, such as whether and how towels, cleaning pads, flannels or gloves are used by the person providing the care.

First, there is usually no necessity for direct contact between the person's fingers and the sexual parts of the other person's body. Second, the task should be done in the least invasive way possible, minimising the use of touch or rubbing which could be experienced as sexually stimulating by the person receiving the care. Clearly there may be instances where this happens but is unintended, such as cleaning under a man's foreskin (Cambridge and Carnaby, 2000b), but the justification for such care interactions needs to be transparent. Third, insertion of fingers or objects should specifically be avoided, as this is potentially a more direct and invasive form of touch or sexual stimulation. The exception would be agreed administering of medication such as pessaries or suppositories. Fourth, if the person reacts sexually, then the carer should have a strategy for withdrawing or closing the care interaction to indicate to the person that it is not of a sexual nature.

Clearly, therefore, any direct or indirect sexual stimulation on the part of the carer would be totally inappropriate and would be defined as sexual abuse under adult protection policy (Department of Health 2000). Moreover, the 2003 Sexual Offences Act makes it an offence for a care worker or anyone else working in services for people with learning disabilities to have sex with a service user, which includes any form of sexual contact such as touching (Wheeler 2004). If a person indicates a wish to masturbate then this should be accommodated through sex education or enabling strategies rather than direct masturbation during tasks of intimate care (Cambridge and McCarthy 1997; Cambridge, McCarthy and McCarthy 2003).

Consent to touch

In many cases we are unable to assess consent to touch on the part of the person receiving intimate and personal care and consequently fall back on 'best interests' or 'duty of care' considerations. However, policy needs to work through these difficult questions. Capacity to consent can be assessed, and comparisons with how people do or don't make decisions in other aspects of their lives can be used to help assess whether someone might be able to give consent to sex (Murphy 2003; Murphy and O'Callaghan 2004) or related aspects such as consent to touch during intimate care. Clearly someone with a profound and multiple learning disability and little or no expressive communication is unlikely to be able to consent in the same way as someone with a moderate learning disability. Indicators may consequently have to be used to help determine their experiences of intimate care, weigh any negative factors against what is in the person's best interests, and what else might need to be done to minimise any negative experiences on their part.

Policies should stipulate the principles for responding to such dilemmas. Nind and Hewett (1994) identify a set of guiding principles to help justify touch: physical contact should only be with the consent of the service user, it needs to have a purpose and it should itself be an important mode of communication. This can be developed into a considered process of checks:

1. Work slowly with the individual.
2. Think carefully about the movements that you make and your body language generally.
3. Sensitivity leads to participation rather than compliance.
4. Use the one-to-one interaction of personal and intimate care as an opportunity for spending time and communicating with the person.

Policies should underline that any negative communication or response on the part of the service user during intimate and personal care, such as facial expression, vocalisation related to distress or pushing the carer away, should always be reported and discussed.

Planning and reviewing intimate and personal care

Policies will need to map out for managers and staff good practice procedures for planning and reviewing the organisation and delivery of intimate and personal care to individuals. This should follow a basic assessment process identifying someone's support needs, what should be in place to effectively meet them and who will ensure that this happens. Everyone receiving intimate and personal care should have individual guidelines, and policy should encour-

rage these to be more than a list of care tasks required and when they should be undertaken – which is often the case (Carnaby and Cambridge 2002). They should ideally record how different care tasks are conducted in ways that have been identified to be least intrusive for the person or preferred by the person themselves, such as the particular materials used and, where possible, who should be providing the care. Policy will therefore need to stipulate how such guidelines are developed, where they are held and how they are used and updated.

As such policies will clearly need to tie in with other aspects of micro-organisation in services for people with learning disabilities. Person centred planning (Department of Health 2001) will need to include the person's preferences and wishes for intimate and personal care with individual service planning, including information on how resources at team level will be used and allocated to ensure intimate and personal care is delivered according to these individualised plans and guidelines. As care planning and care management for people with learning disabilities varies widely between services and local authorities (Cambridge 1999b), it will be important for policies to map such responsibilities and relationships in relation to intimate and personal care.

Key-workers, and care managers where available, will have important roles to play. The key-worker might be the main person responsible for ensuring that intimate and personal care is delivered according to the guidelines and plans and is reviewed through the planning system as well as informally. They may also be the main person directly providing intimate and personal care to the client. The care manager or service manager will be best placed to ensure that individual plans and guidelines are in place in services, that they are consistent between different services and carers, such as those in residential and day services and family carers, and that they are properly reviewed, not only through person centred planning but that the necessary care providers come together to regularly review intimate and personal care. This will be important within residential care itself, where the service manager may need to ensure that members of the team have protected time to review and discuss intimate and personal care provision for individuals.

Same-gender intimate and personal care

Same-gender care principles will undoubtedly need to receive prominence in policy as they underpin most practices. However, policies will need to be clear about the reasons for same-gender care and its inherent limitations. In particular, policy discussion should pay much more attention to the circumstances under which cross-gender care might be appropriate, not only from female staff to male service users, but from men to women where there is a clear rationale for this. This might include circumstances where the care receiver has expressed a

preference or where male to female care is justified for other reasons, such as scarcity of other staff or the availability of agency staff. In any case, the risks to the worker and client will need to be addressed, just as they should be in same-gender care.

One of the primary rationales for same-gender intimate and personal care is that it helps protect vulnerable female service users from sexual abuse by male staff. This is rational in so much as intelligence on sexual abuse (e.g. Brown, Stein and Turk 1995; Buchanan and Wilkins 1991; Dunne and Power 1990; Hard and Plumb 1987; McCarthy and Thompson 1996; Sobsey and Varnhagen 1989) demonstrates that almost all known cases of sexual abuse of people with learning disabilities are perpetrated by men. However, the largest group of perpetrators are other service users (Bergh, Hoekman and Ploeg 1997; Brown *et al.* 1995; McCarthy and Thompson 1996; Turk and Brown 1993), although it is important to acknowledge that male staff generally form the second largest group in those studies which examine this. Regardless of the mixed messages in such evidence, it is irrational to use information on sexual abuse to wholly inform the gender of intimate and personal care relationship and interactions from a number of angles.

First, it fails to protect male service users from sexual abuse from male staff during intimate and personal care. Intelligence on sexual abuse informs us that up to half of the victims of sexual abuse are men with learning disabilities (e.g. Brown *et al.* 1995). Second, it fails to protect both women and men with learning disabilities from physical abuse or neglect during intimate and personal care. Neglect is itself a recognised category of abuse (Department of Health 2000). In hidden and private care situations, such risks increase (Lee-Treweek 1994). Intimate and personal care is generally hidden or invisible as it is conducted in private and is where neglect or physical or sexual abuse could happen with a low chance of being witnessed, although some circumstantial or forensic evidence might be available if abuse was suspected. Third, it fails to protect vulnerable women or men with learning disabilities from sexual abuse from male staff or carers in other care situations and settings.

The bottom line of the argument is surely that our skills in recognising and reporting adult protection concerns should not be so weak that we are incapable of putting supervision, monitoring and review systems in place for intimate and personal care that not only ensure the quality of the care we provide but also help protect the recipients of intimate and personal care from abuse, be this sexual, psychological or physical. Moreover, our general competence in adult protection should be such that we should not need to fall back on assumed 'safeguards' such as same-gender intimate care policies.

At one level it could be argued that same-gender policies screen out potential sexual abusers, which is the argument for police checks and POVA.¹

However, such devices have operational and conceptual holes and cannot and should not replace broader recognition skills and competence in adult protection. They definitely should not deny quality care opportunities for people with learning disabilities or quality care experiences for male staff. Sometimes they achieve the opposite to their intention. For example, they increase risk by allowing or encouraging agency staff, who may be unvetted or unknown to the regular staff team or more importantly to service users, to provide intimate care.

The idea of cross-gender care is embedded in cultural and social norms and expectations. As a society we encourage specific gendered roles in caring as we value caring from women to men and other women. At one level, therefore, same-gender intimate and personal care policies deny the broad cultural appropriateness of caring from women to men, regardless of learning disability. But it is in this area that policies interestingly become elastic and open to pragmatic and resource factors. Men are scarce within and outside social care services, so it is often simply essential for women to provide intimate care to some men with learning disabilities. Moreover, a number of difficulties are associated with the pragmatic interpretation of policies to allow cross-gender care from women to men and the arguable over-zealous interpretation of policies to deny cross-gender care from men to women.

First, such policies often fail to protect women staff from sexual harassment from men with learning disabilities themselves and do not take account of how negatively some women may feel about providing intimate care to men. Second, they inhibit the development of caring roles and caring cultures by men with the implementation of rigid boundaries in one direction excluding men from an important area of care and inhibiting conventional boundaries about the socialisation of gendered roles to be challenged. In the process potentially important resources for providing quality and sensitive intimate and personal care may be denied.

Third, such policies deny choice on the part of people with learning disabilities themselves, which is itself a central policy objective (Department of Health 2001). Although some men with learning disabilities may prefer intimate and personal care from women for inappropriate reasons – for example, they gain sexual gratification from the care interaction – some women may prefer intimate and personal care from a male carer for positive reasons, for example they have a good relationship and level of trust and empathy with the male worker and feel that this should be extended into intimate care relationships.

Fourth, and perhaps most worryingly from the viewpoint of equal opportunities and diversity policies, such policies represent heterosexist assumptions. Technically, of course, they leave both men and women with learning disabilities at risk of sexual abuse from homosexual male and female staff. However, this reduces to an invisible risk from homosexual female staff, given the

evidence about gender and sexual abuse. In relation to the assumed risk of abuse from homosexual men, interpretation of this same evidence would suggest that it is not so much the gender of the victim that is significant to the abuser, rather the exercise of power and control over someone who is vulnerable and relatively powerless.

Those receiving intimate and personal care are indeed the most powerless given their high levels of dependency on others, their likely lack of access to sex education and understanding of what is and is not appropriate in relation to sex and their bodies, and their relative lack of voice, either through poor expressive communication or through exclusion from participation and decision-making more widely in services. Policies on intimate and personal care and individual guidelines for care therefore have to give as much consideration to how powerlessness can be addressed as to gender in the care relationship or interaction. When considering gender, formulations need to be based more on the nature and quality of the caring relationship rather than on simple dogma about same-gender care.

Equal opportunities and anti-discriminatory practice

Equal opportunities policies and principles, along with non-oppressive and anti-discriminatory practice, are as important for guiding the provision of intimate and personal care as any other area of practice, as religion and culture have the potential to impact on how intimate and personal care is provided and by whom. Stark evidence points to discrimination in both access to and the quality of health social care services on the basis of race and ethnicity (Ahmad and Atkin 1996; Skellington 1992), underlining the importance of addressing race and culture in policy. This is also important in services for people with learning disabilities because demographic trends are pointing to increasing representation of minority ethnic groups (Emerson and Hatton 1999). This is important both for the support provided to individuals working on staff teams and for service users themselves. Teams have a particular cultural identity, experience or reality, and this may or may not mesh with those of individuals working on teams or those using their services.

In services where most people are unable to speak for themselves, staff culture is likely to be most dominant. This can result in intimate and personal care being delivered in uniform ways, reflecting the social norm rather than any diversity present in the user group. Gender, age and culture are all relevant to ensuring appropriate and respectful intimate and personal care interactions. Policy should state the ways in which such characteristics might inform intimate and personal care relationships, how cultural identity is to be assessed for a person with a learning disability (Newland 1999) and how processes of cultural assimilation may need to be countered.

Other considerations include how the culture or religion of staff influences their capacity to provide intimate and personal care and how the culture and religion of service users affects their capacity to receive intimate and personal care. In addition to gender and age matching where appropriate – for example, it might be disrespectful to have a young woman provide intimate care to an older man – policies also need to recommend priorities for matching care giver with care receiver on the basis of culture and race to help develop culturally appropriate care interactions. This will include examples of how intimate care can be provided across and within different cultures and religions, and there are unlikely to be rigid prescriptions. Everyone is part of a culture that operates at different levels – family, friends, local communities, wider communities of interest, religious and ethnic identities and sexual and gender identities – affecting the rituals of daily living (Hannah 1994).

Specific examples of good practice should be provided in policies, but also suggestions for the process by which staff and managers design culturally appropriate intimate and personal care. Individual arrangements can be agreed, for example, through discussions between team members or with team members from a particular culture or religion, both with regard to provision of care from their cultural perspective but also the receipt of culturally appropriate care. Rarely will generalisations apply, and often in the past some minority ethnic identities have been overgeneralised in ways disrespectful to religious, language and cultural groups and sub-groups, typified in the use of terms such as 'Asian culture'. Other ways individual arrangements can be mapped out include consultation with family or relatives, religious or cultural leaders and representatives or local community groups.

Staff sexuality

Same-gender policies also tend to make invisible the needs and feelings of lesbian and gay identified staff who provide intimate and personal care. This risks denying their feelings about providing same-gender intimate care and perhaps the concerns of their heterosexual colleagues about the appropriateness of such practices for homosexual staff. In such situations sexuality intersects with gender to compound the rigidity of such policies. Lesbian and gay staff interviewed in studies about intimate and personal care (Cambridge and Carnaby 2000b; Carnaby and Cambridge 2002) have indeed expressed their concern about what effectively amounts to heterosexist assumptions on the part of policy.

Policies should consequently examine the position and experience of lesbian and gay staff in the provision of intimate and personal care. They should, for example, acknowledge that homosexual staff should not automatically be expected to provide same-gender care, that in some circumstances it might be

appropriate for gay men to provide intimate and personal care to women and that it might or might not be appropriate for lesbian or gay identified staff to provide intimate and personal care respectively to lesbian and gay identified service users, depending on how useful such a support relationship might be for reinforcing positive lesbian and gay identities and positive self-image on the part of the service user.

Staff selection, recruitment and supervision

Policies should help to ensure that intimate and personal care is adequately addressed in a range of staffing and personnel processes. This is important to ensure adequate visibility is given to an aspect of social care work that has traditionally been hidden and unspoken about. How many advertisements for jobs in services for people with profound and multiple learning disabilities mention intimate and personal care and in how many interviews is this referenced as perhaps one of the most significant physical aspects of social care work? How many job and person specifications outline expectations or responsibilities for intimate and personal care?

Policies need to work systemically in increasing recognition of the importance of intimate and personal care through all aspects of staff recruitment and retention, underlining how it is a critical aspect of care for many people with learning disabilities – as well as many other groups. But policies need also to stress how it can become a positive aspect of a job and a quality aspect of the support provided to people with learning disabilities, helping move it from the hidden and unspoken realm of 'dirty work' to the visible and empowering realm of 'quality support'.

Part of the job of policies is therefore also to help determine and deliver appropriate staff development. Research on staff values and attitudes (Carnaby and Cambridge 2002) indicates relatively high ratings of dissatisfaction with intimate care tasks such as continence management compared to less intrusive personal care tasks such as hair care, which staff generally report as more satisfying. Such experiences mirror a society that devalues and stigmatises disability and dependency and that values ability, independence and the status of the individual. Training and staff support needs to be targeted at moving intimate and personal care from negative aspects of task completion to the positive aspects of quality interaction.

Training in intimate and personal care also needs to tie together the different policy domains relevant to working with high support needs, including adult protection, sexuality, infection control, equal opportunities and risk management. It needs to be grounded in the real issues that confront support staff and managers on a day-to-day basis in the provision of intimate and personal

care and enable and empower them to develop management and practice competence.

Working with agency and bank staff

Due to resource constraints and difficulties in recruiting and retaining staff and regular demands such as sickness and staff leave, most staff teams will be faced with the necessity to use staff from outside the team. Policies can provide important safeguards for ensuring that agency and bank staff are used appropriately and in a considered way in areas of support such as intimate and personal care where the risks of neglect, mistreatment and abuse are highest. Such risks may be heightened because agency staff may not be familiar with working with people with complex needs, may not be accountable in the same way as staff on the regular team and may not be as committed or experienced as the permanent staff.

Policy could stipulate that the use of agency staff is a last resort and that a bank team of workers known to regular staff and service users is employed under such circumstances, aiming to ensure that most gaps in rotas can be filled at short notice. If it proves necessary as a last resort to use agency staff, then they can be employed outside the provision of intimate and personal care. This frees time for regular staff to conduct more sensitive and individual work and care interactions. In either case, policy should stipulate the principles under which agency staff provide intimate and personal care should this ever become necessary (Cambridge and Carnaby 2000a). These stipulations might include:

- always asking the agency regularly employed by the service to send members of staff who have worked with the team on previous occasions
- not allowing agency workers to deliver intimate or personal care on their initial shifts if at all possible
- providing a thorough introduction to the service and the people using it
- explicit reference to the expectations and standards required for the conduct of intimate and personal care
- support, review and feedback, with discussion and information exchange.

In addition, control over the use of agency staff can be gained by taking a more proactive approach, such as visiting the agencies and talking to them about their values and approach, asking about training in areas such as empathic handling or intimate care or about their supervision and support arrangements, and

assessing their general competencies for working with people with learning disabilities and complex needs.

Integrating health and social care

Policy and practice in intimate and personal care for people with learning disabilities retains stark contrasts across services, agencies and professional settings. In my experience, different approaches tend to be taken between services in health and social care settings to providing intimate and personal care. In the former it tends to be a routine expectation and all staff are expected to provide or assist with care tasks, while in the latter it tends to be more socially constructed and regulated. This mirrors the differences between medical and health models on the one hand and social models of disability on the other. However, policies provide an important opportunity to bring together the health and social care aspects of providing intimate and personal care. For example, policies should encourage all staff involved in intimate and personal care to be alert to the illnesses and conditions which might only be identified at an early stage during such care interactions. Examples include oral hygiene and the presence of bleeding gums, sexually transmitted infections or urinary tract infections signified by vaginal or penile discharge, skin conditions such as fungal infections or eczema, signs of self-injury or self-harm such as skin picking or biting, lumps on breasts or testicles, ingrowing toenails or corns, thrombosis or swelling of legs or ankles, high temperatures and wounds such as cuts or pressure sores not healing, unusual body odours or bad smells in urine or faeces. These are only the key signs to look for, but a host of health issues are more likely to be spotted during intimate and personal care, helping develop a preventive approach that enables early intervention. Policies should alert staff to these and clearly articulate what to do if particular health concerns are recognised.

CONCLUSION

As argued, policies are not a panacea to providing good quality intimate and personal care for people with learning disabilities. However, if properly designed and implemented, they have the potential to help services develop competence in this important area of practice. I have come across situations such as an all-male team where men automatically provide intimate care to women with learning disabilities and challenging behaviour, assuming that this is acceptable. I have organised workshops where women participants have expressed a preference for intimate and personal care in a health care context to be provided by men, on the grounds that men are more considerate than other women when providing cross-gender care. Some cultures demand that women

provide intimate and personal care and others do not. There seem to be no hard and fast rules about what should or what does happen in the provision of intimate and personal care, but policies have the role and function of helping frame decision-making and guiding action.

Risk assessment and risk management are now central to much health and social care practice, and intimate and personal care is one of the highest risk situations in services for people with learning disabilities, with risks evident for both service users and staff. A risk management approach may be helpful in intimate and personal care in that it can help articulate responses and decision-making for difficult care tasks or for intimate and personal interactions in which difficult issues arise. High-risk situations include the presentation of sexual behaviour by service users during intimate care, balancing the rights of dignity and privacy with the risks of abuse in closed care settings and identifying situations where the risk of neglect is most likely.

Services and practitioners that fail to acknowledge and notify risk are more open to allegations of abuse, neglect or simply bad practice. On the other hand, it also needs to be acknowledged that an unhealthy obsession with defensive practice will itself risk staff and services entering into a mindset of the lowest common denominator of practice, with innovation and creativity stifled. But this is also why policy is so important in an area such as intimate and personal care, where consent to touch may be impossible to gauge, professional judgments may need to take precedence over legal considerations and effective practice uncovered through lateral approaches to care and interaction.

Ultimately, this reduces to the task of identifying what a policy on intimate and personal care might look like and need to cover. The following outlines have been developed to provide a model from which policy and guidelines can be developed. Policies will need to be tailored to the provision of good quality intimate and personal care in specific services and organisational contexts and individual guidelines will need to reflect the intimate and personal care needs of individual service users in the context of such policies. Both policies and guidelines will need regular review in light of experience and changing circumstances.

Policies

1. Introduction

- Statement as to why intimate and personal care is important.
- Statement of aims and intent of policy.
- Links with other policies and procedures, such as risk management, adult protection, sexuality and infection control.

2. Definitions and context

- Defining and differentiating intimate and personal care.
- Clarifying the range of care interactions and the different considerations for delivery.
- Acknowledging how these might be experienced by staff and service users.

3. Key principles

- Discussion of how key principles can be promoted during intimate and personal care.
- Choice, respect, dignity, privacy, confidentiality, independence and culturally appropriate support.
- Why these are important and the conflicts these might bring.

4. Key issues

- Identification and review of key management and practice issues.
- Care planning, same-gender care, sexuality, adult protection and the law.
- Examples and case studies of best practices in these areas.

5. Operational issues

- Rules for the use of agency staff and newly recruited staff.
- Support through supervision and line management.
- Key-working and management responsibilities.

6. Decision-making and responsibilities

- Use of individual guidelines and autonomy in decision-making.
- Where to get advice and support when needed.
- Need to know criteria and information sharing.

What might policy statements look like? The following provide simple examples.

Staff carrying out intimate care tasks will be provided with protective clothing such as disposable aprons and latex gloves. All staff should be aware of the safe methods for the disposal of soiled incontinence pads and other items soiled with body fluids and of used protective clothing. All such soiled items to be placed in the yellow medical waste bin.

Areas where intimate and personal care tasks are carried out should be private with a suitable amount of space available for completing the task with the equipment required. As a last resort a screen should be used if there is no suitable space.

Involve the user in all aspects of the care task using their own individual form of communication. Keep them informed of what is going to happen and what is happening, such as any transfers you need to make such as from a wheelchair to the toilet (all transfers should be supported by two members of staff). Where possible ask the person to indicate any preferences and let them know when you will be touching them and why. Be observant of any physical signs of discomfort or stress and reassure the person if this happens. Report any pressure marks, bruising or possible health issues.

Individual guidelines

1. Background to intimate and personal care for the person
 - Who leads and coordinates intimate and personal care for that person.
 - The role of the manager and key-worker.
 - Where more detailed information or accounts on intimate and personal care needs are held.
2. Outline of intimate and personal care task needed
 - The actual tasks the person needs help with.
 - Information on when and where help is usually required.
 - Guidance on how each task is best completed.
3. Care responsibilities
 - Who is best placed to conduct each task and why.
 - Who else is best placed to provide assistance.
 - What should happen in the absence of key staff.
4. Guidance on the care interaction
 - How to communicate most effectively with the person.
 - Responding to the person's preferences and choices.
 - Advice on how to make the interaction enjoyable and positive.

What might statements in individual care guidelines look like? The following provides an example.

Spare pads, pants and communication book are in Claire's shoulder bag. One member of staff to assist. Claire will walk only if holding onto someone's hand or with her walking frame, plus a little assistance and reassurance. She will need assistance in adjusting clothing and in sitting on the toilet. Tuck the toilet paper out of sight as Claire will often pull as much as possible onto the floor. Leave her for about ten minutes, checking

discreetly from time to time. When she is ready she will take a proffered hand and stand up. If she is not ready she will refuse to take it. Then assist her to dress and walk. Female staff should remind each other that Claire is on the toilet and to record in her daily communication book for her mother, whether or not she has had a bowel movement. Toilet times: 9.30, 11.45 (unless she prefers to go straight to the dining room), 1.45 and 3.45.

Currently we are trying to find out whether or not she wipes her bottom and whether we need to wipe her bottom for her. We are also trying to find out more about the significance of the different timings and why the careful monitoring of her bowel movements is necessary. Is it for her health or her mother?

NOTE

- 1 Protection of Vulnerable Adults Scheme, which 'acts as a workforce ban on those professionals who have harmed vulnerable adults in their care. It will add an extra layer of protection to...stop known abusers from entering the care workforce' (Department of Health 2004).

REFERENCES

- Ahmad, W. and Atkin, K. (1996) *Race and Community Care*. Buckingham: Open University Press.
- Alaszewski, A., Harrison, L. and Manthorpe, J. (eds) (1998) *Risk, Health and Welfare: Policies, Strategies and Practice*. Buckingham: Open University Press.
- Alaszewski, H., Parker, A. and Alaszewski, A. (1999) *Empowerment and Protection: The Development of Policies and Practices in Risk Assessment and Risk Management in Services for People with Learning Disabilities*. London: Mental Health Foundation.
- Alaszewski, A., Alaszewski, H., Ayer, S. and Manthorpe, J. (2000) *Managing Risk in Community Care: Nursing, Risk and Decision-making*. London: Bailliere Tindall.
- Bergh, P., Hoekman, J. and Ploeg, D. (1997) 'Case file research: nature and gravity of sexual abuse and the work method of an advisory team.' *NAPSAC Bulletin No. 18*, January. Nottingham: University of Nottingham.
- Brown, H. and Cambridge, P. (1997) 'Policies and their contribution to coherent decisionmaking.' In P. Cambridge and H. Brown (eds) *HIV and Learning Disability*. Kidderminster: British Institute of Learning Disabilities.
- Brown, H. and Stein, J. (1998) 'Implementing adult protection policies in Kent and East Sussex.' *Journal of Social Policy* 27, 3, 371-396.
- Brown, H., Stein, J. and Turk, V. (1995) 'The sexual abuse of adults with learning disabilities: report of a second two year incidence survey.' *Mental Handicap Research* 8, 1, 1-22.
- Buchanan, A. and Wilkins, R. (1991) 'Sexual abuse by the mentally handicapped: difficulties in establishing prevalence.' *Psychiatric Bulletin* 15, 601-605.
- Buckinghamshire County Council (1998) *Independent Longcare Inquiry*. Buckingham: Buckinghamshire County Council.

- Cambridge, P. (1999a) 'The first hit: a case study of the physical abuse of people with learning disabilities and challenging behaviours in a residential service.' *Disability and Society* 14, 3, 285–308.
- Cambridge, P. (1999b) 'Building care management competence in services for people with learning disabilities.' *British Journal of Social Work* 29, 393–415.
- Cambridge, P. (2002) 'Taking the risk: assessing and managing risk.' In S. Carnaby (ed.) *Learning Disability Today*. Brighton: Pavilion.
- Cambridge, P. and Carnaby, S. (2000a) *Making it Personal: Providing Intimate and Personal Care for People with Learning Disabilities*. Brighton: Pavilion.
- Cambridge, P. and Carnaby, S. (2000b) 'A personal touch: managing the risks of abuse during intimate and personal care for people with learning disabilities.' *Journal of Adult Protection* 2, 4, 4–16.
- Cambridge, P., Carnaby, S. and McCarthy, M. (2003) 'Responding to masturbation in supporting sexuality and challenging behaviour in services for people with learning disabilities.' *Journal of Learning Disabilities* 7, 3, 251–266.
- Cambridge, P. and McCarthy, M. (1997) 'Developing and implementing sexuality policy for a learning disability provider service.' *Health and Social Care in the Community* 5, 4, 227–236.
- Cambridge, P. and McCarthy, M. (2001) 'User focus groups and best value in services for people with learning disabilities.' *Health and Social Care in the Community* 9, 6, 476–489.
- Cambridge, P. and Parkes, T. (2004) 'Good enough decision-making? Improving decision-making in adult protection.' *Social Work Education* 23, 6, 711–729.
- Carnaby, S. and Cambridge, P. (2002) 'Getting personal: an exploratory study of intimate and personal care provision for people with profound and multiple learning disabilities.' *Journal of Intellectual Disability Research* 46, 2, 120–132.
- Department of Health (2000) *No Secrets: Guidance on Developing and Implementing Multi-Agency Policies and Procedures to Protect Vulnerable Adults from Abuse*. London: The Stationery Office.
- Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*. London: Department of Health.
- Department of Health (2004) *Protection of Vulnerable Adults (POVA) Scheme in England and Wales for Care Homes and Domiciliary Care Agencies: A Practical Guide*. London: Department of Health.
- Dunne, T. and Power, A. (1990) 'Sexual abuse and mental handicap: Preliminary findings of a community based study.' *Mental Handicap Research* 3, 111–125.
- Emerson, E. and Hatton, C. (1999) 'Future trends in the ethnic composition of British society among British citizens with learning disabilities.' *Tizard Learning Disability Review* 4, 4, 28–32.
- Hannah, C. (1994) 'The context of culture in systemic therapy: an application of CMM.' *Human Systems: The Journal of Systemic Consultation and Management* 5, 69–81.
- Hard, S. and Plumb, W. (1987) *Sexual Abuse of Persons with Developmental Disabilities: A Case Study*. Unpublished manuscript.
- Harris, J. (2002) 'From good intentions to improved practice – developing effective policies.' In D. Allen (ed.) *Ethical Approaches to Physical Interventions*. Kidderminster: British Institute of Learning Disabilities.
- Kent Social Services Department (2000) *Multi-Agency Child Protection Policy/Protocols/Procedures for Kent and Medway*. Maidstone: Kent County Council Social Services Directorate.
- Lee-Treweek, G. (1994) 'Bedroom abuse: the hidden work in a nursing home.' *Generations Review* 4, 1, 2–4.
- Macintyre, D. (1999) *Macintyre Undercover*, BBC1, 16 November.
- McCarthy, M. and Thompson, D. (1996) 'Sexual abuse by design: an examination of the issues in learning disability services.' *Disability and Society* 11, 2, 205–217.
- Murphy, G. (2003) 'Capacity to consent to sexual relationships in adults with learning disabilities.' *Journal of Family Planning and Reproductive Health Care* 29, 3, 148–149.
- Murphy, G. and O'Callaghan, A. (2004) 'Capacity to consent to sexual relationships among people with intellectual disabilities.' *Psychological Medicine* 34, 1347–1357.
- Newland, J. (1999) 'Assessing cultural identity in people with learning disabilities.' *Tizard Learning Disability Review* 4, 4, 20–24.
- Nind, M. and Hewett, D. (1994) *Access to Communication: Developing the Basics of Communication with People with Severe Learning Disabilities through Intensive Interaction*. London: David Fulton.
- Skellington, R. (1992) *Race in Britain Today*. London: Sage.
- Sobsey, D. and Varnhagen, C. (1989) 'Sexual abuse and exploitation of people with disabilities: towards prevention and treatment.' In M. Wapo and L. Gougen (eds) *Special Education Across Canada*. Vancouver: Centre for Human Development and Research.
- Turk, V. and Brown, H. (1993) 'The sexual abuse of adults with learning disabilities: results of a two year incidence survey.' *Mental Handicap Research* 6, 3, 193–216.
- Wheeler, P. (2004) 'Sex, the person with a learning disability and the changing legal framework.' *Learning Disability Practice* 7, 3, 32–38.