

PRACTICE ISSUES IN

sexuality

and LEARNING
DISABILITIES



Edited by ANN CRAFT

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Practice issues in sexuality and learning disabilities

Practice Issues in Sexuality and Learning Disabilities is designed as a practical guide for all those who work in services for people with learning disabilities. It will challenge service providers to re-evaluate the implicit and explicit standards which operate in relation to sexuality and sexual expression.

Ann Craft, the editor, has an international reputation for her work on aspects of sexuality and learning disabilities, and for this book she has brought together contributions from authors in Britain, Canada and the USA. Drawing upon professional expertise from a broad range of backgrounds—social work, education, psychology, psychotherapy, medicine—the contributors tackle the practical issues and dilemmas which confront all those who work with people with learning disabilities. The contributions range from a description of the development of a statutory agency's policy document on sexuality to a carefully detailed case example of sensitive work done with pregnant women with severe learning disabilities; and from a chapter on HIV/ AIDS and safer sex counselling to a discussion of the legal position in Britain with regard to sexuality and learning disabilities. They also discuss the problems of definition and response to 'difficult' sexual behaviour, and explore the issues raised by sexual abuse.

Down-to-earth and up-to-date in its approach, the book provides practical ideas and suggestions which will be of immense value and interest to all whose work brings them into contact with people with learning disabilities—professionals, carers, parents and advocates.

Ann Craft is Senior Lecturer in the Department of Learning Disabilities, University of Nottingham Medical School.

Practice issues in sexuality and learning disabilities

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Michael Gunn would like to point out that since his chapter of this volume; ‘Competency and consent: the importance of decision-making’ was written in 1991, there have been many developments. Most notably, the Law Commission has progressed its work on Decision-Making and Mentally Incapacitated Adults, with the production of three new consultation papers: *Mentally Incapacitated Adults and Decision-Making: A New Jurisdiction* (1993, HMSO); *Mentally Incapacitated Adults and Decision-Making: Medical Treatment and Research* (1993, HMSO); and *Mentally Incapacitated and other Vulnerable Adults; Public Law Protection* (1993, HMSO). That chapter should be read in the light of the contribution these papers make to the debate discussed therein, and in the light of the developments indicated therein.

1

Personal relationships and sexuality

The staff role

Ann Craft and Hilary Brown

INTRODUCTION

Whether members of staff are conscious of it or not, they play a central part in the personal relationship needs of people with a learning disability. They are inevitably drawn into a form of intimacy, in physical caring, in emotional responsiveness, in social activities and networks, which has no obvious parallel. To meet the demands placed on them they may draw on a range of models to guide them about appropriate involvement and boundaries, they may base their relationships on those they have with their children or siblings, with friends or colleagues, or on more established 'professional' roles such as that of a teacher, counsellor or social worker. Any of these may be valid, in whole or in part, but all imply different approaches to:

- goals of intervention
- style of work
- expertise and knowledge
- appropriate distance
- mix of control and empowerment
- accountability and openness.

By looking more closely at what these roles involve it is hoped that we can delineate a distinctive mode of working on sexuality issues, which enables staff to be more purposeful and empowering in their work with individuals with a learning disability.

The chapter has three main sections. First we will look at the general context of professional interactions between staff and individuals with a learning disability. Second we shall explore the various aspects of a positive staff role in relation to the personal relationships and sexuality needs of service users. Third, we will consider the needs of staff if they are to fulfil this positive role.

THE CONTEXT OF STAFF/SERVICE USER RELATIONSHIPS

Before looking specifically at the staff role in relation to client needs in the area of personal relationships and sexuality, we need to look at the general context in which professional staff interact with clients who have learning disabilities. As Brechin and Swain (1988) point out in their thoughtful analysis, 'Relationships between professionals and people labelled as having a mental handicap have their origins in past and present social structures and attitudes'. The authors characterise and describe the two main approaches to people with learning difficulties which have been prominent in the past fifty years—the medical approach and the educational approach. Both approaches:

assume that existing social constructions of normality define the goal to which people with learning difficulties must aspire; both define and understand the 'problems of mentally handicapped' people in such a way as to indicate clearly the impossibility of ever achieving that goal (the best hope being to build up patterns of skills which approximate to 'normal' behaviour); and both create a professional/client relationship which enshrines the professional in a world of exclusive and privileged knowledge, and consequently entombs the individual with learning difficulties in a fundamentally dependent role.

(Brechin and Swain 1988)

Brechin and Swain suggest that the aims of the comparatively recent self-advocacy movement, with its emphasis on self-actualisation and an open-ended process of growth, can be used 'as a kind of litmus test of appropriateness against which professional approaches can be measured'. Their outline for shared action planning (Brechin and Swain 1987) is an attempt to foster partnership, to build up a 'working alliance' (Deffenbacher 1985).

In conclusion, Brechin and Swain (1988) suggest that from the perspective of people with learning disabilities, a working alliance with professionals should seem:

- to be an entitlement rather than an imposition
- to promote self-realisation rather than compliance
- to open up choices rather than replace one option with another
- to develop opportunities, relationships and patterns of living, in line with their individual wishes rather than rule-of-thumb normality
- to enhance their decision-making control of their own lives
- to allow them to move at their own pace.

Each of these six points has relevance when we consider the personal relationship and sexuality needs of individuals with a learning disability and the way in which services and members of staff respond to them.

An important part of this context of staff/service user relationships is the 'increasing tendency to articulate a set of principles setting out what are believed to be the "rights" of clients' (Hudson 1988). Craft (1987) suggests six rights pertaining to sexuality:

- the right to grow up, i.e. to be treated with the respect and dignity accorded to adults
- the right to know, i.e. to have access to as much information about themselves and their bodies and those of other people, their emotions, appropriate social behaviour, etc. as they can assimilate
- the right to be sexual and to make and break relationships
- the right not to be at the mercy of the individual sexual attitudes of different care-givers
- the right not to be sexually abused
- the right to humane and dignified environments.

However, because of the nature of intellectual disability, societal attitudes and the structure of services, many individuals with learning disabilities require some degree of help and assistance in exercising those (and other) rights. This enabling process may take place at different levels, ranging from one-to-one counselling to the adoption of policy guidelines across a whole service.

THE STAFF ROLE

Staff members as role models

Whether staff members like it or not, whether they acknowledge it or not, they are enormously powerful in the lives of people with learning disabilities. Powerful in terms of the physical environments that are provided in day and residential services; powerful in terms of the social environments that they create; powerful in the spoken and unspoken feedback they give about client aspirations and behaviour; and powerful in offering models of adult men and women with adult lifestyles making adult choices (Bandura 1977).

Much of the modelling is at a very informal level. Nevertheless it has strong influences on many of the people with whom staff members come into contact. The way that managers interact with staff, staff with colleagues, with people with a learning disability, the way that staff members show pleasure, anger, approval, disapproval, that they are upset, that they are having an off day, all give

messages to others. Do members of staff model respect for the feelings and attitudes of others in the way that they talk to them? Do they respect people's need for space and privacy? Does the language they use accord dignity to people? Is it age-appropriate? The danger is that staff members' way of relating gives the message, 'do as I say, not as I do'. Implicitly staff may model one way of interacting with others, while explicitly they are telling those others that they should behave in a different way.

As in the example below, some of the models of adult interaction offered by members of staff can be a source of confusion and frustration to individuals with learning disabilities.

Gerald, a man with moderate learning disabilities, had recently moved from a hospital setting to a group home. After a few months staff asked for help in managing Gerald's 'aggressive outbursts'. On one occasion he had broken the windscreen wipers on a visitor's car, on another he had smashed the same car's headlights. He had also pulled his key worker's hair and threatened to punch her when she remonstrated with him for giving her a bonecrushing hug.

On investigation it transpired that Gerald, coming from a male hospital ward with male staff, was convinced that his female key worker's enthusiastic involvement in his progress and wellbeing was a sign of sexual interest. This misapprehension had been fostered unthinkingly by other members of staff, who at first jokingly agreed with Gerald when he referred to his key worker as his 'girlfriend', then actively promoted by teasing remarks such as, 'poor Gerald, your girlfriend's not here today'.

Gerald's key worker was inexperienced. She had not challenged Gerald's early references to her as 'my girlfriend'. As she said, 'I didn't think there was any harm in it, and he looked so pleased to see me I didn't want to spoil the relationship I was building with him'. Similarly, although she later commented that Gerald's physical approaches increasingly made her feel uncomfortable, she had not objected at first because she knew how emotionally impoverished his life in the hospital had been. The damaged car belonged to the key worker's boyfriend, understandably seen by Gerald as a rival for her affection.

Gerald, with few models to draw upon, was for a time confirmed in his beliefs by the explicit validation and repetition of his verbal claims, and by the acceptance of physical touch. Staff chose to amuse themselves with what they saw as 'only harmless teasing'; Gerald's key worker allowed her boundaries of personal space to be invaded on the mistaken assumption that she was somehow compensating for past deprivation, and that this and the joking remarks were justifiable because they increased the rapport she needed to establish as a good key worker.

While members of staff and the key worker were all clear in their own minds where the boundaries lay—that Gerald was not, and would never be her boyfriend—Gerald had no means of knowing this. The seemingly abrupt volte-face by his key worker and the disapproval of other staff when their limits of tolerance were reached confused and upset Gerald. It required careful reappraisal on everyone's part to arrive at acceptable boundaries of language and touch. Gerald paid an unacceptably high price in terms of his mental health, his self esteem and self confidence.

It is not only personal boundaries which can become confused in this way but more diffuse gender expectations and roles may be passed onto people with learning disabilities in contradictory ways. Despite equal opportunities statements and commitments, services on the whole replicate patterns of inequality within the home, with their predominantly female workforce but male management. Men with learning disabilities are thus offered role models of men 'in charge', who are able to command respect and use their status with the women who are employed as care staff, while they themselves are 'under' the control of those women. Men with learning disabilities react differentially to staff depending on their place in the hierarchy. Brown and Ferns (1991) filmed a black woman who reported an incident in which a resident had taken advice from a male care worker and from a white woman who was a deputy manager, but ignored her input. These issues are difficult to acknowledge but important. This man, while his behaviour, being racist and sexist, is unacceptable, is perhaps also trying to find out where *he* stands in the hierarchy, and how he *can* legitimately assert himself as a man in the way that he sees other men assert themselves.

Services may also pass on roles and expectations which are at odds with learned patterns of behaviour within service users' families and within their wider religious or cultural communities. 'Unisex' attitudes, which tend to prevail in mixed group homes, may jar with people who come from families which have fairly prescribed and *different* roles, rules and responsibilities for men and women. Helping men and women reach an acceptable compromise between traditional values and new or unfamiliar roles is something which requires adaptability and sensitivity on the part of staff rather than dogmatic and sometimes ill-informed idealism. In creating an environment in which men and women with learning disabilities can express 'gender' as well as sexuality, staff need to be aware of the backgrounds of the people who use the service and of the impact men and women's roles in either family or service environments have had on their skills, interests and aspirations.

Staff as teachers

Staff may work with individuals with learning disabilities in a number of contexts. Providing a member of staff is competent in, and feels comfortable with, setting up and running structured programmes covering personal relationships and sexuality, that person is in an ideal position to do so. She or he will know the students in the group well, and will have an understanding of individual needs. However, it should not be assumed that everyone will be comfortable with the more formal teaching role (see the section on training, p. 19).

There are now a number of teaching resources available, many specifically designed for students with learning disabilities, which offer an overall structure of personal, social and sexual education. See for example Brook Advisory Centres 1987; Craft and Members of the Nottinghamshire SLD Sex Education Project 1991; Dixon 1992; Dixon and Craft 1992; Craft, 1992. Each of these packs or programmes provides flexibility, so that the needs of individual students or groups can be accommodated.

Staff do not only have a role in setting up and running structured education programmes, but also, and very importantly, in responding to what educationalists call ‘the teachable moment’. This is when an opportunity to teach arises naturally from a situation or event. For example, when a person with a learning disability asks a particular question, or shows evidence of confusion about behaviour which is acceptable in private, but not in public. For staff members to feel comfortable with this aspect of their role they need policy guidelines and support from senior management (see section on staff needs below).

Staff as counsellors

Whether or not an establishment has a structured programme on personal relationships, some people with learning disabilities will need individual or pair counselling about aspects of their lives. Again, some staff members will not want to see themselves as counsellors, and others, who in principle would be interested to develop their skills in this area, need training opportunities to do so.

The need for counselling about personal relationships and sexuality can be seen at a number of different levels. The PLISSIT model offers a helpful way of looking at these levels (Annon 1974). PLISSIT stands for different levels of counselling and intervention: Permission, Limited Information, Specific Suggestions and Intensive Therapy. The model posits a decreasing number of clients at each of the levels, with the majority of people presenting for counselling only requiring the first level—permission giving. At this level the counsellor, by the non-judgemental and reassuring approach adopted, ‘allows’

the client to engage in behaviours in which they are already engaging, but which they think are abnormal; or gives permission to engage in behaviours they have been avoiding. When we think about people with learning disabilities, often the 'permission giving' has to include their parents and care staff in helping them to understand that it is to be expected, not abnormal, for such individuals to have sexual feelings and to want to give expression to those feelings. Moreover, for people with learning disabilities this permission giving may have to overturn previous, sometimes explicit 'prohibitions' arising from negative feedback and imagery. People with learning disabilities will sometimes be heard verbally admonishing themselves for their own sexual behaviour as they give voice to the previously unchallenged disapproval of those around them. Indeed there is evidence that as a group they have internalised attitudes about sexuality which are more conservative and negative than those of other people (Watson and Rogers 1980a, 1980b; Brantlinger 1985).

A smaller number of people will need more than permission giving and will require limited information directly related to their sexual concerns. A decreasing number of clients will require specific suggestions, with the counselling assisting them to set and reach goals. The final level of intensive therapy is needed by the least number of clients, but is the most serious and is likely to be long term rather than the relatively brief intervention at the other three levels. Intensive therapy requires a high degree of professional competence and should *not* be attempted by anyone who has not undertaken supervised training in sexual counselling.

This hierarchy is helpful to keep in mind because it signals that besides different levels of client need, there are also different degrees of professional competence needed. No staff member should be pressured to undertake work beyond what they feel is their level of competence. Sometimes staff fall (or get pushed) into the trap of believing that they should be able to answer every single question, be able to deal with every single difficulty or anxiety presented by the person with a learning disability. It is important to be clear that it is a very legitimate and professional position to recognise and acknowledge that there will be limits to everyone's expertise and individual members of staff should not be pressured into work that goes beyond that point. It should in no way be seen as a failure when a staff member engaged in counselling comes to a point when they need to ask for help themselves, or to refer the client on. Indeed, counsellors should have access to a supportive supervision system within which such concerns can be aired.

Liaising with other professionals and/or with parents

This will not be the role of every staff member, but in each setting it should be clear whose responsibility it is to do that liaison work. All too often day and

residential services operate in isolation from each other, to the detriment of the person with a learning disability who moves between both.

Part of this role will be acting as a 'broker' —bringing in or buying in services to meet people's needs. A prerequisite for doing this is to build up a network list of local resource people and services. For example, Health Education Units (see under your Health Authority in the phone book) are often useful sources of sex education teaching materials; RELATE may be able to suggest a counsellor or sex therapist; local Brook or family planning clinics may welcome organised visits; the HIV/AIDS Education Officer will have up-to-date information and may help with individual work or teaching (for example, over the course of a year in one Nottingham school for pupils with severe learning difficulties, the HIV/AIDS Education Officer came in regularly to work with older students, and run seminars for staff and a much-welcomed workshop for parents).

Where links on behalf of clients are attempted with generic services an important feature of the liaison role is to help professionals in those services to develop confidence and competence in working with people with learning disabilities. All too often the first response from those in a generic service is likely to be an inclination to exclude individuals on the grounds that their service is not designed for people with learning disabilities; the presence of a learning disability means that the person would not be able to benefit from the service; nothing in their professional training prepared them for working with such clients and they would not know where to start. However, there are ways of overcoming these hurdles. For example, it is helpful to make links with generic colleagues to discuss the possibility of any future referrals. This could be with staff at your local family planning clinic or with the Rape Crisis Centre team. You can also explore opportunities for joint working, bringing together a professional from services for people with learning disabilities and a generic specialist, each pooling ideas and strategies drawn from their own experience and training. It might be possible to set up sessions of counselling or psychotherapy for a client, jointly supervised by a professional from a generic service and one from the specialist service (Craft and Slack, in press). Fundamentally, the needs of people with learning disabilities are far more similar to those of the rest of the population than they are different, and many, if not all, of the strategies and approaches used by professionals in generic services will be applicable. Working in tandem can enable you to plan any adaptations which may be needed.

In liaison work, staff need to show sensitivity towards the anxieties of parents. Parents have very real concerns about the perceived vulnerability of their daughters and sons (Brown 1987). The parents of adults may never have had the chance to be supported in thinking through the implications of their offspring as sexual beings with physical and emotional needs. There are welcome signs that more and more schools are now working with parents along these lines (Craft

and Cromby 1991) but it is rarer for the parents of adults to have such opportunities. However, some helpful models do exist. See for example chapter two by Rose and Jones in this book; Lewisham Special Needs Sexuality Project (1988); Open University (1986).

Staff as protectors

As a group, individuals with learning disabilities are likely to have increased vulnerability to sexual exploitation and abuse (see [chapter five](#) in this book by Sobsey; Turk and Brown 1992)). Management and staff have a responsibility towards the personal integrity and safety of individuals with learning difficulties within care systems. Walmsley (1989) offers an analysis of the ways in which the organisation and delivery of services can enhance or decrease protection, and in his chapter in this book ([chapter five](#)), Sobsey shows how the ethos of an establishment can shape or 'license' staff behaviour that is exploitative or abusive.

We have referred to policy documents on the personal relationships and sexuality of individuals with learning disabilities. Another welcome trend is the development of procedural guidelines on service responses to the abuse or vulnerability of adults (Nottingham Health Authority and Nottinghamshire Social Services Department 1992; ADSS 1991; Brown and Stein, in preparation). The existence of guidelines puts the subject onto the official agenda of services, and also spells out individual staff members' responsibilities (see note at end of chapter on NAPSAC, and Brown and Craft, in preparation).

However, many dilemmas facing staff hover on the borders of definitions of exploitation and abuse. Where service users with differing degrees of intellectual and physical disability interact it is often open to individual and arbitrary interpretation whether one person with a learning disability is exploiting another. Brown and Turk (1992) help us explore the dimensions involved in the concepts of abuse and consent. As Gunn points out in [chapter six](#), the issue of capacity to consent is a thorny one. Where one or both parties has a severe learning disability and therefore capacity to consent is debatable (see Gunn 1991), [Figure 1.1](#) offers an approach which can clarify decisions and remove them from the domain of the individual staff member. (See also the role play exercise entitled 'We'd Better Call a Case Conference' in Brown and Craft 1992 which reminds us that different interested parties will have different agendas.) We suggest that the relationship or encounter giving rise to concern is analysed separately for each party, as it is important not to muddle their needs, intentions and impact on each other.

With sexual abuse staff clearly have a protective role to play. In other circumstances it is tempting for staff to steer either for the Scylla of over-

Figure 1.1 Exploitation or not?

(Use this form separately for *each* of the parties concerned)

Definition

- What is the behaviour which is causing concern (afterwards referred to as 'behaviour under review')? Be as precise as possible, ie.:
 - what can you see happening?
 - what are you afraid might be happening behind closed doors?
- Who is involved?
- What makes you think that the person you are concerned about is:
 - in distress
 - in need of protection
 - in need of intervention?
- Do you think that the person is under pressure:
 - physically
 - sexually
 - emotionally
 - financially?

protectiveness (where they actively, but unrealistically, attempt to prevent *any* emotional upset befalling service users) or the

Charybdis of *laissez-faire* (where nearly all forms of sexual risk-taking and expression are mistakenly seen as part of normalisation). Neither position is helpful to those with learning disabilities. Personal and sexual relationships have the potential for pain and heartbreak as well as pleasure; that is an integral part of the human condition. Some risks are necessary for learning and personal growth. At the other extreme, there is no comparable degree of risk-taking between, for example, a man without a learning disability who knows about safer sex but chooses on occasion not to wear a condom, and a man with a learning disability who knows little or nothing about HIV, little or nothing about condoms or how to put one on. Similarly, a woman with a learning disability, encouraged all her life to do as she is told, with little sense of personal danger, is engaging in risk through ignorance, not choice, if she agrees to go home with the man who picks her up at the disco. There *is* a path between over- and under-protection of service users. It will be a different path for different individuals, but the process of delineating it should be guided by service principles of good practice rather than be left up to one member of staff. Carson (1992) suggests that it would often be appropriate to subject any 'proposed intervention to a risk analysis, to ensure that the expected benefits sufficiently outweigh the anticipated harms'.

Staff as interveners

Where a particular sexual behaviour brings a person with learning disabilities into conflict with legal and societal boundaries, it may be necessary for staff to

- Has the behaviour under review begun recently, or does it have a long history?
- How frequently does it occur?
- What happens before/after the behaviour under review?

Background

- Under ordinary circumstances, how does the person you are concerned about usually indicate pleasure/distress?
e.g. — smiles, claps hands when parents arrive to take her/him out
— becomes withdrawn and moody, sleep disturbed when upset.
(Different staff may pick up different cues, so check with as many staff as possible.)
- Under other circumstances, how does the person you are concerned about protect her/himself or resist things they do not want to happen?
e.g. — makes high-pitched noise, resists physical prompts by running off or kicking out when s/he does not want to come in from the garden.
- Has this person had, or do they have, similar relationships/encounters with a number of other people?
- How does the person you are concerned about usually get on with the other person? Record views of different staff members.
e.g. — one party ignore other(s) except when s/he wants to engage in the behaviour under review
— often seek out each other's company.
- Has the person you are concerned about ever complained about the behaviour of the other(s) involved in the behaviour under review? Under what circumstances?
- Following the behaviour under review, has any physical harm to the person been recorded?
- Following the behaviour under review, do any of the parties concerned show signs of pleasure/distress? What are these signs?

Discussion

- What do you and your colleagues think are the advantages/disadvantages of the behaviour under review to the person concerned?

Recommendations

- Following information-gathering and discussions, what recommendations do you now wish to make?

Review

- Does the implementation of the recommendations need to be reviewed? If so, set a date to do this.
-

intervene. Indeed, as Carson (1992) asks, could service providers be seen as negligent for *not* intervening?

If a client regularly behaves in a socially inappropriate manner, for example, exposing himself in public, then his participation in the community and enjoyment of it, is likely to be reduced. He is experiencing

a significant loss. Failing to do something, to help this individual behave in a lawful and more socially acceptable manner, is not a neutral or a safe option for service providers.

(Carson 1992)

Carson goes on to spell out how an intervention process should be developed in ways that are consistent with standards of good professional practice.

Shelton (1992) describes a carefully monitored intervention to help a man with profound learning disabilities learn a masturbation technique which increased his low rate of ejaculation and decreased his high risk of self-injury. Mitchell (1985) offers a behavioural approach to interventions relating to sexual activity, which emphasises the importance of careful recording and clarity of definitions. Brown and Barrett in their chapter in this book ([chapter three](#)) help us tease out the complexities involved in what we label 'difficult sexual behaviour'.

Any intervention which aims at reshaping sexual behaviour should be carefully considered and planned. It should also be well documented, with clear reference to who is responsible for doing what, under what circumstances, over what time period and with what monitoring and evaluation. Crisis situations may require swift on-the-spot response, but no individual member of staff should take it upon her or himself to instigate a longer-term intervention relating to a client's sexual behaviour without the official sanction and support of the staff team, arrived at through the consultation process.

Staff as advocates and supporters of self-advocacy

In many areas, not least among them personal relationships and sexuality, a staff member may find themselves speaking up for people who, for a variety of reasons, are not able to speak powerfully or effectively on their own behalf. This may be to representatives of the management structure, to colleagues or to an individual's parents. The existence of policy guidelines relating to sexuality and individuals with learning disabilities can facilitate this role as the policy is likely to have clearly articulated individual rights (see section above on the context of staff/service user relationships and [chapter thirteen](#) by Fruin). These rights may need to be translated into the everyday operation of services. For example, what is the forum for discussing and reaching decisions about an individual client's needs in relation to his or her personal relationships and expressions of sexuality? Is it an automatic part of the IPP or review process (Jones *et al.* 1991)? If so, how is confidentiality guarded? If not, how do such issues get onto the agenda in a way that is not solely a response to a 'problem' or a 'crisis'? In any review, how are the religious and cultural dimensions of the person's life taken into account?

In recent years there has been a growth of local self-advocacy initiatives (EMFEC 1991; Whittaker 1991). These implicitly and explicitly encourage exploration of a sense of personhood—Who am I? How am I the same as others, how am I different? What do I like/ dislike? What do I want? How do I ask for what I want? How can I achieve what I want without stopping others from doing what they want? How do I see my future? There has also been an increase in opportunities to explore what it means to be a woman or a man with the label of ‘learning disability’ in women’s or men’s groups (see for example the videotape *Between Ourselves*). Any work done on self-awareness, personal integrity, decision-making, adulthood, relationships and sexuality inevitably spills out beyond the confines of the learning context into other areas of people’s lives. This is something to be nurtured.

However, if people with learning disabilities exercise more power, someone has to relinquish it—this may be the staff, it may be parents. It is not easy to do. Here we touch upon central questions of control, of protection, of best interests, of responsibilities. It moves us into the area of risk-taking, never an easy nettle to grasp, for staff or for parents. Power is very one-sided within most service structures—this makes it difficult for staff members to ‘hear’ or to treat seriously aspirations of service users which do not fit, which threaten to upset the system, which challenge a staff member’s sense of their own role as someone ‘in charge’, who ‘knows best’. But, as Brechin and Swain (1988) tell us:

Self-advocacy is in essence about a process of self-actualisation. It is about people coming to identify and express personal feelings, wishes and circumstances and coming to understand what contributes to the positives and negatives of their existence. It is about opening up ideas about the range of choices which could and should be available to them.

Any professional approach that does not concern itself with supporting and facilitating these same processes of growth for people with learning difficulties must be seriously open to question. Similarly, approaches which seem to imply a pre-knowledge of the aims and goals of other people’s lives, and lack the willingness to retain an open mind, to live with uncertainties, possibilities and transitions—these too must be seen as professional approaches with little to recommend them.

(Brechin and Swain 1988)

Staff as empowerers

This sums up the staff role. It is about enabling individuals by a process of encouragement, facilitation and the imparting of skills to exercise power over their own lives and to make their own choices at their own pace.

The process of support has to be an active one, for as Brechin and Swain (1988) point out:

It is too simplistic to suggest that by offering improved opportunities in a less restrictive setting, individuals with often severe learning difficulties, frequently additional disabilities, and histories of damaging experience, will thereby have *access* to improved, more satisfying life-styles. Access requires more than just the existence of possibilities.

Within the context of this chapter—personal relationships and sexuality—this means that:

- individuals with learning disabilities are encouraged to learn as much as they can about their physical growth and development, their emotions, themselves as sexual beings, risks and consequences
- opportunities for a rich social life are actively pursued with them and on their behalf
- individual sexual needs are addressed within an agreed professional structure which has a built-in partnership with the person concerned
- individual sexual needs are responded to in ways which accord dignity and respect and which take into account the person's religious and cultural values
- counselling services are readily available and accessible
- service delivery is guided by a written policy within which individual rights to privacy etc. are clearly delineated.

STAFF NEEDS

In order to take on the multifaceted role outlined above, members of staff themselves need an enabling structure within which to operate.

Managing the tension arising from ambiguities

In seeking to define a helpful stance for workers in relation to sexuality, managers of services need to be aware of conflicts at several levels. Individual staff members may shift from one role to another as the situation dictates, or in response to their own mood, experience or prejudices. They may for example be very facilitative to heterosexual couples who have agreed not to have children but act in a punitive way to same sex couples, or to partners who want to be parents. They may hover between being protective and taking a *laissez-faire* stance. There will also be differences within staff teams which, if managed well, enable group decisions to be more objective and balanced than judgements made in isolation. If conflicting views can be made explicit and respected (even if

disagreed with) they can provide additional safeguards to those service users on whose behalf decisions are being made and/or services are being delivered.

There may also be inconsistencies within the wider organisation, for example, liberal policies undermined by prohibitive resource decisions, or half-hearted support for empowering service users which is withdrawn at the first high profile decision which is contentious. Local politicians, lay management boards and the community at large may all put a restraining influence on senior managers.

Parents' groups may also seek to restrain and are often polarised from staff for many reasons (Brown 1987). The protective response they seek from staff may stem, in part, from their experience of the community's ambivalence to their sons and daughters and their more cautious approach to independence reflects their day-to-day contact with, and often responsibility for, the person's dependency needs.

Against this background it is easy to see why sexuality is a contentious issue and a cause of stress to staff. This stress which is often characterised as personal 'up tightness' has its roots in the organisation's inability to clarify a coherent agenda around sexuality issues. However clear the agency's explicit values with reference to supporting people with learning disabilities in seeking positive sexual options, there may also be a pull towards conservatism which is mirrored in the behaviour of individual staff.

It is important to clarify this divergence since it creates a tendency for services to become paralysed and to 'split off' opposing views. These splits fragment services' input along emotive 'fracture' lines with different stakeholders polarised on either bank. Permissiveness v. protection, staff v. parents, victim v. perpetrator, the list of false choices could go on. The reality is that services, if they are to square the circle, have to provide both protection and sensitive opportunities, they have to work with people who have been abused and with those who abuse others (sometimes in the same person, let alone service), they have to find ways not of excluding families but of bringing them in on the task of supporting adulthood and adult options.

Thus the real choice for services is not along those particular fault lines but about the extent to which they *actively* support and empower service users in their personal and sexual lives. Most services avoid difficult issues by 'lying low' and hoping nothing happens. Such an approach almost guarantees that nothing will happen, or that if it does it will be met with a 'containing' rather than empowering reaction. Sadly, this is as true of dealing with positive sexual relationships as with difficult sexual behaviour.

Sexuality, in effect, becomes a source of immense stress for staff whose personal values and professional skills jostle for place in this organisational vortex. An understanding of the sources of this stress will help staff towards a more appropriate role. Organisational analysts identify two kinds of stress where roles are problematical. 'Role ambiguity' is the technical term for the kind of

personal discomfort wherein individuals are uncomfortable about the role they are being asked to perform. 'Role conflict' describes the position of staff being asked to undertake incompatible tasks or roles, in situations where explicit aims are not consistent with unspoken agendas and where the result is confused expectations. Both of these situations are accurate predictors of staff stress, dissatisfaction and turnover (Handy 1976; Jackson and Schuler 1985). Both are common in relation to sexuality.

Policy guidelines

It is against this background that policy guidelines have to be formulated. As well as informing staff, guidelines work to put limits on role ambiguity and role conflict. Early guidelines such as those from Hounslow (1982) acknowledge the problem of role ambiguity and later guidelines develop the point and reassure staff that they will not be asked to be involved beyond a threshold of personal tolerance:

There are no doubt aspects of these guidelines which, on the basis of their own ethical or moral code, some staff might disagree with or find personally unacceptable. It should therefore be stated that there is no expectation that they should change their own standards. Equally, however they would not be expected, as professionals, to impose these standards upon their clients.

(Hounslow Social Services Department 1982)

Reaching an understanding of the sexual needs of someone with a learning disability is difficult for care givers. This is so because we are now coming to understand that it is simply not good enough either to ignore the issue or to respond only when and if an individual begins to act in overtly sexual ways. As the Social Services Committee statement puts it, there is recognition of **'the rights of adults with mental handicaps to understand, develop and express their sexuality'** within certain limits. Your role is more than, and subtly different from, the role of a friend or an outside advocate; it encompasses a specific duty to act, as an aspect of your professional task.

You may have definite views yourself about what is right and wrong in sexual matters, but at work you should be guided by this recognition.

(East Sussex County Council 1992, emphasis in the original)

Guidelines should thus attempt to outline a role which is consistently proactive and supportive, one which is 'professional' in the sense that it has proper boundaries and accountability built in and one which is consistent with the

philosophy of the service. By assuring staff that they do *not* have to be all things to all people, that, if they have used appropriate consultation procedures, they do not have to carry all the risks alone, guidelines should help staff to deal with role ambiguity.

A recent conceptualisation of job related stress is one set out by Karasek and Theorell (1990) which looks at jobs in terms of the level of psychological demands they present and the scope for decision-making and autonomy. Active jobs which incorporate a high degree of control tend to lead to 'healthy stress', whereas those in demanding jobs in which people have less control over decision-making run the greatest risk of psychological or physical ill effects. Since sexual issues, and care work in general, are inherently demanding we can see that a key function of guidelines must be to define the greatest possible leeway within which individual workers and teams can reach their own decisions. While stress is often characterised as the province of high-flying decision-makers, Karasek and Theorell are unequivocal that 'It is the bossed, not the bosses who experience most stress in our society...' and that it is 'constraints on decision making, not decision making per se which is the major problem for most workers'.

Guidelines then have two functions, to draw some acceptable boundary around the personal and the professional and to define the boundaries within which individual workers can respond as they think best. Since increased decision-making is the aim, training and information must be made available to equip front-line staff with the skills and knowledge they need to act authoritatively both on behalf of, and sometimes in relation to, service users.

Periodic formal reviews of policy documents can be the forum to re-evaluate practice, and should be an important feature of service organisation.

Training

Training is absolutely essential if staff are to be enabled to carry out the roles we have discussed. Training has to be on at least two levels. All staff need an *awareness* training—awareness that individuals with an intellectual disability have needs and rights in relation to their sexuality. They also need *information* on a range of issues such as local services, educational resources available, HIV transmission, pregnancy and so on. Such training can be given as part of an induction course or part of in-service work.

At a second level, some, but not all staff, will wish to undertake further training so that they can become the teachers and the counsellors. Such courses, if not available locally, can be had from a variety of national organisations, for example, the British Institute of Learning Disabilities (BILD); the Association to Aid the Personal and Sexual Relationships of People with Disabilities (SPOD);

the Education and Training Department of the Family Planning Association; Brook Advisory Centres, Birmingham.

Support

The support offered to staff by the existence of policy guidelines has already been mentioned. With the acceptance of such guidelines should come support from managers for staff working within the established procedures (Brown and Ferns 1991).

Not everyone in a particular setting will be involved in formal teaching or in counselling, but those who are should be able to receive support from colleagues, so that their work is not undermined. For this to happen there needs to be a system of feedback which does not sacrifice confidentiality, but which allows non-involved staff to be aware that counselling is still in progress, or that the sex education group has reached a particular point in the agreed curriculum.

An important source of support is via monitoring and evaluation. This can be on an informal basis, for instance by the co-teachers of a sex education group setting aside a regular time to reflect on the teaching session; or more formally, where for instance, a counsellor receives supervision from a qualified person.

In a number of areas people who work in different services for people with learning disabilities have formed a special interest group focusing on issues relating to sexuality and personal relationships. Such a group can fulfil several purposes—it brings staff members into contact with other supportive and concerned professionals; it offers a forum for discussing dilemmas, for reviewing new resources and for sharing ideas about good practice.

CONCLUSION

In this chapter we have attempted to define the different roles staff have to play in response to the personal relationships and sexuality needs of people with learning disabilities. These roles are played out against the background of the tenor and tone of professional interactions between members of staff and individuals with learning disabilities, and in the general context of the ethos of service organisations. As we went on to explore, the sexuality of service users throws up particular challenges, ambiguities and tensions both for individual staff members and for services as a whole. Policy guidelines, training and support are all required to enable staff to act positively, constructively and responsibly in response to the individual sexual needs of people with learning disabilities.

NOTE

NAPSAC (the National Association for the Protection from Sexual Abuse of Adults and Children with Learning Disabilities) is an information network for professionals and agencies. For further information contact NAPSAC Development Officer, Department of Learning Disabilities, University of Nottingham Medical School, Queens Medical Centre, Nottingham NG7 2UH.

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