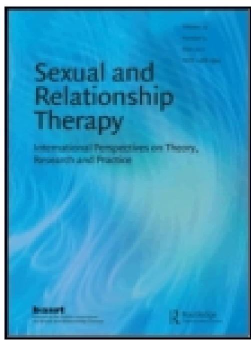

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R. Sheppard & R. Sheppard Dip H.S., Dip T.M.H.A., C.S.S., Manager

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AWARENESS PAPER

Sex therapy and people with learning difficulties

R. SHEPPARD
Strawford Centre, Blatchford Close, Horsham, West Sussex RH13 5QR

ABSTRACT *This article was written as an awareness paper, in an attempt to open up a field which has been devoid of therapeutic work by sex therapists for too many years. Firstly, it brings to the attention of the sex therapist the problems surrounding those with learning difficulties, and secondly it shows how this group of people should be helped by our skills. It starts by looking at societies' historical attitudes and responses to mental handicap, followed by the moves to community care, including a look at recent legislation, the principle of normalization and human rights. Areas of work for the sex therapist are divided into three divisions: (1) working with staff; (2) working with clients and (3) counselling staff. Case histories are given as practical examples of situations and work done to resolve them. As well as the physical aspects of sex and relationships a close look is taken at assertiveness, the right to say 'yes' and 'no' and the vulnerability of people with learning difficulties to sexual and other forms of abuse.*

Introduction

Throughout history people with a learning difficulty (mental handicap) have only been viewed as a social problem. Recent years, however, have seen a considerable increase in the therapeutic input to helping this group of people live fuller and more independent lives. Multi-disciplinary teams now exist with various therapies represented: speech therapy physiotherapy, occupational therapy, psychology, community nursing and social casework are all offered. Unfortunately sex therapy is often deficient.

The role of sex therapy, in the field of people with learning difficulties, offers an exciting and rewarding challenge. The individual therapist, however, will need to be very flexible both in structure and approach as greater practicability will be needed with this client group.

Historically, people with learning difficulties have been treated by the rest of society, in such a manner that the images and the roles created for them have

Note: the term 'social worker' is used, in this text, to describe residental, day care, community team member or any other social work professional taking on a key worker role with clients, as is modern practice.

devalued and segregated them. This has been identified by Wolfensberger (1975) as shown in Table I (Gilbert, 1985).

TABLE I. Historical attitudes and responses

Images and attitudes	Service response
Sub-human	
1. Lacks the emotional and physical needs of normal people. Primitive and unpredictable behaviour	No rights. Mentally handicapped people are segregated and controlled.
Threat to society	
2. A weak mind in a strong body with potential for unpredictable behaviour and procreation.	Control and segregation leading to a denial of freedom and possibly destruction.
The eternal child	
3. Catered for as children with no responsibilities but no rights either.	Stress on care but not on development.
Scapegoat	
4. Tolerated and cared for until society comes under pressure.	Segregated and perhaps killed at times of societal stress.
The uneconomic unit	
5. A burden on society when economic pressures are high.	Segregation into units to fit economics of scale and exploitation.
Burden on charity	
6. Judgement of weakness from a strong moralistic standpoint.	Basic needs are met in return for submission and gratitude.
Objects of pity	
7. Suffering individuals of whom no demands should be made.	Paternalistic. Shelter against risk. Low expectations.
Sick person	
8. Seen as sick and the passive recipient of medical care.	Hospital model of care with emphasis on diagnosis and prognosis. All matters come under the auspices of the medical practitioner.
Over recent years, however, there has been a change away from the old images and attitudes towards what Wolfensberger referred to as:	
Developing individual	
9. An optimistic view of the individual who is seen as having potential for growth.	Stress on individuality, dignity and personal responsibility.

The move towards care in the community was one service response to the concept of the 'developing individual'. This was foreseen by the Government, which, in 1971 published their White Paper 'Better Services for the Mentally Handicapped', which set target dates for the start of the move from hospital care, which was seen as being sexually repressive and over-protective (Bancroft, 1989), to smaller family-type hostels and community homes.

Two basic principles need to be considered when planning for the service needs of people with learning difficulties: normalization and human rights.

Normalization

Normalization was defined by Wolfensberger (1972) as "The utilization of culturally valued means in order to establish and/or maintain personal behaviours, experiences and characteristics that are culturally normative or valued." Normalization is not something that is done to a person—"It is a principle for designing and delivering the service a person needs" (O'Brien & Tyne, 1981). Griffiths (1990), sets out five facets to the principle of normalization.

(1) Community presence, i.e. creating conditions that provide as many opportunities as possible for individuals to experience a wide range of community settings.
(2) Protection of human rights and promotion of personal interest, i.e. staff provide organized support for people to develop the ability to choose, to communicate interests and preferences in everyday activities and where possible in programme planning and meetings.
(3) Competence development, i.e. building on individual skills, strengths and interests in order to decrease a person's dependency.
(4) Status improvement, i.e. develop and maintain a positive self-image for people and minimize negative stereotypes.
(5) Community participation, i.e. actively supporting people's natural relationships and widening each individual's network of friends to include increasing numbers of people who are not handicapped.

Human rights

The United Nations Declaration on the Rights of Mentally Retarded Persons (Williams & Shoulty, 1975) states: "The mentally retarded person has to the maximum degree of feasibility, the same rights as other human beings." This statement is put into practice and made reality by encouraging people, with help and guidance, to become independent, make their own decisions, and take their rightful place in society.

In its latest White Paper "Caring for people—community care in the next decade and beyond' (1990) the Government has taken these two principles and tried to turn them into reality by recognizing the need for change, reviewing funding procedures and providing an approach to achieving better care. Whilst this White Paper has a generic approach, it is particularly important to people with learning difficulties as it places the role of assessment, case management and securing the delivery of services firmly with the social services departments, "not simply by acting as direct providers, but by developing their purchasing and contraction role to become Enabling Authorities." This philosophy, whilst new to the United Kingdom has been in operation in Canada, under the title of 'Service Brokerage' for several years, where it has proved to be "an exciting new way of delivering services which allows real power to be passed to people with handicaps" (Brandon & Towe, 1989).

Whilst a lot of progressive forward-looking work is being carried out by health

authorities and social services departments to ensure that those with learning difficulties have their rights protected and can develop as individuals, the area of sexuality is often ignored or forgotten.

Many social workers, nurses and care assistants can talk of daily difficulties encountered with learning disabled clients, where the problem is of a sexual nature. Lack of knowledge, embarrassment, internal policies, codes of practice or external pressures may mean, however, that they are unable to implement suitable ongoing programmes for their clients, without the outside advice and assistance of a sex therapist.

There are three main areas of work where the sex therapist can be particularly useful:

(1) facilitating workshops for the staff group;
(2) working with clients, in a co-therapy role with a social worker;
(3) counselling to the staff groups.

Facilitating workshops for the staff group

This may differ from establishment to establishment, and from team to team, but before entering into work on sexuality with others, the staff will need to look at themselves both individually and as a group. Areas covered could include: How will this work affect relationships? Who feels comfortable taking on this task? Who doesn't? Do those who do not wish to be involved feel they can support their colleagues? Exercises similar to those described by Heather (1987) may be useful, to help increase knowledge and awareness of sexuality and understanding of personal relationships.

Working with clients in a co-therapy role with a social worker

Ideally, co-therapy pairs of a sex therapist and a social worker will be working with individuals and couples, but, being realistic of costs, groups of four to six are more likely in the early stages of the programme.

It is worth considering that clients' needs will, to a large extent, depend on their mental and emotional ability: for example, the closeness of a boyfriend/girlfriend relationship may be appropriate for some people; others may wish to have sexual intercourse; whilst others may need help with learning how to masturbate.

Andrew's story

Andrew is a 21-year-old man who is profoundly handicapped. He is doubly incontinent, and needs to be fed and helped with drinking. He is a happy and contented man, with a good sense of humour and reasonable comprehension. Although he has no speech he makes sounds to show pleasure and rocks when he wants to be turned. Andrew thoroughly enjoys being in the company of others, he enjoys swimming and going on outings.

Because of sexual frustration Andrew would spend most of his free time masturbating. However, because of his disabilities, he could only do this by rocking in his chair, or on the floor with his legs tightly crossed and held out straight in front of him. Andrew has been known to ejaculate by doing this, but only on rare occasions when his obvious delight and enjoyment prompted us into trying to help him masturbate more effectively.

Through observation of Andrew throughout the day and in different situations, we have been able to help him achieve this. By assisting him to roll over on his front on a firm floor mattress, covered in towelling, and ensuring he is free from the constraints of nappies and clothing Andrew is able to masturbate in a much more comfortable and self-controlling manner. By giving him a private free period like this each day, two of Andrew's management difficulties have been resolved. Firstly, as he is not constantly feeling frustrated, he does not spend all day trying to masturbate and, secondly, as a result his behaviour is now more acceptable to others. The consequence of this positive outcome is that his parents and other carers involved with Andrew are now happier to take him out more often so he can mix socially with others, which, as previously stated, is one of his great joys.

The method of presenting sex education/relationship programmes to people with learning difficulties, will be more or less the same as for any other group. However, as a consequence of limited social interaction, especially with their able-bodied peer group, these people may fail to develop psycho-sexually through observation of normal role models. Therefore it may be necessary to start the programme at a very basic level, as in the examples given below. Here, care must be taken to ensure that the language, material and methods used are presented in a manner appropriate to the clients age and level of understanding, that will neither de-value the individual or be too complicated for their level of comprehension (O'Brien & Tyne, 1981).

Self-image—I am a man
—I am a woman
Here the use of mirrors is particularly useful.
Questions can be asked—What do you see?
—Is your hair tidy?
Discussions can be started—Can you see where you have not shaved?
This type of work can be supported by the use of photographs, silhouettes, drawings and community facilities.

Differences Again questions can be asked:
—What is the difference between a man and a woman?
—Why do some men shave and some women wear make up?
—Experiment with make up, etc.

Jenny's story

Jenny, a 25-year-old woman with a moderate learning difficulty, had been taking part in an Independent Living Skills course. As part of this course the group did

some work on dress, i.e. appropriate clothing for weather conditions, what to wear for which occasion, etc. When the time came to transfer the learning out of the centre and into the community Jenny went into town on a shopping trip to give her the opportunity to put some of her newly learnt skills into practice by selecting her own choice of clothes. Jenny would not look at the women's fashions, but went straight to the children's clothes where she bagan to select inappropriate clothes for her age and shape. Whilst Jenny was able to accept at a theoretical level what she had learnt, because of her family background and limited experiences (having clothes purchased for her in her absence) she was unable to relate it to herself at a practical level.

As a result of the experiences learnt with working with Jenny in this way, it was decided to ask her if she wished the join one of our groups working on self-image and differences (as described above). To this Jenny agreed. Having the opportunity to explore herself and others in a safe, structured way, and given time Jenny was able to see herself as a woman and an individual and to acknowldge what this means to her and to others.

Jenny is now able, not only to recognize, but to select appropriate dress. Now with the help of her key worker, taking on the role of advocate and helping her communicate her needs to her parents, she is beginning to dress in a more mature manner. She has changed her hair style and is presenting in every way more of a young woman rather than an overgrown child. Jenny has accepted her identity as a woman.

Apart from sex education in its physical sense, it is anticipated that some clients will require help with the emotions associated with relationships and sexuality. This, in many respects, is a more difficult area in which to offer support. Like the rest of society, people with learning difficulties cannot be protected from the pain and joy of life. They have emotions like the rest of us, but they may need extra help and support in accepting and dealing with them. For example, they may need to be taught many things that are assimilated and accommodated by non-handicapped people during the course of normal development. These interpersonal social skills sometimes need to be actively taught (Mittler, 1979) to those with learning difficulties. Skills can be learnt, and, "there is a substantial body of evidence, both from research and from practice, which indicates that mentally handicapped people of all ages are able to improve their abilities and respond to skilled teaching... Development cannot be left to chance, it must be consciously fostered" (HMSO, 1977). With this positive statement in mind, possible topics for teaching and discussion could include:

—What is a relationship?
—The give and take of relationships.
—The responsibility of relationships.
—How to overcome disagreements.
—How to compromise, etc.

Other areas such as assertiveness and the right to say 'yes' and 'no' can also be investigated.

Assertiveness

"Assertion training involves a person in learning about himself and developing his own sense of self-worth and personal power as well as learning new skills to deal with the situation more effectively and assertively" (Townsend, 1985). For the person with learning difficulties, assertiveness is only effective if they can come to the point when they are able to feel equal to others. This is a very difficult concept even for most non-handicapped people to absorb into their own lives. Hence the number of people joining assertive training workshops and courses. Books on assertiveness training are very useful for planning, ideas and direction, but we must remember that repetition is the principle pedagogical tool used with people with learning difficulties to help them develop new skills. These can frequently be 'set up' in role play/drama exercises and can be as diverse as required to meet the individual needs of the group. This can be a particularly useful method of teaching and can be extended into social drama (Way, 1985). Extracts can be taken from television programmes and soap operas, stopping the video at the appropriate place and getting the group to discuss or explore outcomes, possibly acting them out. The Open University (1990) also has some useful tapes and resource material in this area.

The right to say 'yes' and 'no'

Saying 'yes' or 'no' is a matter of choice. The smaller choices like, "What shall I eat today?" are not very important to us, or those we come into contact with. What are important are the big choices like having sex or getting married. These are the choices that need thought and careful preparation if we are not going to hurt ourselves or others (Hollins & Grimer, 1988). People with learning difficulties find it much more difficult to make a decision as many of them have lived in hospitals, other institutions, or families where survival required that they agree and not challenge the authority that nurtured them. Others may never have been given the opportunity to exercise judgement let alone choice. They may therefore find it extremely difficult when faced with having to say 'yes' or 'no', especially if someone may be offended by the reply.

Ruth and Paul's story

Ruth is a 50-year-old woman, she has mild learning difficulties and moved into her own tenancy housing association flat two and a half years ago. Paul is 54 years old, again with mild learning difficulties but he has a physical handicap, walking with a zimmer frame. He is also registered partially sighted. Paul lives with his older, bachelor brother, who has looked after him since the death of their mother several years ago.

Paul and Ruth have just started spending weekends together in Ruth's flat. Paul expected Ruth to pander to his every need, which she did, dutifully, all day Saturday and Sunday. Paul was most upset that Ruth did not want sex every night and he felt

very rejected, especially having waited for over 2 years for his brother to 'allow' him to visit her for a weekend. For her part, Ruth was totally exhausted by bed time having had to care for all Paul's physical needs.

As a result of discussion, Ruth and Paul agreed that they needed help in order to resolve the problem. We looked for a concrete, familiar example on which to base our work—Paul is always trying to persuade Ruth to have a cream cake with her coffee break, to which Ruth nearly always refused as she is conscious of her figure. It was pointed out to them that they both feel OK about this, Ruth feeling at ease to say 'no' and giving a reason why. As a result Paul does not take her refusal personally. The next step was to transfer this understanding to their sexual problem. Ruth learnt that it is alright to express what she feels, making it clear to use 'I' statements, e.g. "I am too tired" instead of "you have worn me out." Within a short time Paul began to understand the problem from Ruth's point of view. We were then able to initiate discussion including alternative times for sex, this in itself becoming another teaching/learning situation.

Clients with learning difficulties are particularly vulnerable to sexual abuse because they have "increased trust in strangers and those close to them, an inability to determine what is appropriate behaviour in those caring for them, a tendency to more positive, obedient and affectionate behaviour, and often poor judgement" (Dunne & Power, 1990) Sex education will aim to prevent abuse, giving clients both physical and psychologic knowledge and awareness of their bodies (Rioux, 1988). Below are two examples of the vulnerability of people with learning difficulties from sexual, mental and physical abuse.

Cindy and Jim's story

Cindy and Jim have been living together for a number of years in their own tenancy council flat. They both have mild learning difficulties but Cindy is also registered as partially sighted.

Jim and Cindy arrived at the Day Centre one Monday morning both extremely agitated and very upset. They related the following to their key worker. On her way home from the local corner shop Cindy met one of their neighbours, a man, who invited her in for a cup of tea. As Cindy and Jim had both been in his home before she accepted willingly. During the course of conversation the man offered Cindy money to go to bed with him. Why she agreed she could not say, possibly a combination of fear, and pressure. Fortunately, he used a condom and was not aggressive or violent towards her. After it was over Cindy rushed home and told Jim what had happened. Jim broke down and within a short period was puffing on his inhaler as the stress had induced one of his bad asthma attacks.

Cindy wanted help from her key worker to ensure it would not happen again and Jim needed help to calm him down and to understand and control his anger, as he was ready to go and punch this man on the nose. This would do nothing more than put him in a vulnerable position, both physically and legally, thus increasing their problems.

Barbara's story

Barbara is 36 years old, has a mild learning difficulty and lives in a very run-down home with her ageing parents, where she has always done more than her fair share of household tasks—cleaning, shopping and cooking.

There has been a suspicion of unproven incestuous relationships since she had a termination of pregnancy several years ago. Recently, Barbara's 20-year-old nephew moved into the house and has made many more demands on her or as she puts it, "he treats me like a slave". He is violent and abusive towards her. In addition, Barbara's parents have stopped her short stays at the local hostel as they need her to do the extra housework and shopping. Barbara has got to the stage where she is saying that "life at home is not very good" and is asking to move into the hostel on a permanent basis.

Lengthy counselling, support, guidance, advice and sensitive co-ordination of a multi-disciplinary group of staff are all essential, if we are to help the abused client and families. The 'client group' need to understand what has been happening to them, how to adapt their lives accordingly and to come to terms with their individuality. Unfortunately, this task is not made any easier due to the fact that there is no clear legislation covering the abuse of adults with mental impairment. It is therefore essential that all those involved in the care and training of people with learning difficulties ensure that they have a full understanding of the physical and emotional aspects of sex. Clients also need to be able to say 'no' when necessary. If this fails they need to have the confidence, strength and assertiveness to inform key workers so that preventative action can be taken to prevent abuse becoming a pattern within their lives, thus robbing them of their rights to define their own actions and limitations.

Postscript

With the support of multi-disciplinary intervention and programmes similar to those previously described the following events have occurred. Jim and Cindy have since married and moved to a new flat on the other side of town. Jim is working at a local supermarket and Cindy still attends the Day Centre. Cindy tries to avoid getting herself into vulnerable situations, but if she does is confident she will be able to say 'no' as part of her newly attained independence.

Barbara moved into the hostel where she has settled well. She has done a lot of work both individually and in groups on creating a self-image with which she can live comfortably. She now does part-time voluntary work in one of the charity shops when not attending the Day Centre. She has a regular boyfriend in whose company she finds companionship and pleasure which is freely reciprocated. Thus she is finding her identity as a 'woman in her own right'.

Counselling to the staff group

Good social work practice is based on three elements of staff supervision: managing, education and support (Kadushin, 1976). It may, however, in practice be difficult, or unacceptable, for staff to discuss the implications and pressures brought about by this emotive work, with their line managers. By undertaking this counselling role,

the sex therapist can enable staff to cope with any personal feelings and changes that may occur, without affecting the managerial relationship.

In conclusion, people with learning difficulties are beginning to take their rightful place in society, and become valued members of their communities. If they are to achieve greater sexual freedom, then the sex therapist can offer a more active and supportive role in their development.

It is worth considering that it is not just social workers, care assistants, or sex therapists who want this change to take place, but the clients themselves. For, as Carol, a woman with a learning difficulty, said "I want to be with my boyfriend because I love him very much. My Mum and Dad don't want me to be like that, but my life is more important. I'm different to my Mum and Dad. My relationship with my boyfried is more important to me" (Atkinson & Williams, 1990).

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Contributor

R. SHEPPARD Dip H.S., Dip T.M.H.A., C.S.S., *Manager*