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Number KFC 84/141

PERSONAL RELATIONSHIPS AND PEOPLE WITH MENTAL HANDICAP

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July, 1984

Price 75p.

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This paper was written by Paul Chamberlain, Senior Clinical Psychologist, Coldeast Hospital, Portsmouth Health District. It was originally produced for care staff working in the Portsmouth and Southampton Area and is used in the training and induction courses there. It was felt it would be useful to make this paper available for discussion to a wider audience, and Paul Chamberlain would be pleased to receive comments at the above address.

CONTENTS

Personal Relationships and People with Mental Handicap - Guidelines for Care Staff

1. INTRODUCTION

"People with mental handicap are 'people first' and have the same needs as any other person. They also have the same civil and human rights as any other citizen".

"People with mental handicap develop personal relationships just as other people do and have the right to express their feelings within these relationships".

(a) Most of us would agree with these two statements, though, because of the controversial nature of people with mental handicap's personal and sexual relationships, it is true to say that we have tended to ignore or at best only partially meet these particular needs and recognise the rights involved. When we have considered these needs, our response has frequently been restrictive and protective. This is quite understandable; indeed it is difficult to provide the opportunity for social development and growth of personal relationships (with the possible risks involved) and yet protect people from exploitation. But there is "dignity in risk" and learning from experience in a controlled and adequately prepared fashion is something we all value.

(b) People with mental handicap do explore their own sexuality and care staff do make decisions concerning matters which are directly related to personal relationships involving their clients. Because of the lack of a set of clear directives, it is easy to see why Care Staff, albeit with the best will in the world, may make decisions concerning these personal relationships that limit rather than enhance a person with mentally handicap's learning experiences. Staff attitudes and behaviour heavily influence the development of their clients.

(c) It is clearly not acceptable for us to continue in this fashion. People with mental handicap need an appropriate educational input to help them to develop their personal relationship skills/feelings and they need to know where they stand if restrictions are placed on their behaviour because of their living environment. In the same way, staff need guidelines as well. They need to have a clear set of directives so that they are more able to gauge their responses to their clients, and so that they feel supported when making these responses.

(d) These guidelines are intended for the use of all staff who work with people with mental handicap. They are by no means the final word on the matter, and will need revising in the light of experience. It is hoped that they will provide sufficient direction for staff to (1) feel confident about responding positively to identified emotional/sexual needs of their clients, and (2) to encourage staff to discuss in a multi-disciplinary setting their own thoughts, anxieties, ideas concerning their clients' personal relationships.

(e) It is likely that individual care staff may find certain aspects of these guidelines personally unacceptable and contrary to their own ethical, moral or religious code. However, there is no expectation that staff should have to change their own beliefs/standards. Equally, however, as professional people, they should not want to impose their own beliefs/standards on their clients.

Staff will not be expected to undertake any activity which is likely to contravene the current law (which although restrictive is intended for our clients protection and must be respected) and throughout these guidelines it is indicated where the law is particularly important and the legal appendix should then be referred to.

2. THEORETICAL ISSUES

(a) Philosophy of Care

Views about people with mental handicap (their potential needs etc) have changed significantly over the last decade. We now recognise the fact that the people with mental handicap are people and have the same human value as any of us. They also have the same needs and the same civil and human rights as any member of our society. Developments in services to the people with mental handicap and their families must recognise these facts. This philosophical standpoint is often called "Normalisation".

(b) Normalisation

This is a word which has become linked to the field of mental handicap. It is a misleading word because it contains the word normal. That often makes people think that we are talking about "normalising" people with mental handicap i.e. making them "normal".

The word "normalisation" actually encompasses some very complex ideas that relate to the fact that people with mental handicap are not valued by society. It is this devaluing process which needs to be reversed if people with mental handicap are to have their rights and needs met, and be treated as 'people first' and handicapped second.

The principle of normalisation is 'simply' stated as follows:-

"The use of means which are valued in our society in order to develop and support personal behaviour experiences and characteristics which are also valued in our society".

(For further information see reading list attached)

(c) Privacy

Central to a fuller understaning of these guidelines, and within our overall philosophy of normalisation, we need to examine ways in which we can facilitate greater personal growth and responsibility. This will involve looking at, for example, how we can provide private spaces for both physical and emotional needs within our establishments, when often clients have to share 'bedrooms' and other facilities.

There seems little value in teaching people skills if we are not going to provide the environments in which they can practise and use these skills. Unless we provide an appropriate environment then the skills are unlikely to be practised and will soon be lost. Perhaps this question needs to be addressed before we can begin to plan appropriate instruction dealing with personal relationships!

(d) Taking Risks

Many of the more repressive aspects of institutional life have resulted from an attempt to create a risk-free environment. In reality, however, such an environment is unattainable and indeed undesirable, since the removal of an element of risk would seriously diminish the quality of life for residents and staff alike. It must be acknowledged by families and professionals concerned with the welfare of people with mental handicap, than an environment which allows an appropriate degree of personal choice and privacy can never be risk-free.

(e) Sex Education

There is no evidence that sex education will necessarily alter behaviour. However, the basic philosophy behind all education is that the individual if taught appropriately, internalises what is taught resulting in changes in behaviour which will affect the quality of life of the individual (Craft & Craft, 1982). If a person with mental handicap is given an appropriate education in personal and sexual relationships, and lives in an environment that encourages personal development by means of its physical layout (e.g. privacy) and staff attitudes, then that person will necessarily experience a higher quality of life and one which respects a person's civil and moral rights.

The argument really is not about whether a person with mental handicap should or should not have sex education - people with mental handicap are exposed to sexual attitudes and experiences in their everyday lives already. Their "current" education is almost totally experiential with reference to their residential environment.

The argument can be simply stated as follows:

Should people with mental handicap be given a planned education in the area of personal and sexual relationships with reference to their particular needs and abilities, or should they receive an unplanned 'experiential' education that will naturally occur within their living environment, and perhaps pay no heed to the needs and abilities of any individual.

3. PERSONAL RELATIONSHIPS

(a) When introducing the concept of sex education programmes to care staff it is perhaps understandable that many staff may think that the goal of such a programme is to teach people with mental handicap how to have sexual intercourse in a socially acceptable fashion. People then turn their thoughts to the most severely handicapped and the problems of informed consent, free choice and coercion and start to question the relevance of such a programme.

(b) It is important to remember that sexual behaviour is best taught in the context of developing personal relationships and that any programme should necessarily begin at a basic level that is 'easily understood' (e.g. differences between fully clothed males and females in terms of appearance) and gradually introduce the student to more complex ideas about the physical functioning of the body and the development of relationships from 'ordinary' friendship (e.g. hand holding and 'wanting to be with') to more emotional expressions of friendship (e.g. kissing and petting) before introducing the student to sexual intercourse as an expression of total caring.

(c) If a programme is planned in this way (from simple to the more complex) then it will be relatively easy to pace the progress of the teaching to the needs and abilities of the people with mental handicap in participating. Not all individuals will complete the course, especially when it gets into the more complex areas of birth control, pregnancy etc.

However, our duty is to help/educate the person with mental handicap so that he/she may function at an optimum level of ability. A flexible programme that presents material in an easily understood manner, and develops from the simple to the more complex, is most likely to meet this need. (See Appendix B)

4. PARENTAL INVOLVEMENT

In the past, parents have not been generally encouraged to contribute their own ideas to any training programmes designed to meet the need of their handicapped son or daughter. As a result many parents have gradually reduced contact with Training Centres or hospitals to a minimum. The contact they do have is frequently passive and often "subordinate".

A further result of this restricted dialogue between parents and institution is that parents are frequently not aware of the Philosophy of Normalisation on which many new developments are based. Indeed many parents may even seem on the surface to encourage some of the very restrictive and de-personalising practices that the philosophy argues against.

It is clear that parents should be included in planning services and teaching programmes at all levels.

As far as sex education programmes are concerned, the involvement of parents in curriculum planning should be part of the regular contact staff have with parents over all aspects of a handicapped son or daughter's training and care.

5. SEXUAL CONTACT

(a) Sexual Intercourse

A person with mental handicap has as much right as any other person to express his/her sexual feelings, albeit within the limits of the law. Whilst it is accepted that adults with mental handicap have this right, certain problems can arise when the person is receiving residential care. Life in an institution of any sort sets some limits on the freedom of the individual. One of our jobs is to balance these limits with people's needs and civil and moral rights. Our second task is to ask whether these "limits" are always necessary, and whether we can better meet the needs of our clients by reducing the limits and providing a relevant teaching input.

Sexual intercourse as a full expression of love and caring, would ideally be taught as part of the programmed educational plan (see Section 14). Clearly it is not always such an "expression" and occasionally the issue of consent among adults causes concern. Because of the communication problem that some people with mental handicap have, "free consent" can be difficult to establish and one has to "gauge" consent by the actions of the individual people concerned. In all situations, the issues should be discussed by a multi-disciplinary team before any action is taken.

Clients who either wish to establish a full sexual relationship, or who have already done so, should be given appropriate sex education/counselling on the relevant areas as outlined in these guidelines. They will also need counselling by a member of staff who knows them, on the effects their relationship may have on others living in the immediate environment. Group living requires consideration of and co-operation with other adults and this may need to be made explicit.

However, if two people with mental handicap establish a full sexual relationship and are expected to conduct the more intimate elements of that relationship in private, private places must be made available to them.

In arriving at a decision concerning contraception advice and/or allowing residents to share accommodation, the implications of the Law, particularly as it affects the severely mentally handicapped must be kept in mind (see Appendix A, Nos. 1,2,4,5,7 and 8).

(b) Petting

Interest in ones own and other people's bodies is quite normal and sexual exploration of ones own and other people's bodies occurs at every stage of normal development. Sexual exploration of others' bodies is often called petting and petting is a normal expression of sexual intimacy. As with many forms of sexual contact it is more usually the situation (where) in which the behaviour occurs rather than the behaviour itself which causes problems. In most cases, clients need to be taught what is socially acceptable behaviour and what is not. The age, ability and degree of maturity of the client will need to be considered whenever an intervention is planned.

(c) Masturbation

(i) Masturbation is a normal sexual behaviour which takes place among people of all ages and all levels of ability. As with petting, it is the occurence of this behaviour in public which usually causes problems for the client. The fact that masturbation is normal but should take place in private is usually all that needs to be communicated to the client. The most handicapped client can be taught that it is acceptable in one place but not another.

However, if masturbation is acceptable in private then private places must be available to the client.

(ii) If masturbation is deemed problematic by care staff, then it is necessary to ask why it is taking place. Boredom, release of tension, lack of instruction in socially acceptable public behaviour. Indeed, the "why" may differ from situation to situation, and needs to be taken into consideration when an intervention is planned. Some clients may masturbate for long periods of time without reaching any tension release or 'climax'. The "why" in this instance may relate to a skill deficit and this skill deficit may well constitute the client's problem.

(iii) Any problem associated with a client and masturbation should be discussed at a Care Review or multi-disciplinary case conference so that an appropriate programme that protects the staff's rights and meets the client's needs can be decided upon.

6. CONTRACEPTION

(a) Contraception, if used properly, is an effective method of avoiding unwanted pregnancies and although motives may be well intentioned, it has been used with mentally handicapped clients as a means of relieving staff or parental anxieties. However, the clients' needs are the most important consideration, and the use of contraception is not an acceptable alternative to a well structured educational/counselling programme.

(b) If contraceptive advice is given to clients then it is important that the relative merits and disadvantages are made clear to the client. Local Family Planning Clinics may serve as a useful resource to staff and staff should be acquainted with all such resources.

(c) Any problems associated with a client concerning contraception should be discussed at a Care Review or mult-disciplinary case conference so that an appropriate programme that protects the staff's rights and meets the client's needs can be decided upon.

7. STERILISATION AND ABORTION

(a) Sterilisation may seem to be a very effective solution to a person's 'sexual problems'. However, it is a drastic and usually permanent process and has serious implications (e.g. civil and legal rights) over and above that of its contraceptive value.

(b) Abortion is also an 'extreme' solution to an unwanted pregnancy and has similar serious implications.

(c) If sterilisation or abortion are to be considered, it is imperative that the client understands the implications and consents, free of any form of coercion.

(d) Parental demand for abortion or sterilisation may be insistent and one understands the fears which may prompt it. Nevertheless, the well-being of the handicapped person and the protection of their rights is the primary concern.

(e) If sterilisation or abortion are to be considered, then such a discussion should only take place at a multi-disciplinary team meeting with both parents and the client present.

8. PERSONAL HYGIENE

(a) Menstruation and Nocturnal Emmissions

Often the first 'naturally occurring' incident that will involve staff responding to 'sexual' needs of a person with mental handicap will involve issues relating to personal hygiene e.g. menstruation in women and nocturnal emmissions (wet dreams) in men. How staff respond to such occurrences are clearly important. Physical explanations are complex and may be too advanced for the person concerned, especially if they have not been part of a programme course of instruction. Staff should provide reassurance of the normality of such an occurrence in a sensitive and understandable way. Such incidents can provide the stimulus for further planned sessions of instruction.

(b) Sexually Transmitted Disease

The recognition/treatment and avoidance of sexually transmitted diseases would form part of any sex education training programme. Clearly, a large number of more severely mentally handicapped people will not benefit from the more advanced elements of the programme and will have decisions made for them by Care Staff. To ensure that such decisions are in the interests of the client and keep in mind personal freedom, choice, etc. such decisions should only be made at a multi-disciplinary Care Discussion.

9. PREGNANCY AND PARENTHOOD

(a) People with mental handicap have the same right as any other citizens to be parents. However, these rights have to be balanced with the responsibilities of parenthood. These responsibilities are the same whether the client is mentally handicapped or not.

(b) If clients wish to be parents then it is imperative that these responsibilities are discussed in depth and the clients expectations and needs identified.

(c) Some of the areas which need to be explored with the couple who wish to be parents are as follows:

i) Do the couple possess sufficient skills to live independently?

ii) Are there support services available which would enable or facilitate more independent living?

iii) Does the permanence of the relationship need discussing with the couple?

iv) Is genetic counselling needed?

v) What are the couple's expectations about being parents?

vi) Can the couple support themselves and a family financially?

d) Couples should be encouraged to discuss their plans for parenthood or pregnancy with a suitable member of staff and the staff member's approach to this should be discussed at a care review.

10. MARRIAGE/COHABITATION

(a) Wanting to marry a partner and live independently is a normal desire and if clients express such a desire then it is important that a suitable member of staff is available to discuss the various implications with them. The thought of people with mental handicap marrying has proved itself a controversial one though it should be borne in mind that we often demand guarantees that a marriage/ cohabitation between two people with mental handicap will 'work' whereas we do not make the same demand of a normal couple irrespective of their age, maturity or motives.

(b) If a client or clients express a desire to marry then the client or more preferably the couple, should be encouraged to discuss plans for marriage or cohabitation with a suitable member of staff and the staff member's approach to this should be discussed at a care review. Section 12 (d) of the Matrimonial Causes Act 1973 must be considered. (See Appendix A,6) So too should the law relating to the severely handicapped. (See Appendix 1,2 & 7)

(c) Cohabitation in an institutional setting may well cause staff problems. However, many institutions provide facilities for such couples and if the problem is only one of accommodation then this needs to be identified and dealt with.

11. SEXUAL VARIATIONS

(a) Unusual sexual practices are usually referred to as sexual variations. Such variations are as much a part of the sexual behaviour of many non handicapped people as they are of handicapped people. Such variations are occasionally seen in institutional settings and it is sometimes difficult to identify whether the behaviour is occurring through a real choice or whether the behaviour is a product of a restrictive environment.

(b) If such a behaviour is occurring and is either concerning staff or occurring in a public place, then the behaviour should be discussed at a mult-disciplinary care meeting. Issues such as choice, consent and environmental restrictions will need to be considered. It may be that the client needs only to be directed to a more private place.

(c) Although staff may find some sexual variations personally unacceptable it is nevertheless important not to necessarily impose our own moral views on our clients. Any action taken should be decided upon at a multi-disciplinary care review.

12. HOMOSEXUALITY

(a) Homosexual behaviour is a normally occurring sexual variation for a significant percentage of the population. Many staff may find such behaviour difficult to accept but it is important that they do not impose their own views on consenting mentally handicapped adults.

(b) Physical attraction to members of the same sex is considered by many to be a normal stage of development, and few people would call this mature homosexual behaviour.

(c) The counselling of clients who wish to pursue homosexual relationships should be similar to that given to hetrosexual clients. The need for privacy, full consent, an understanding of legal issues (see Appendix A, 3 & 4) and consideration of others would all be considered in any counselling contact.

(d) It can be argued that a person who has spent most of his/her life in a single sex residential environment, has had little opportunity to experience heterosexual contacts of any sort, and may indeed have little option than to explore homosexual ones. This should be considered when discussing any problems in a multi-disciplinary context.

13. PORNOGRAPHY

Pornographic and erotic material is freely available to the general public and an interest in pornographic material can be seen as a normal part of growing up and exploring one's sexuality. However, pornographic material is rarely instructive and can hardly take the place of a properly structured educational course when dealing with matters involving personal relationships. Clients should not be admonished for possessing pornographic or erotic literature but the situation could be used as a starting point for discussions concerning the distortions such literature perpetrates.

14. SEX EDUCATION/TRAINING

(a) Sex Education Programme

The value of beginning to teach sex education at an early age is now clearly recognised. It is important to respond postively to any enquiring question or deal appropriately with any exhibited sexual behaviour as and when it occurs. All are potential learning situations. And the learning experience is a function of the response made. Most mentally handicapped adults have had little or no programmed sex education and it is probable that any experiences they have had were distorted or inaccurate depending on the situation and source.

Appendix B gives some ideas for a gradually developing sex education programme. Education on sexual and emotional issues should be a continuous process and counselling should take place as situations arise. Clearly any planned programme must take into account the individual needs and abilities of the client. Not all clients will be able to undertake all elements of a planned programme, but programmes should be planned from the simple to the more complex so that any individual can remain 'in' until the limits of their abilities, at that point in time, have been reached.

(b) Staff Training - Counselling

(i) Care staff may find themselves faced with a sexual problem that needs dealing with immediately. They have to be sensitive and confident enough to respond to people with mentally handicap's needs as they arise.

(ii) Counselling services at their simplest mean that adults who are in contact with people with mental handicap should have thought out their own answers to sexual needs for themselves and the handicapped people with whom they are in contact. Their counselling or talking through should not consist of negative directions such as 'Don't do that' or 'that's bad, stop'. Care staff should be ready with a positive approach, so that when they see signs of sexual need or are asked questions of a sexual nature, they can say "that's important" and either discuss the need on the spot, or if it is not convenient, plan to discuss the issue at a more appropriate time.

(iii) Training and counselling people with mental handicap in issues concerning personal relationships is no easy task. Many staff may find the content of such a training course difficult to teach or personally embarassing. However, although a structured training course is best taught by an appropriately trained person, all staff will at some time or another be confronted with one or other of the situations referred to in these guidelines. They would be expected to respond in the best interests of their client and in line with the directions given in the guidelines.

(iv) It is the responsibility of the person in charge of any residential setting to ensure that all staff are acquainted with these guidelines and are given an opportunity to discuss their implications.

(v) If a structured course of training is required then the person in charge should contact the staff training departments that support the residence and its staff.

This paper was initially produced by Paul Chamberlain for care staff, working in the Portsmouth and Southampton area. It was felt that it would be helpful to make this paper accessible to a wider audience. PAUL CHAMBERLAIN would welcome any comments on the paper, at COLDEAST HOSPITAL, SARISBURY GREEN, SOUTHAMPTON SO3 6ZD.

APPENDIX 'A'

LEGAL ASPECTS

(a) Introduction

All Care Staff are rightly concerned about the legal implications of 'helping' the handicapped in matters of personal and sexual relationships. In a field as yet virtually untried in case law, each employing authority is entitled to its own view, which means that any case brought to law (in fact prosecutions under the following Acts have been rare and commonly failed) is likely to be tried on its own merits. (Craft and Craft 1982).

The law acts as a safeguard, protecting the 'helpless' from the 'unscrupulous', but where it can be shown that the service provided is, in professional judgement, a positive aid to the handicapped, it would be expected to protect those providing such services.

For a fuller explanation of the legal position see chapter 7 in the Crafts' book 'Sex and the Mentally Handicapped. A Guide for Parents and Carers'.

(b) The Relevant Acts

1. It is an offence under Section 7 of the Sexual Offences Act (1956) for a man to have unlawful sexual intercourse with a woman suffering from severe mental handicap unless he does not know and has no reason to suspect that she is severely mentally handicapped. This does not apply to those clients who are not severely mentally handicapped.

2. Section 128 of the Mental Health Act (1959) makes it an offence for a man to have unlawful sexual intercourse with a woman suffering from any form of mental disorder if the man is a manager of, or on the staff of a hospital or residential nursing home at which the woman is an in-patient, or to have such intercourse on the premises of any part of that hospital or home with a woman who is for the time being receiving such treatment there as an out-patient. This applies to any mental disorder.

   The same prohibition applies to guardians. In all cases, no offence is committed unless the man knows or has reason to suspect the woman to be a mentally disordered patient.

3. Section 1(3) of the Sexual Offences Act (1967) states that a man suffering from severe mental handicap, within the meaning of the Act, cannot in law give 'consent' to homosexual acts.

   Section 1(2) provides that an act which would otherwise be treated for the purposes of this Act as being done in private shall not be so treated if more than two persons take part or are present.

4. Neither a severely handicapped man or woman can give consent which, for any other person, would prevent any act from becoming an indecent assault (Section 14(4) and Section 15 (3) Sexual Offences Act (1956)).

5. It is prohibited for a person to procure a severely mentally handicapped woman for the purposes of unlawful intercourse. (Section 9 Sexual Offences Act 1956).

6 All people are entitled to marry and their marriage will be regarded as valid as long as it can be shown that they understood the nature and responsibilities of the "contract" into which they were entering. If either party did not give valid consent, the marriage is voidable, meaning it may be ended at the wish of either party. Under Section 12(d) of the Matrimonial Causes Act 1973, a marriage is voidable if "at the time of the marriage either party, though capable of giving valid consent, was suffering (whether continuously or intermittently) from mental disorder within the meaning of the Mental Health Act 1959, of such a kind or to such an extent as to be unfitted for marriage". This is rarely used as a ground for annulment.

7. Section 27 of the Sexual Offences Act 1956 makes it an offence for the owner or manager of any premises to induce or allow a severely mentally handicapped woman to be on the premises for the purpose of having unlawful sexual intercourse with a man.

8. Staff should keep in mind that it is an offence to assist the commission of a crime, which may arise even if a member of staff does not himself/herself commit one of the crimes referred to above.

APPENDIX 'B'

Principles of a Sex Education Programme

1. Identification of the different sexes.

2. Identification of body parts.

3. Discussion of body functions

   (a) Urination/defaecation
   (b) Menstruation
   (c) Ejaculation
   (d) Hygiene
   (e) Enhancing self image/attractiveness
   (f) Wet dreams

4. Relationships between adults.

   (a) Friends - physical contact
   (b) Holding hands
   (c) Embracing
   (d) Kissing
   (e) Petting - erections
   (f) Intercourse
   (g) Masturbation

5. Emotions

   (a) love, jealousy, guilt, anger, sadness
   (b) sex drive, frustration
   (c) development of emotions and relationships
   (d) dating

6. Birth control, Contraception, Sterlisation, Abortion

7. Pregnancy

8. Marriage and Cohabitation

9. Sexual variations, e.g. homosexuality

10. Pornography

11. Exploitation and self protection

12. Sexually transmitted diseases

13. Where to get help and advice on sexual and emotional matters

Suitable References

1. Sex and the Mentally Handicapped. A Guide for Parents and Carers. Revised Edition. Michael and Ann Craft. Pub. Routledge & Kegan Paul, 1982

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3. Guidelines for Planning a Training Course on Human Sexuality and the Retarded: W Kempton - Planned Parenthood: Association of South Eastern Pensylvania Philadelphia, 1972

4. An Ordinary Life - King's Fund Project Paper Number 24. Pub. King's Fund Centre, 126 Albert Street, London NW1 7NF, 1980

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Acknowledgements

The stimulus for sections of this paper was gained from a set of guidelines for staff working in the Home and Day Care establishments for Mentally Handicapped clients in the Hounslow area. The Hounslow Policy which is called "Sexuality of People with Mental Handicap - Guidelines for Care Staff", was the product of a working party of Social Services Officers from the London Borough of Hounslow, Homes and Day Care and Fieldwork Divisions.


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