To the Graduate Council:

I am submitting herewith a thesis written by Cristy F. Huntley entitled "Reducing Barriers to Sex Education and Counseling for Clients Who Are Mentally Retarded: Professional Views." I have examined the final copy of this thesis for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Master of Science, with a major in Special Education.

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REDUCING BARRIERS TO SEX EDUCATION AND COUNSELING FOR CLIENTS WHO ARE MENTALLY RETARDED: PROFESSIONAL VIEWS

A Thesis

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Master of Science

Degree

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ABSTRACT

Individuals who are mentally retarded need and have a right to sex education and counseling, yet systematic sex education and counseling is not widely available to this client population. Barriers inhibiting the development and implementation of sex education and counseling programs were identified in a pilot project. The main research question was formulated to explore how these barriers could be reduced: What would enable the staff of agencies serving adults or adolescents with mental retardation to provide systematic sex education and counseling for their clients?

Through the use of two survey instruments and a structured interview process, professionals of sixteen agencies addressed the issue of how to reduce the barriers. On the basis of the research data and a thorough review of related literature, the researcher made recommendations in five areas for enabling professionals to provide systematic sex education and counseling for their clients: 1) self-advocacy and self-determination for the client population; 2) individualistic program design; 3) staff training and support; 4) parental involvement; and 5) interagency cooperation. Two suggestions for further study were presented.

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CHAPTER 1

STATEMENT OF THE PROBLEM

Introduction

The revolutionary changes in treatment and care of persons who are mentally retarded, which began in the late 1960s, have steadily continued to the present. The processes of normalization and mainstreaming have created remarkable opportunities in education, vocational training and placement, community living arrangements, and recreation/leisure activities. It would appear that the sexuality of individuals who are retarded, however, continues to be largely ignored by many of their parents, by society in general, and by the professionals who serve them. Because sexuality is an integral and important aspect of any personality, ignoring this dimension in the lives of persons who are largely dependent upon others for education and training is to deny those individuals full personhood.

Purpose of the Study

This study is concerned with sex education and counseling with persons who are mentally retarded. The fact that sex education and counseling for this population is neither widely nor systematically available is established and the reasons inhibiting the delivery of

such services are explored. The research focuses on enabling staff members to move beyond the present barriers and develop and implement sex education and counseling programs which will help their clients lead richer, fuller lives.

Research Questions

The intent of this study is to determine ways of moving beyond present barriers which appear to be blocking the development of systematic sex education and counseling for persons with mental retardation. The main research question is:

> What would enable the staff of agencies serving adults or adolescents with mental retardation to provide systematic sex education and counseling for their clients?

Five sub-questions have been developed to facilitate the research:

1. What methods and evaluative tools could professionals use to assess the sexual needs of the individual client and to plan programming to meet those needs?
2. What methods could professionals use to sensitize parents, staff, and board members to the sexual needs and rights of their children and clients?

3. What resources do professionals need to provide better sex education and counseling for their clients?

4. What staff position within each facility researched can best be assigned the major responsibility for sex education and counseling?

5. In what ways could interagency cooperation enable individual agencies to provide better sex education and counseling programs to their clients?

Terms and Definitions

The term sexuality as used in this study is a comprehensive term which includes many specific issues and topics. Some of these issues and topics are expressed in the following terms: sex education and counseling, sex education programs, sexuality-related issues, sexual expression, sexual abuse, social/cultural attitudes towards sexuality, sexual development, sexual needs, and the concept of human sexuality. Whenever these specific terms are used, they are addressing a sub-topic of the broader topic of sexuality. The definitions presented below are employed for the purpose of this study.

Sexuality is the physical, psychological, intellectual, and social aspects of sexual being.

Sex education and counseling is the systematic dissemination of information regarding physical sexual

growth and development; and systematic attention to the physical, psychological, and social sexual needs of each individual at his level with the goal of facilitating whole and healthy personality development.

Systematic implies a high level of organization, quality, and consistency resulting in the individual educational and counseling needs of the client population being effectively met.

Persons who are mentally retarded refers to individuals who "manifest significantly subaverage general intellectual functioning (performance which is more than two standard deviations from the mean) existing concurrently with deficits in adaptive behavior during the developmental period" (Grossman, 1983). The corresponding levels of mental retardation and IQ ranges for the Stanford-Binet (Grossman, 1983) are as follows:

mildly retarded -- 67 - 52;

moderately retarded -- 51 - 36;

severely retarded -- 35 - 20;

profoundly retarded -- 19 and below.

When reference is made to levels of functioning, such references are based on this classification system.

Competent adult who is retarded is any person over the age of eighteen with retardation who functions legally without a court-appointed guardian.

Client population refers to persons who are mentally retarded who receive services from agencies or organizations which exist to meet their special needs.

Theoretical Assumptions

There are four assumptions which underlie this study.

1. It is best for society as well as for individuals who are mentally retarded if systematic sex education and counseling is provided for and with persons who are retarded.

2. The respondents were honest and open in providing information despite the sensitive nature of the topic.

3. Resource materials and resource persons addressing sex education and counseling for persons with retardation are widely available and offer a variety of approaches.

4. Sex education and counseling for persons with mental retardation is a dynamic area. New developments are occurring rapidly.

De-limitations

This study was limited geographically to the east Tennessee region of the United States. Within that area, there is a well-balanced mix of urban, rural, and small town settings. A possible influence related to

geography is a "Bible belt mentality" which was mentioned by four of the sixteen respondents as a possible inhibiting factor in implementing sex education and counseling with the client population.

The survey was limited to agencies who have service contracts with the Tennessee Department of Mental Health and Mental Retardation (DMHMR). No church-related or church-funded agencies were surveyed. The exclusion of church-related facilities may reduce the "Bible belt mentality" influence.

Resistance to Sex Education for the General Population

A study of twenty-three communities' experiences in the late 1970s revealed two main barriers to attempts to implement sex education: administrators' fear of opposition, more than opposition itself; and supporters' inadequate political skills (Scales, 1989). These reasons reflect the emotional and controversial nature of sexuality in our culture. Sex education is an issue which causes administrators to refrain from taking action at the mere thought of the opposition they might encounter. It is an issue which must be handled politically. Johnson (1981) described the main problem which proponents of sex education face: "In few other areas of human concern must the teacher or counselor be

prepared for such gross evidence of psychological conflict and irrationality" (p. 64).

Notwithstanding this cultural climate, recognition of the importance of sex education appears to be increasing. Between eighty and ninety percent of U.S. adults support sex education programs in the public schools (Kaplan, 1989; Scales, 1989). Support for such programs is strong in state education agencies and large school districts (Kaplan, 1989). Twenty-three states now mandate sex education and twenty-three more encourage the teaching of sex education (" 'Disaster prevention'," 1990).

Scales (1989) observes that while sex education in the schools has increased to the extent that most students participate in a sex education course, most of the programs are quite limited. Based on research showing that only fifteen percent of U.S. students participate in a comprehensive sex education course, Scales points out that this figure represents only a modest increase over ten percent receiving in-depth instruction in the early 1980s. Scales also deals at length with barriers still inhibiting comprehensive sex education in American society. The concept of human sexuality among professional theorists and educators has changed dramatically from a basically biological understanding to a holistic understanding (Welbourne-Moglia & Moglia, 1989). The

current concept views sexuality as a part of every person's life, from birth until death. Sexuality is a dynamic and essential element of human well-being (Welbourne-Moglia & Moglia, 1989; Hawkins, 1980).

Another characteristic of current sex education programs is that they generally respond to crises such as AIDS, teen pregnancy, and sexual abuse. Robert Selverstone, president of the Sex Information and Education Council of the U.S. (SIECUS), calls such an approach "disaster prevention" (" 'Disaster prevention'," 1990). He goes on to comment:

> All too few programs address the important questions for young people of affection, dating responsibility in relationships, communication and decision-making skills, and similar issues which dominate their thinking and feeling. (p. A-8)

This negative approach renders programs ineffective in facilitating students to attain overall sexual health and have meaningful sexual activity within mature interpersonal relationships (Kaplan, 1989).

Progress in the development and delivery of sex education is undeniable. Nonetheless, opposition and barriers rooted in strong emotions continue to prevent comprehensive sex education on a wide scale. Johnson (1981) observed, "Nearly all of us are mentally retarded with regard to sex, and many intellectually bright

people are not even educable or trainable in this respect" (ix). By facilitating mentally retarded individuals in their human quest for sexual identity as part of their wholeness, it is possible that society as a whole will be well-served (Johnson & Kempton, 1981).

Sexual Development and Persons with Retardation

From birth, children with retardation often receive negative reactions towards any display of sexual behavior (de la Cruz & La Veck, 1973). While most adolescents do not receive adequate sex education, such services for adolescents with mental retardation are even less adequate (Brantlinger, 1985). Although eighty-nine percent of the population with mental retardation functions at approximately the sixth grade level intellectually and socially, it is rare for adults and teen-agers who are mildly retarded to be provided with sex education (Abramson, Parker & Weisberg, 1988). Many administrators are overly cautious in dealing with sexual behaviors in their facilities and avoid responsibility for developing sex education programs. In addition, most residential facilities have no clearly stated policies concerning the sexuality of their clients (Brantlinger, 1983).

Monat (1982) paints a vivid picture of the plight of persons with retardation concerning their sexual

experiences:

> Included in . . . infantalization is the concept of asexuality or lack of sexuality, which extends to the lack of necessity for learning about one's self, one's sexuality, or one's psycho-sexual development. Therefore, as they go through the process of maturation, many mentally retarded individuals find themselves in a position where no one in their environment is willing to deal with or even recognize their developing sexuality. (Preface, x)

This inadequate attention exists despite twenty years of effort on the part of many professionals to improve attitudes and services regarding the sexual needs of persons with retardation. Sponsors of a conference on human sexuality and persons who are mentally retarded held in 1972 addressed the issue straightforwardly and with great conviction. The premise for the conference was that, "Mentally retarded persons share with the rest of mankind the usual human interest in closeness, physical contact, affection and being in on things" (de la Cruz & La Veck, 1973, p. 58).

The fact that mildly and moderately retarded persons go through the same sexual developmental stages from infancy through adulthood as the rest of the population is accepted in the health care and medical professions. Even though this development may be slowed due to mental and environmental limitations and conditioning, the needs and desires of this population are similar to those of the general population and should be

treated seriously (de la Cruz & La Veck, 1973; Monat, 1982; Craft & Craft, 1983; Evans, 1983; Daniels, Chipouras, Cornelius, & Makas, 1979; Monat, 1982; Taylor, 1989).

Legal and Human Rights of Persons with Retardation

The rights of persons with retardation to sexual expression, knowledge and information, physical/medical services, and counseling is often cited in the literature (Daniels, et al., 1982; Monat, 1982; Abramson, et al., 1988; Evans, 1983; Bernstein, 1985; Wolfensberger, 1982). Swedish young adults with retardation, in fact, included three items concerning their sexual lives in a "bill of rights" which they composed at a national conference in Malmo in 1970:

> We want to have leisure time together with other youngsters of the same ages.
>
> We want the right to move together with members of the opposite sex when we feel ready for it, and we also want the right to marry when we ourselves find the time is right.
>
> Even in institutions, we want to be able to go steady and live together with members of the opposite sex without having the personnel meddle in our private lives. (Wolfensberger, 1982, p. 190)

The President's Committee on Mental Retardation which met in 1974 in order to predict needs and plan services for the next twenty-five years, formulated a minimal set of seven rights for the retarded population,

one of which was the "right to marry and raise children" (Plog & Santamour, 1980). The Full Citizenship Task Force which wrote the set of rights underlined that these rights are guaranteed by the Constitution.

Eight specific rights related to sexual development are clearly stated by the authors of Who Cares? A Handbook on Sex Education and Counseling Services for Disabled People (Daniels, et al., 1982). The statement, ". . . mentally retarded people are sexual and will behave as such, which is their innate right," precedes the rights. The eight rights include: 1) right to sexual expression; 2) right to privacy; 3) right to be informed; 4) access to needed services; 5) right to choose marital status; 6) right to have or not have children; 7) right to make decisions which affect one's life; and 8) right to develop to one's fullest potential.

Developing to one's fullest potential is closely related to the right to be informed. The following quotation from an article about sex education in the U.S. (Welbourne-Moglia & Moglia, 1989) lays out a scenario of positive results to come from systematic sex education and shows the link between knowledge and individual development:

> Knowledge is exciting and powerful. It can help individuals feel a sense of control over their lives. Knowledge can give an individual a sense

> of hope and opportunity. Individuals prepared with this type of knowledge have the potential of returning their gift to the society. (p. 163)

The right to self-protection also mandates better sex education and counseling for persons with retardation. A recent study concerning legislation in Connecticut aimed at protecting adults with retardation from abuse showed an increase in the number of sexual abuse allegations since the legislation was enacted (Furey & Haber, 1989). The authors suggest that these statistics point up a need for educating adults who are retarded about sexuality, relationships, and sexual abuse.

Problems Associated with Lack of Sex Education

The absence of systematic sex education and counseling for persons with retardation is well-established in the literature (Abramson, et al., 1988; Brantlinger, 1983, 1985, 1988; Daniels, et al, 1979; Monat, 1982) and accounts for many serious problems. Evans (1983) states that ". . . sexual suppression of retarded persons precipitates the very kind of social deviance it is designed to prevent" (p. 257). The same point is made by Craft and Craft (1978), prominent British experts in this field:

> . . .the very behavior[s] [inappropriate masturbation and [homosexuality] that [were] originally feared [were] shaped by the enforced segregation from the normal emotional patterns of life and from members of the opposite sex. (p. 15)

Another problem created by not dealing with sexuality issues with this client population is that adolescents and adults may get into legal trouble or other difficulties because they do not understand the changes of puberty nor do they know how to deal with these changes and the feelings which accompany them. The fact that the sexual behavior of women with retardation over the age of fourteen is the greatest single contributing factor to their institutionalization (Evans, 1983) confirms the existence of this problem. Furthermore, the "sexual apartheid" experienced by individuals who are retarded in a society where others are allowed to develop sexually in a more natural and open manner is damaging to their already fragile self-esteem (de la Cruz & La Veck, 1973).

In his book The Lives of Mentally Retarded People (1983), Evans relates an anecdote that crystallizes the issue:

> A mentally handicapped friend of mine, in addressing all the prohibitions she faced in her desire to have a moderately mature sex life, gave about the best commentary on the whole issue I have heard: "Sometimes when you're retarded, a person can't win." (p. 266)

Descriptions of typical sexuality-related situations involving adults with retardation taken from this researcher's personal and professional experience are presented in Figure 1. This anecdotal material further

A thirty-nine-year-old woman was normal for her first thirteen years at which time she suffered brain injuries in an auto accident. Since then, she tests in the mildly retarded range, her speech is very slurred, her lips droop, her facial features are distorted, her gait is halting and unsteady, and she is afflicted by other physical handicaps. Shortly after the accident, her parents and family doctor decided it would be best to have her sterilized and the operation was performed. At a summer camp, she confided to a counselor that she is very bitter that this procedure took place. She also confided that she was in love with a staff member at the camp. There are few opportunities for her to share her feelings concerning sexuality or to be taken seriously in her home situation.

When a classroom instructor at a vocational training center returned to the classroom after stepping out for a few minutes, she surprised a young man and woman obviously engaged in sexual activity with each other. The flustered and embarrassed instructor reacted angrily, the couple feebly apologized, and the matter was dropped.

A vivacious young woman who is moderately retarded exuberantly showed an instructor/friend at her sheltered workshop two lovely rings given to her by her boyfriend. The instructor/friend admired the rings and then asked the proud recipient if her parents knew about the rings and the boyfriend. The young woman's smile quickly faded as she nervously stuffed the rings back in her pocket and shook her head.

A woman with moderate retardation who is in her fifties has been married for nine months. She is frequently seen holding hands, hugging, and kissing male clients at the day center she attends. The staff counsels her that her behavior is inappropriate, but is at a loss as to how to deal effectively with the problem.

A male teen-ager who is profoundly retarded lives in a group home where he masturbates on the beds of other clients, leaving messes. He also likes to rub women's feet and will even approach women whom he does not know and attempt to rub their feet. These problematic situations are handled differently by different staff people.

Figure 1. Anecdotal Material Illustrating the Need for Sex Education and Counseling

points up the need for and appropriateness of sex education and counseling for persons who are retarded, as well as their families. Despite these situations and similar ones, there are many signs of encouragement. A leading authority on the sexuality of persons with retardation, Sol Gordon, has expressed the opinion that many professionals and parents have finally reached the point of believing that there is an urgent need to address the sexual needs of persons who are retarded (Craft & Craft, 1983).

Resources for Sex Education and Counseling

There are numerous sex education currucula available designed especially for persons with retardation. When a variety of topics is offered at workshops for professionals who serve the client population, sessions concerning sexuality issues are frequently offered. Planned Parenthood, the Association for Retarded Citizens (ARC), and other organizations as well as individuals, offer training and education for professionals. Materials and equipment such as anatomically correct dolls and mannequins and board games which specifically address the learning levels of the client population are continually being developed and are readily available.

Two nationally syndicated television shows with a panel discussion format have recently dealt with the topic of sexuality and persons with retardation. One panel addressed the broad topic and the other was concerned with persons who are retarded becoming parents. Both panels included professionals as well as adults with retardation who expressed their beliefs, feelings, and experiences coherently and honestly.

Existing Systematic Sex Education: Results of a Pilot Study

Presently, however, persons with retardation do not appear to have widespread access to systematic sex education and counseling. This state of affairs is supported by a pilot study which this researcher conducted (Huntley, 1989). The study involved seven agencies in metropolitan Knoxville, Tennessee, which provide services for 315 persons who are mentally retarded. The findings revealed that not one of the seven agencies surveyed provided systematic sex education and counseling for its clients. Six out of seven of the administrators contacted expressed the conviction, nonetheless, that such services are appropriate, desirable, and important.

The study also included an intensive examination of the reasons, and combinations thereof, which inhibited these agencies in the development and implementation of

sex education services for their clients. Six of the seven agency administrators participated in an interview which focused on the inhibiting factors. Table 1 presents the factors which were identified and the frequency of identification. The percentage of participants identifying each factor is also included.

Many of the responses were accompanied by qualifications, explanations, and experiences. Certain statements were made with a doubt factor. "Resistance of parents" was cited as a very important inhibitor. Three respondents stated, however, that they were not sure how strong this resistance really was, as the matter had not been raised in a clear manner with all parents. This same speculative quality applies to "resistance by board members."

Qualifications concerning "lack of suitable curricula" included that a serious search had not been made and also that good curricula had been found, but did not pertain to all mental levels. "Socially controversial" was qualified as a protective rather than a hostile attitude by one respondent and perceived as pertaining only to sexual intercourse between clients by another. "Lack of funds" was considered a minor factor by two of the three respondents who cited it.

The "low priority" factor is interpreted by this researcher as a product of other reasons than simply low

TABLE 1

PERCEIVED FACTORS INHIBITING SEX EDUCATION & COUNSELING IN SIX AGENCIES

Inhibiting Factors	# of times cited (n=6)
resistance of parents	4 (75%)
lack of staff trained in this area	4 (75%)
lack of suitable curricula	4 (75%)
low priority in view of more pressing concerns	4 (75%)
social controversy	3 (50%)
lack of funds	3 (50%)
resistance of board members	2 (33%)
insufficient staff time allotted for program development	2 (33%)
lack of administrative leadership, including lack of an agency policy re. sexuality	2 (33%)

priority. The negative forces of resistance and controversy, not generally associated with areas such as vocational training or community travel skills, combine with other barriers, such as "lack of funds" and "insufficient staff time," to give sex education a low priority. The unpleasantness of resistance and controversy may, in fact, cause professionals to refrain from attacking other inhibiting factors aggressively. The result in these six agencies seemed to be a static condition regarding the development of sex education and counseling programs for their clients.

Summary

Society and the professional community serving persons with mental retardation are making great strides in recognizing this special population as whole persons. An important part of wholeness is sexuality and yet sex education and counseling for this population lags far behind development in academic, vocational, residential, and leisure/recreational areas.

A pilot study found that not one out of seven agencies serving adults or adolescents with mental retardation was providing systematic sex education and counseling for their clients. Six out of the seven agencies, however, expressed a desire to develop better services in this area. The researcher did an in-depth study of

the factors these six agencies felt were inhibiting their progress in developing sex education and counseling.

The present study focuses upon moving beyond the inhibiting factors by asking professionals who serve clients who are mentally retarded what would enable them to provide better sex education and counseling within their agencies. On the basis of the suggestions, ideas, and experiences of the professionals, the researcher will draw conclusions about the best ways for agencies to approach the development and implementation of systematic sex education and counseling for persons with mental retardation.

CHAPTER II

REVIEW OF THE LITERATURE

Overview

Historically, the sexuality of persons with retardation has been treated quite negatively in relevant literature. Society holds immature, negative attitudes towards sexuality and towards disability. The combination of the two creates a high level of discomfort resulting in avoidance, if not hostility (Daniels, et al., 1979; Monat, 1982; de la Cruz & La Veck, 1973). Referring to sexuality and disability as taboos, Johnson (1975) aptly observed, " . . . the mind tends to be fascinated by each taboo, but is rendered inoperative by the two in combination" (p.5). Craft (1983) observes, however, that there has been a dramatic shift of emphasis in the literature from the negative consequences for society of sexual expression by persons who are retarded to a positive approach concerned primarily with the rights and needs of this special population.

Common Myths

Background information for a discussion of the sexuality of persons with retardation in current literature often includes the listing of various myths which have

been operative in the culture. The fact that these issues and attitudes are described as myths when once they were discussed as legitimate scientific, moral, and social problems illustrates the positive shift to which Craft referred. The shift is not complete, however, and these myths continue to have impact. They must be included, therefore, when exploring positive approaches to providing systematic sex education and counseling with persons who are retarded.

These seven myths are accompanied by alternative viewpoints and/or corrective information. This material is taken from a variety of sources (Daniels, et al., 1979; Wolfensberger, 1982; Craft & Craft, 1978; Evans, 1983).

Myth	Reality
1. Persons with retardation are asexual. If one is partially disabled, one is completely disabled.	Presently, it is accepted in the health care and medical fields that persons who are mildly and moderately retarded follow the same developmental pattern of sexuality as non-retarded persons (de la Cruz & La Veck, 1973). The sexuality of persons who are severely and profoundly retarded is more mysterious, particularly in regard to psychological and emotional areas; but the majority of them go through the same biological growth and development as non-retarded persons (Monat, 1982).

Myth	Reality
2. Persons with retardation are oversexed. Individuals who are retarded are viewed as animal-like and bestiality is associated with their sexuality.	One study found the opposite to be true. A research project in a 2000-bed facility for retarded persons with limited staff supervision found that the residents employed great sexual restraint. On the rare occasions that sexual intercourse occurred the persons involved expressed guilt and remorse. They were also admonished by their peers (Craft & Craft, 1978). Perske (1972) has had considerable experience and involvement in this area and he comments that most persons with retardation exhibit remarkable sexual self-control.
3. Persons with retardation are dependent and childlike. They must be protected. Sexuality is avoided and denied. Dependence and helplessness are sometimes unwittingly encouraged. There is a prevalent attitude even now that "if we don't tell them about sex, they won't think of it."	This "eternal child" viewpoint is archaic in the modern world where independence and developing to one's fullest potential are basic principles in services for the client population. Age-appropriate activities are stressed and sexuality must be dealt with as an important part of the maturing process (Monat, 1982). The protective environment has left retarded persons psychologically and physically endangered (McCarthy, 1984).
4. Women who are retarded are more fertile than non-retarded women and are likely to produce more offspring.	At least two studies cited by Craft and Craft (1978) have found women with retardation to be of average or slightly below average reproductive ability. The most important consideration in this issue is that modern birth control methods deal in a positive way with this concern. What is crucial is providing the client population with knowledge of and access to birth control methods.

Myth	Reality
5. All parents object to sex education for their children with retardation.	This is not universally true anymore, reflecting the trend with parents of non-retarded children. Often, there is a sense of relief on the part of parents when the subject is raised and they have some support in dealing with the sexuality of their children (Daniels et al., 1979).
6. Sexual satisfaction is dependent upon reaching orgasm during sexual intercourse.	It is vital when dealing with the sexuality of persons with retardation to foster other options for physical sexual satisfaction since the restraints of their residential and social situations may prevent sexual intercourse. Masturbation is the most common alternative and is a natural and healthy means of sexual expression (Monat, 1982; Johnson & Kempton, 1981).
7. The sexual problems of individuals with retardation always stem from their retardation.	Persons who are retarded may suffer from sexual dysfunctions or be able to benefit from counseling concerning psychological or emotional aspects of sexuality. The inaccurate assumption that any sexual problem stems from the retardation would discourage such a therapeutic approach (Daniels, et al., 1979).

Elements in the Design of Sex Education and Counseling for Persons with Retardation

Professionals in the area of sex education and counseling for persons with retardation have provided numerous models and resources to aid other professionals

in planning for their client population. Naturally, there are elements which are repeatedly addressed in this body of literature. For the purposes of this discussion, these elements have been categorized into five broad areas: parental involvement, community-based planning and implementation, selection and support of facilitators, content, and client sensitivity.

Parental Involvement

Sensitivity to the parents of persons with retardation and respect for their feelings seems to be considered basic to a sound sex education and counseling program. Monat (1982) expresses this sensitivity:

> Most parents want very badly for their children, regardless of handicap, to have the fullest life possible. Nevertheless, it is very difficult for most parents of mentally retarded individuals to admit to their offspring's becoming sexual. The parents see this factor as the beginning of endless frustration. The parents just cannot see any end that will allow the mentally retarded offspring to feel and experience those sexual experiences which the parents have found to be meaningful to them (p. 78).

An example of parental frustration is seen in the comment of one father: "Why bring sex into these children's lives? Do they understand any part of it? . . . why expose the retarded to this?" (Selders-Powell, 1980, p.38).

In a study of parental and teacher attitudes, Hawkins (1983) surveyed fifty-one teachers and forty-four

parents and found that ninety-five percent of them felt sex education was important for their students and children. One hundred percent felt sex education should be shared between home and school. The most frequent parental attitude encountered in another study cited by Hawkins was, "I want to do the right thing, but I don't know what is appropriate." Some parents will not want to be involved, but all should be included to the extent they each desire (Johnson & Kempton, 1981).

In relating the perils of not involving parents, Kempton (Johnson & Kempton, 1981) describes "one of the most unpleasant evenings" in her long career as a sex educator. She had been invited to speak to a parents' meeting at a special school which had implemented a sex education program two years earlier. In an atmosphere of anger and anxiety, parents relentlessly attacked the curriculum. Kempton's judgment was that the anger stemmed from parents being left out of the planning and implementation of the program. She cites four anxieties that almost universally trouble parents concerning sex education of their children. The professionals in this case had made no attempt to allay these fears and assure parents:

> . . .that sex education did not mean teaching "how to do it" but rather would emphasize sex roles, understanding the body, and socialization skills;

> . . .that the sex education program would not sexually stimulate their children or motivate them into undesirable behavior;
>
> . . .that research indicates that students who understand their sexuality and the responsibilities that go with it are less likely to get into trouble than students who are uninformed;
>
> . . .that the character of the persons presenting the program would be taken into consideration and that they would be instructed not to impose their moral standards or values on their students. It would be understood that the parents would have primary responsibility for values and morality building, as long as it was not interfering with the general well-being of the child in the school situation (p. 78).

In the nursing field, Taylor (1989) formulated a plan for nurses to counteract parents' tendency to deny their retarded adolescent's sexuality. The plan is based on Watson's theory of nursing as a science of caring. The seven assumptions of Watson's theory provide a framework within which to respect and be sensitive to parental anxieties and concerns.

Blue (1989) and others advocate parental involvement because of the importance of consistency and carry-over between what the clients or students learn away from home and what goes on when they are at home. He also places the values/morals aspect of sex education as most appropriately addressed in the home. In addition, he sees parents as potential advocates and suggests that parents refuse to sign their child's individual

education plan (IEP) unless it addresses sex education or family life.

Community-based Planning and Implementation

In 1972, Bass stated that ninety-five percent of persons who were retarded in the U.S. lived within the community. Today, this percentage is probably higher due to the effects of the normalization and mainstreaming movements. The importance of involving community agencies and persons in planning and implementing services for the client population is, therefore, vital. Most of the model programs include a planning committee of representatives of community agencies and organizations. Among those persons mentioned to be considered for such a committee are medical doctors, clergy, lawyers, special educators, law enforcement personnel, public school health and physical education teachers and coaches, and parents (Blue, 1989; Bass, 1972; Fischer, Krajicek, & Borthick, 1974; SIECUS/AAHPER , 1971). Further advice is to have meetings and events convened by influential community-based organizations such as schools, Family Services, mental health organizations or departments, or an interagency board (Blue, 1989; Bass, 1972). Bass suggests at least two meetings before implementing new programs and a third meeting if there seems to be continued opposition. She also suggests

beginning with material about family life roles, a less threatening subject, and then moving into sex education out of that context.

Another possibility for community involvement is field trips and experiences in the community for the client population. Bass (1972) provides two examples. First, she suggests that visiting institutions where babies are waiting to be adopted would help students see the consequences of irresponsible sexual behavior. Secondly, persons with retardation could work in day care centers, either as volunteers or employees. Such a working relationship would provide an opportunity for assessing parenting skills. In addition, this involvement might help to satisfy parental desires in retarded adults who decide not to have children (Monat, 1982).

Once the community is involved, it is important that the involvement continues. Persons with retardation need to practice mainstreaming by using public services and facilities whenever appropriate (Daniels, et al., 1979). Johnson (1981) reports that special groups which have ventured into sex education and counseling have not experienced anti-sexual backlash the wider community.

Implementation of sex education programs in the community may be fraught with frustration and difficulty because of the controversial nature of the topic.

Further discussion and additional guidelines concerning community implementation are available and may prove helpful in the planning process (Bensley, 1988; American School Health Association, currently in press).

Selection and Support of Facilitators

There are three considerations relevant to those persons who would serve as facilitators in the area of sex education and counseling for persons with retardation: selection, training, and on-going support.

Selection. Monat (1982) states that the best people to provide sex education and counseling are the professionals who work most closely with the clients and know them well. Ideally, these professionals would work closely with parents to coordinate efforts towards sex education and counseling of the adult or adolescent child/client. The present discussion, as well as this study is limited, however, to professional services.

Staff attitudes and responses to sexuality-related incidents are important. Hawkins' survey (1983) involving fifty-one teachers and forty-four parents found that ninety-five percent of the respondents believed sex education for their students and children was important. One hundred percent thought the responsibility for such programs should be shared by home and school. These

data show a willingness on the part of these teachers to take responsibility for sex education with the client population.

Selders-Powell (1980) surveyed fifty-one para-professionals who work directly with the client population as primary caregivers on a daily basis. Sixty-one percent of them reported that they were serving in formal and informal ways as sex educators and counselors with their clients. Staff and teacher behaviors towards the sexuality of clients and students is often, however, perceived as negative and obstructive to any sexual expression (Johnson & Davies, 1989; Handis, 1981; Mims, 1981; Brantlinger, 1983). Johnson and Davies (1989) conjecture that the minority of staff who have " . . . more restrictive attitudes exert a disproportionate amount of power, due perhaps to the majority's often-stated feelings of inadequacy and ambivalence in dealing with sexual issues" (p. 20).

There is a consensus in the literature that only staff who want to have primary responsibility for sex education and counseling should be used in this way. Blue (1989) gives three qualities as criteria for choosing staff to serve as sex educators and counselors: sexually comfortable and stable themselves; can talk comfortably about sex; and can relate well to people

with retardation. These qualities are commonly cited by other authorities in the same way.

Training. Many workshops are offered for training of staff persons in this area. Four objectives of a workshop developed by Handis (1981) reflect the basic aims of all the workshop and training events reviewed. The objectives are part of an introduction addressed to participants.

> 1. to encourage your awareness that mentally retarded people are sexual beings, with sexual feelings, needs, rights, and responsibilities;
>
> 2. to allow you to become comfortable in openly dealing with the sexuality of the retarded;
>
> 3. to increase your knowledge in the area of human sexuality;
>
> 4. to make you aware of available materials in the area of sex education for retarded persons (p. 39).

On-going support. The primary support for staff needs to come from the administration for which they work (Blue, 1989; Johnson & Kempton, 1981; Monat, 1982; Bass, 1972). "The administration's support should be so strong that it is evident to teachers, others responsible for instruction, and the community that the administration is backing the program completely and is committed to its success" (SIECUS/AAHPER, 1971. p. 12). Administration support is especially important in light of the potentiality of serious legal situations (Johnson

& Kempton, 1981). Professionals can provide support systems and consultation to the primary facilitators to help them develop competence, confidence and comfort when dealing with sexuality (Monat, 1982; SIECUS/AAHPER, 1971).

Content

Socialization and normalization are the two main principles underlying the content of curricula reviewed. Four curriculum concepts are specified in A Resource Guide in Sex Education for the Mentally Retarded (SIECUS/AAPHER, 1971):

> 1. awareness of self -- becoming a boy [male]; becoming a girl [female]; content emphasizes the role of the individual in relation to his environment;
>
> 2. physical changes and understanding of self -- becoming a man; becoming a woman; bodily changes which occur during puberty and early adolescence are stressed;
>
> 3. peer relationships -- boyfriends; girlfriends; boy and girl friends: emphasis is primarily on each individual's responsibilities to various groups with which he is associated and on the influence of peers on individual behavior and action;
>
> 4. responsibilities to society as men and women -- contrasts and similarities between single life and married life are spotlighted. The focus is on contraception, financial responsibility, and family care in preparation for marriage (p. 17).

Monat (1981) further specifies curriculum content with a list of nine subjects:

1. Anatomy and physiology
2. Maturation/body changes
3. Birth control
4. Venereal disease
5. Masturbation
6. Responsibility of being sexual
7. Same-sex and opposite-sex behavior
8. Psychosocial-sexual behavior
9. Parenthood and marriage (p. 39)

Client Sensitivity.

Individuality is paramount when developing sex education and counseling for persons who are retarded. McCarthy and Fegan (1984) note:

> Intellectually retarded people have varying degrees of reproductive ability, sexual interest and sexual activity. In other words, intellectually handicapped people show the same range of sexual response as the rest of the population. The fact that someone is mentally retarded tells us little about the sexuality of that person (p. 1)

Giles (1987) advises attention to the following individual characteristics when developing programs: the learners' ages and developmental levels, the social settings in which they live, and the needs within those settings. Monat (1982) develops separate approaches based on the four levels of retardation. She suggests designing a specific program for each client and then ". . . to work with that individual and the environment to make it a positive experience with appropriate gains and acheivements commensurate with the retarded person's ability" (p. 63).

Individual assessment of sexual knowledge, behaviors, concerns, and interests helps to ensure an individualistic program. Some assessments are completed by staff (Monat, 1982). Others are administered to the individual by a staff person or other professional, sometimes using pictures (Fischer, 1974).

Summary

Attitudes in the literature concerning the sexuality of persons with retardation have shifted from negative to positive. There are several myths concerning this topic, however, that continue to influence public opinion as well as development and implementation of sex education and counseling for persons who are retarded.

Most resources designed to aid professionals in developing and implementing sex education and counseling for the client population address parental involvement, community-based planning and implementation, selection and support of facilitators, content, and client sensitivity. The content of most curricula in this area is similar. Based on guidelines and models found in this literature review, as well as the research data, the researcher will suggest ways of overcoming present barriers to systematic sex education and counseling with persons who are mentally retarded.

CHAPTER III

METHODS AND PROCEDURES

Introduction

The research design and implementation are described in this chapter. Included are a description of the respondents, the development of the data-gathering instruments, the procedures for gathering the data, and the methods used for analyzing the data.

Respondents

The respondents for this research project were sixteen professionals who work in agencies serving adolescent and adult clients who are mentally retarded. The sixteen agencies are located in east Tennessee and were identified with the help of an official of the Tennessee Department of Mental Health and Mental Retardation (DMHMR). All of these agencies have service contracts with DMHMR for residential services for retarded clients. Seven of the agencies located in the metropolitan Knoxville area were involved in a pilot study this researcher conducted in the Spring Semester of 1989. The other nine agencies were not previously involved in the present research project.

Data-gathering Instruments

Data were gathered through a two-stage procedure: 1) completion of survey instruments, and 2) a structured interview process. Two survey instruments were used. First, a "Sex Education Survey" was developed to gain a profile of the clientele and to ascertain the state of sex education and counseling available in each participating agency. This instrument was originally created in a graduate seminar on research techniques in special education (Appendix A). Seminar participants and faculty assisted the researcher in designing the survey so that the questions were clear and concise and would solicit the desired information in a non-threatening manner. After being used in the pilot project, the survey was further refined to its present form (Appendix B). A working definition of sex education and counseling appeared at the top of the survey form to enhance the reliability of the responses.

The second survey instrument developed was the "Checklist of Possible Approaches to Providing Sex Education & Counseling" (Appendix C). Items for this survey were derived from the inhibitors to sex education and counseling with retarded persons which were established in the pilot project (Huntley, 1989).

For each of the inhibiting factors, which are presented in Table I (see page 16), approaches which might enable professionals to deal positively with the inhibitor were developed. These positive approaches became the twenty items on the checklist. A working definition of sexuality appears at the top of the instrument to enhance the reliability of the responses.

The final data-gathering procedure was a structured interview (Appendix D) based on the five subquestions of the main research question (see Chapter I, page 18). The interview contained eighteen focused questions (see Appendix D) which were asked of each respondent.

Procedures

The seven professionals involved in the pilot project were sent the "Checklist of Possible Approaches to Providing Sex Education & Counseling" along with a cover letter (Appendix E) asking for their participation in this new phase of the study. Each professional was asked to complete the checklist and participate in the structured interview. The interview was subsequently scheduled by telephone. Since the seven pilot project participants had completed the original version of the "Sex Education Survey," they were not sent the

revised form. The only additional information needed (percentage breakdowns describing the client populations) was gathered from the agencies by telephone.

The executive directors of the nine agencies not involved in the pilot project were sent a letter (Appendix F) explaining the research project and soliciting the participation of the respective agency. The "Sex Education Survey" and the "Checklist of Possible Approaches to Providing Sex Education & Counseling" were enclosed and their completion requested. The structured interview was also requested and subsequently scheduled by telephone.

All data forms were retrieved. All sixteen interviews were conducted by the researcher. Twelve of the interviews were conducted face-to-face at the facility of the respondent and were tape recorded. One interview was conducted in a restaurant, because of the respondent's schedule, and was not taped. Three interviews were conducted over the telephone due to scheduling difficulties and were not taped. Notes of responses were taken by the researcher for all of the interviews.

Data Analysis

Data from Survey Instruments

The "Sex Education Survey" established clientele characteristics of the sixteen agencies as well as the nature of sex education and counseling currently provided. The data were then analyzed to identify patterns existing between agency characteristics and services provided. For example, the size in terms of client population was examined in relation to the sex education and counseling services provided to see if larger agencies offered more systematic or less systematic services.

Responses on the "Checklist of Possible Approaches to Sex Education & Counseling" were tabulated in terms of how many respondents checked each item and arranged in order of the frequency with which they were checked. Then items were categorized in the following manner: 14-16 checks--highly enabling; 10-13 checks--enabling; 6-9 checks--somewhat enabling; less than 6 checks--minimally enabling.

Data from Structured Interview

The structured interview data were organized, analyzed, and discussed using the research questions as a

framework. The data were also divided into two types. Data which were obtained directly from answers to the interview questions were referred to as direct data. Data consisting of additional comments and anecdotal material which did not directly answer the interview questions but were nonetheless relevant to the study were referred to as indirect data.

Direct data. Of the eighteen interview questions, thirteen could be answered with a "yes", "no", or "other" response. Responses to these thirteen questions were tallied according to those three categories. The meaning of the totals were discussed in relation to the research questions.

The other five questions were open-ended and required individual analysis and categorization. Respondents' qualifications, explanations, and examples articulated while answering the questions were also analyzed in relation to the research questions.

Indirect data. In analyzing the indirect data, items and issues cited were valued according to how many professionals cited them throughout the course of the interview, in the following manner: 8-10 citations--of vital concern; 5-7 citations--important to consider; 2-4 citations--worthy of consideration. Items were also classified according to the five areas

addressed by the research sub-questions and a sixth area of new issues raised.

Summary

Respondents for this study were sixteen professionals from agencies which provide residential services to mentally retarded adults or adolescents. Seven of the agencies had been involved in a pilot study on the topic of providing sex education and counseling to their clients. Two survey instruments and a structured interview were developed to collect data which would answer the research questions. The survey forms were mailed to the sixteen agencies with cover letters. Subsequently, interviews were arranged by telephone. All interviews were conducted by the researcher. Data were analyzed to gain agency profiles and to answer the research questions.

CHAPTER IV

RESULTS

Introduction

In this chapter, the results of the research are presented and analyzed. The two survey instruments provide the following data: 1) characteristics of each of the participating agencies, the sex education and counseling services provided by each agency, and any patterns between the characteristics and the services; and 2) enabling approaches to providing sex education and counseling in rank order as identified by the respondents. The questions of the structured interview serve as a framework for presenting and analyzing the interview data. Data are summarized in tables and appendixes.

Survey Instruments

Sex Education Survey

Characteristics of participating agencies. The characteristics were: the number of clients served, whether or not mixed-gender housing arrangements exist, and three client characteristics (levels of functioning of clients, other disabilities present, and gender).

There was a wide range of responses for all characteristics which are displayed in Table 2.

The size of the client populations ranged from a low of twelve to a high of 176. The total number of clients served by all sixteen agencies was 1,168 with an average client population of seventy-three.

While one agency's client population was 100 percent mildly to moderately retarded, another's was 100 percent severely to profoundly retarded. The average level of functioning for all sixteen agencies was sixty-two percent mild to moderate with thirty-two percent severe to profound.

The highest percentage of any client population with physical handicaps was fifty-five and the lowest was zero with the average being thirteen percent. Percentage of client populations suffering from mental illness ranged from zero to 100 percent with an average of thirteen percent.

Gender percentages included one client population which was 100 percent male while all others were of mixed gender. The overall averages were fifty-six percent male and forty-four percent female. Eleven agencies provided mixed gender living arrangements. Five agencies did not.

TABLE 2

CHARACTERISTICS OF SIXTEEN AGENCIES SURVEYED

Ag. #	Num. Serv.	Levels of Functioning		Other Disab. Present		Gender		Housing Arr.
		Mild-Mod.	Sev.-Prof.	Phys. Hand.	Ment. Ill	M	F	Mixed Gender
1	130	67%	33%	10%	20%	62%	28%	Yes
2	104	65%	35%	1%	7%	65%	35%	Yes
3	117	50%	50%	25%	30%	66%	34%	Yes
4	84	68%	32%	11%	6%	46%	54%	Yes
5*	12	100%	0%	0%	100%	100%	0%	No
6	60	40%	60%	8%	13%	42%	58%	Yes
7	20	80%	20%	0%	60%	80%	20%	Yes
8	54	80%	20%	3%	3%	31%	69%	No
9	52	0%	100%	0%	2%	50%	50%	No
10	54	57%	43%	55%	10%	57%	43%	Yes
11	148	45%	55%	17%	5%	46%	54%	Yes
12	17	35%	65%	0%	6%	40%	60%	No
13	23	74%	26%	10%	0%	35%	65%	No
14	176	88%	12%	12%	9%	50%	50%	Yes
15	100	62%	38%	12%	15%	61%	39%	Yes
16*	17	100%	0%	2%	0%	76%	23%	Yes
Total 1168		Averages 62%	38%	13%	13%	56%	44%	Yes=11 No= 5

*adolescent population

Sex education and counseling services provided. The sex education and counseling services provided by the sixteen agencies is exhibited in Table 3. Two of the sixteen provided "systematic sex education and counseling." Two provided "classes concerning physical aspects of sexuality" while only one provided "sessions concerning psychosocial-sexual needs." The services provided by the most agencies (fourteen) was "response to individual situations not of a crisis nature." The next most provided service (thirteen) was "response to individual situations of a crisis nature."

These data confirm that systematic sex education and counseling are not widely available for adults and adolescents who are mentally retarded since only two out of sixteen agencies provided such systematic services. The individualistic nature of sex education and counseling for retarded persons was verified by the high number of agencies (fourteen) responding to individual situations. Thirteen agencies practicing crisis intervention confirmed the idea reviewed in the literature that sexuality is often dealt with from a negative point of view after a crisis has arisen.

Patterns. There appeared to be no patterns between the characteristics of the agencies and the types of services provided. For example, agencies 11 and 12 were

TABLE 3

SEX EDUCATION AND COUNSELING SERVICES PROVIDED BY SIXTEEN AGENCIES SURVEYED

Agency #	Code number of services provided as described below						
	I	II	III	IV	V	VI	VII
1						X	
2		X				X	X
3				X	X	X	
4					X	X	X
5				X	X	X	X
6				X	X	X	X
7					X	X	
8				X	X	X	X
9				X	X	X	
10					X		
11	X				X	X	
12	X	X	X		X	X	X
13				X	X		
14					X	X	
15				X	X	X	X
16				X	X		

I. systematic sex education and counseling
II. classes concerning physical aspects of sexuality offered on a regular schedule (e.g. annually)
III. sessions concerning psychosocial-sexual needs offered on a regular schedule (e.g. annually)
IV. occasional sessions concerning sexual issues
V. response to individual situations or requests not of a crisis nature
VI. crisis intervention with sexuality-related problems
VII. referral

the only agencies which provided systematic sex education and counseling yet they were not similar in size, percentage of clientele with physical handicaps, or housing arrangements. Agencies 5, 6, 8, and 15 provided identical sex education and counseling services, but were nonetheless quite dissimilar in characteristics. The same analysis was true for agencies 3 and 9. On the basis of the foregoing information, it was concluded that the characteristics of the agencies had little effect on the types of sex education and counseling services provided by these agencies.

Checklist

The results of the "Checklist of Possible Approaches to Providing Sex Education & Counseling" are presented in Table 4. The possible approaches are rated as "highly enabling," "enabling," "somewhat enabling," or "minimally enabling." These ratings were determined according to how many respondents checked each response. Only the results of the checklist are discussed here. Analysis of these data is integrated with the discussion of structured interview data, which is organized by research questions in the following section.

Highly enabling. "Staff training and sensitization" was checked by 100 percent (16) of the respondents making it the most highly enabling approach of all.

TABLE 4

RESULTS OF "CHECKLIST OF POSSIBLE APPROACHES TO PROVIDING SEX EDUCATION & COUNSELING"

Approaches listed in order of enabling quality	# of checks by respondents (N=16)	% of resp. checks
HIGHLY ENABLING (14-16 checks)		
• staff training & sensitization	16	100%
• info. about psychological & social issues	14	88%
training in how to handle practical situations	14	88%
• information about clients' sexual rights	12	75%
individual assessment re. sexuality of each client	12	75%
interagency cooperation in developing and implementing sex education programs	12	75%
ENABLING (10-13 checks)		
• agency policy regarding sexuality-related issues	11	69%
• indiv. plan of action re. sexuality of each client	10	63%
resource library of relevant materials	10	63%
parental involvement	10	63%
SOMEWHAT ENABLING (6-8 checks)		
• allocation in agency budget for "Sex Education"	8	50%
• parents on comm. to develop sex ed. programs	7	44%
education/sensitization event for parents	7	44%
involvement of board members	7	44%
involvement of interested public	7	44%
• educational/sensitization event for public	6	38%
publicity re. positive aspects of sex ed. for retarded persons	6	38%
MINIMALLY ENABLING		
• educational/sensitization event for board members	4	25%
bd. members on comm. to plan sex ed. programs	4	25%

"Information about psychological and social issues" and "training in how to handle practical situations" were also rated highly enabling with eighty-eight percent (14) of the respondents checking them.

Enabling. "Information about clients' sexual rights," "individual assessment re. sexuality of each client," and "interagency cooperation" were viewed as enabling by seventy-five percent (12) of the respondents. Sixty-nine percent (11) viewed an "agency policy regarding sexuality-related issues" as an enabling approach. Sixty-three percent (10) of the respondents rated "individual plan of action re. the sexuality of each client," "resource library of relevant materials," and "parental involvement" as enabling.

Somewhat enabling. Fifty percent (8) of the respondents checked "budget allocation for sex education and counseling" as somewhat enabling. Six approaches related to the education and involvement of parents, board members, and the public were rated somewhat enabling by forty-five percent (7) or thirty-eight percent (6) of the respondents.

Minimally enabling. Two items relating to specific involvements of board members in agency sex education and counseling programs were checked by only twenty-five

percent (4) of the respondents. Board member involvement, therefore, was minimally enabling as viewed by these agency administrators.

Structured Interview

Five broad sub-questions of the main research question provided the framework for the structured interview. Under these five broad sub-questions, eighteen focused questions were posed to the respondents. The following discussion is presented according to the five broad areas provided by the sub-questions.

Structured interview data are presented in two appendixes and one table. Table 5 provides a tabulation of responses to questions which could be answered with "yes," "no," or "other." Appendix G is a composite of direct data (as defined in Chapter III, page 42). Appendix H is a composite of indirect data (as defined in Chapter III, page 42). Appendix I consists of items and issues cited by respondents valued according to the number of citations.

Sub-question I. What methods and evaluative tools could professionals use to assess the sexual needs of the individual client and to plan programming to meet those needs?

The broad area under discussion in this question was assessment of individual clients' sexual knowledge

TABLE 5

DIRECT DATA -- STRUCTURED INTERVIEW QUESTIONS WHICH COULD BE ANSWERED BY "YES," "NO," AND "OTHER"

Question		Yes	No	Other
I.				
A.	Does your agency presently do a written assessment of the sexual needs and knowledge of each client at least annually?	1	14	1
B.	Are you familiar with any sexuality assessment instruments?	1	13	2
C.	Is each client's sexual needs and growth discussed in annual staffings?	2	3	11
E.	If you are not presently doing systematic sexuality assessment, do you think such assessment would enable your agency to provide better sex education and counseling to your clients?	12	0	1
II.				
A.	Does your agency have a written policy concerning the sexuality of the clients?	3	9	4
	If so, are staff and parents aware of the policy?	2	0	1
B.	Has your agency provided an in-service training event for the entire staff which centered on client sexuality?	10	3	3
F.	Can you identify parents and board members who might be willing to serve as advocates for the sexual needs and rights of retarded persons?	11	5	0

Question		Yes	No	Other
III.				
A.	Does your agency maintain an up-to-date library of resources pertinent to sex education and counseling with retarded clients?	3	2	11
B.	Are you aware of persons knowledgeable in the field of sex education and counseling with retarded people whom you could use as resource persons?	14	0	2
C.	Does your agency's budget allocate money for sex education and counseling?	7	0	9
IV.				
	Is there a staff position presently designated within your agency as having primary responsibility for overseeing sex education and counseling?	4	6	6
	If so, is adequate time provided within the job duties of that position so that a quality sex education and counseling program can be pursued?	3	3	0
	If not, do you think such a staff designation would enable the agency to provide a better sexuality program?	12	2	0
V.				
A.	Have you experienced any inter-agency events or discussions or efforts which have enabled your agency to provide better sex education and counseling?	7	7	2
B.	Do you think your agency would pursue sex education and counseling with more confidence and vigor if you knew that other agencies in the area were doing so?	7	2	7

and needs. Subsequent programming for the individual according to his or her assessment was also included.

Individual Assessment. One agency currently did an annual written assessment while fourteen did not. One agency did a written assessment upon entrance to the program, but not annually thereafter. The two professionals whose agencies did individual assessment felt that the assessment enabled them to provide more appropriate sex education and counseling to their clients. Twelve of the fourteen professionals whose agencies were not presently doing such assessment, however, agreed that individual assessment would be an enabler to providing systematic sex education and counseling. This response indicates an openness to new ideas in the pursuit of systematic programming since thirteen of sixteen respondents were unfamiliar with any sexuality-related assessments. Checklist data also rated individual assessment as an enabling approach.

Staffings. Matters relevant to clients' sexuality were routinely discussed at staffings by only two agencies. Three professionals stated that their agencies did not discuss sexuality-related issues at clients' staffings. The most common approach in addressing clients' sexuality was described by the remaining eleven agency professionals: sexuality-related

issues are discussed only in response to problems. This approach mirrors the larger society's approach, as reviewed in the literature, which is to respond to negative aspects of sexuality-related issues rather than initiating positive approaches to the topic. Data from the checklist rated individual plans of action regarding the sexuality of each client as an enabling approach.

Individual functioning. Some respondents expressed the opinion that assessment and programming may not be necessary for every client, particularly low-functioning individuals who display no interest in sexuality. Special attention needed by individuals with mental illness was cited as well as the discovery of and attention to PMS as a result of attention to the individual. There was a suggestion that different approaches to similar problems or needs may be necessary because of individual differences. Finally, several respondents pointed out the right of any mentally retarded adult to make her own decision regarding participation in sexuality-related programs.

Integration of assessment and programming. The everyday lives of the clients afford many opportunities for spontaneous and informal assessment and programming. Respondents cited increased sexuality-related incidents in residences and problems in workshops and supported

employment situations as opportunities for both assessment and programming. In addition, respondents stressed that addressing client sexuality often dealt effectively with seemingly unrelated behaviors because clients were viewed as whole persons and began to see themselves in that way. As their self-image improved, so did their behavior.

Program components. Respondents mentioned the following as four important components of sex education and counseling programs:

> developing interpersonal relationships--one respondent commented, "Clients are so institutionalized that many of them don't know how to love."
>
> opportunities for social interaction as well as intimacy--to encourage relationships without the opportunity to develop and enjoy them is a common yet unfair situation
>
> responsibility for one's own body and the right to say "no"
>
> AIDS and STD education and protection--as one respondent said, "This is not a luxury item, but a matter of life and death."

Sub-question II. What methods could professionals use to sensitize parents, staff, and board members to the sexual needs and rights of children/clients?

Involvement of three groups--staff, parents, and board members--was discussed in this question. The discussion included agency policies, staff training and development, and communication between these groups

concerning the sex education and counseling programs of the agency.

Written policy. Nine agencies had no written policy concerning the sexuality of their clients. Three agencies did have written policies and one was working on a written policy. Three respondents cited adult rights as relevant policy although it did not address sexuality exclusively. One respondent was unsure whether or not his agency had a written policy. An agency policy regarding sexuality-related issues was rated as an enabling approach on the checklist. It seems likely, therefore, that more agencies will develop such policies.

Professional development. Ten agencies had provided in-service events for their entire staff which centered on client sexuality. Three were planning such in-service events. The remaining three agencies had sent individual staff members to sexuality-related events elsewhere. These data support the checklist rating of staff training and sensitization as a highly enabling step in the developmental process of providing sex education and counseling. Respondents cited four benefits of staff training: sensitization to the mentally retarded individuals as whole persons; emotional desensitization of the topic of sexuality with increased

comfort in dealing with it; learning practical approaches to specific situations; and establishing a team approach within the agency.

Staff orientation. According to respondents, none of the sixteen agencies addressed client sexuality in a major way in the orientation of new staff members. Instead, the issue was addressed incidentally through the reading of policies and procedures including clients' rights. It was also commonly addressed through references to individual situations/problems and how to handle them. One agency was in the process of developing an orientation segment focusing upon client sexuality.

Communication with parents. The respondents described channels of communication between parents and the agencies as very open. The consensus was that parents could raise any concern at anytime, through several channels including the social worker, parents' groups, and staffings and team meetings. Communication concerning the sexuality of their adult or adolescent children, however, was seldom initiated by parents except in response to problems.

Parental attitudes. Parental reactions to agency-initiated discussions of sexuality-related issues were quite mixed according to the respondents. Five

respondents identified parental denial of their adult or adolescent child's sexuality as a common reaction. Five respondents also said that parents often felt threatened, uncomfortable, and reluctant to discuss the issue. Seven respondents, by contrast, described parental reaction as basically positive and said parents were usually willing to work through any problems. Three respondents stated that parents are not routinely involved in sexuality-related matters--or any matter--if the client is a competent adult. Lastly, three respondents described minimal parental involvement as well as situations in which the client was a ward of the Department of Human Services (DHS) whose personnel sometimes attended staffings.

Parents as advocates. Eleven respondents could identify parents and board members who might be willing to serve as advocates for the sexual needs and rights of retarded persons. Five respondents could not identify such advocates. Possible ways in which this type of advocacy could enable the agencies to provide better sex education and counseling services included education and sensitization of others, pressure on agencies to provide better services in this area, and assistance to clients in healthy sexual development by serving as role models.

Sub-question III. What resources do professionals need to provide better sex education and counseling for their clients?

This question focused on resources which may enable agencies to provide better sex education and counseling. Three types of resources were discussed: written and audio-visual materials; knowledgeable persons; and financial resources.

Resource library. Three respondents reported that their agencies maintained a library of materials relevant to sex education and counseling while two said they did not. Two respondents reported that they were in the process of developing libraries. The most common response, given by the remaining nine respondents, was that individual staff people in the agency had materials but the materials were not organized into a library.

Concerning the use of a library, three respondents commented that staff did not appear to have time to use it and one respondent said that the expense of materials might be a problem. Reasons respondents cited for having a library included: to use as a resource in responding to individual situations; for staff development; to engender openness to the topic; and for client education. Checklist responses rated a resource library as enabling.

Resource persons. Fourteen respondents were aware of persons knowledgeable in the field of sex education and counseling who could be used as resource persons. The most common idea respondents had for using resource persons was as in-service leaders. Other ideas for using resource persons were: as consultants concerning specific situations; as consultants for program development; as counselors for individual clients; and to help alter public perceptions.

Financial resources. None of the sixteen agencies had a budget allocation specifically for sex education and counseling. Nine respondents stated, however, that there was money available budgeted under other titles, such as "staff development" or "resource materials." Only two respondents felt that a specific allocation would have an enabling effect. On the checklist, budget allocation was rated as somewhat enabling. This discrepancy can probably be explained by the difference in the survey instruments. Given the opportunity to discuss the matter at greater length in the structured interview, thirteen respondents concluded that lack of funds is not a major barrier in providing sex education and counseling programs. One respondent observed that many materials are available at no cost.

Sub-question IV. What staff position within each facility researched can best be assigned the major responsibility for overseeing sex education and counseling?

This question centered on staff assignments. The concept of assigning responsibility for sex education and counseling to one specific staff person or position within the agency was discussed.

Staff responsibility for sex education. Four agencies did designate one staff position specifically as having responsibility for sex education and counseling. Three of those four respondents stated that adequate time was provided within the job duties of the designated position to pursue a quality program while one respondent stated that adequate time was not provided. Six agencies have informal rather than official staff designation concerning responsibility for sex education and counseling programs. The final six agencies have no staff assigned specifically for this purpose. Twelve respondents thought that such a staff designation would enable the agency to provide better programming. Two respondents did not think such a staff designation would make any difference.

Several respondents stressed the importance of the person responsible for sex education and counseling feeling comfortable dealing with sexuality. One

respondent advised that if no staff persons within the agency felt comfortable, the agency should get resource persons from elsewhere to provide the services. While such an arrangement is not ideal, the respondent admitted, it would be better than not providing any services at all.

Sub-question V. In what ways could interagency cooperation enable individual agencies to provide better sex education and counseling programs to their clients?

The final question of the structured interview dealt with interagency cooperation in the area of sex education and counseling. Respondents' experiences, attitudes, and ideas concerning cooperative efforts between agencies were explored.

Seven respondents' agencies had experienced interagency cooperation of some type that had had an enabling effect on their sex education and counseling programs. Seven respondents' agencies had not had such an experience. The other two respondents were unsure if their agencies had been involved in any interagency events.

Seven respondents stated that their agencies would probably pursue sex education and counseling programs with more confidence and vigor if they knew that other area agencies were doing so. Five respondents projected that other agencies' efforts would have no effect on

their own, although cooperation would be welcomed. One respondent said her agency would not pursue sex education and counseling programs regardless of what other agencies were doing because it was not high priority for the executive director. In contrast, one respondent said his agency would pursue programming aggressively regardless of other agencies' actions.

Respondents generated the following ideas for interagency cooperation in this area:

- combined in-service programs;
- interagency team to provide leadership;
- pilot program to serve as model for others;
- social events for clients;
- cooperation with women's centers;
- sharing of ideas between agencies;
- and newsletters.

Additional Findings

Several additional items mentioned by respondents deserve recognition even though they do not relate directly to the structured interview questions. Two respondents called for self-advocacy concerning sexuality-related issues, including having clients serve on decision-making bodies. One respondent stated that sexual preference of clients should be respected while the written policy of one agency was to discourage

homosexuality. A political approach to the topic was advised by one respondent who suggested working through widely accepted family and social values rather than introducing socially controversial ideas. This suggestion matched an approach recommended in the literature.

Summary

Research data were presented and analyzed. Data included results of the "Sex Education Survey," the "Checklist of Possible Approaches to Providing Sex Education and Counseling," and the structured interview. Characteristics of agencies and services provided by each agency were established. No patterns were found to exist between characteristics and services provided. Responses to the structured interview sometimes confirmed findings in the literature. The responses will be used in drawing conclusions about what would enable professionals to provide systematic sex education and counseling to their clients who are mentally retarded.

CHAPTER V

CONCLUSIONS AND IMPLICATIONS

Introduction

The purpose of this study was to determine what would enable professionals to provide systematic sex education and counseling with adult and adolescent clients who are mentally retarded. A review of pertinent literature and a survey of professionals from sixteen agencies have provided much material to answer the research question. The purpose of this chapter is to combine the research material with the ideas of the researcher to make recommendations about providing sex education and counseling with the client population. The following five areas are addressed: 1) self-advocacy and self-determination for the client population; 2) individualistic design; 3) staff training and support; 4) parental involvement; and 5) interagency cooperation.

Self-advocacy and Self-determination for the Client Population

Persons who are mentally retarded are reaching increasingly higher levels of independence and making greater contributions to society. With this independence comes responsibility and with responsibility there ought to be self-determination. Responsible decision-making is a skill that mentally retarded individuals

need to develop. They are having to make more and more decisions--on-the-job, on-the-street, within community living arrangements and within relationships. Sexuality--because of its far-reaching effects, both positive and negative--is one of the most important areas where the client population will make decisions. It is imperative, then, that they be armed with knowledge and values to make the best decisions possible.

One respondent suggested that clients be included as members on boards which make decisions affecting them. Concerning sex education and counseling programs, it would be appropriate for clients to participate in the planning and implementation of such programs. Two respondents called for self-advocacy on the part of clients regarding sexuality. They could be included effectively as presenters at workshops and meetings to establish the fact that persons who are retarded are whole persons, which includes being sexual. This type of involvement needs strong support from staff and others to assist clients so that the success of client participation and presentations is insured as much as is possible.

Encouraging self-determination and self-advocacy can open up many new opportunities for increased quality of life for retarded individuals. If they are supported in developing as whole persons, sexuality can be placed

in a proper context of one of many natural and healthy aspects of human existence. Other areas of development might include using the library, voting, getting a driver's license, involvement in a religious community, or taking lessons of some kind.

While this discussion is focused primarily upon competent adults, the principles of self-determination and self-advocacy can also be applied to lower functioning and younger individuals. Appropriate choices regarding sexuality for their age and/or level should be encouraged. Privacy should be respected. Social appropriateness should be expected and encouraged.

Individualistic Design

Nine respondents stressed that sex education and counseling programs for the client population must be sensitive to the individual person. This principle was also established in the literature. The group of people identified as "mentally retarded" is an amazingly diverse group of individual personalities, functioning levels, and life experiences. Naturally, there is going to be a wide array of needs and interests concerning sexuality.

Individual assessment, which fourteen out of sixteen respondents thought would be an enabling approach, would lay the groundwork for effective programming.

Several respondents commented upon the difficulty of assessing very low functioning clients and, indeed, the development of sexuality in low functioning individuals is mysterious. Nevertheless, observation and nonverbal methods such as picture identification can help to gain clarity in this area.

Assessment is naturally followed by systematically addressing the individual needs and interests of each client. The best way to do this is through already existing structures and forms, for example the annual staffing and individual program plan that the staffing generates. Appropriate questions to ask at staffings include: Is the client living independently enough that she needs to be instructed very thoroughly about protection against pregnancy and diseases? Is he interested in or in need of relationship building skills? Does she need conditioning to learn socially appropriate functioning in regard to masturbation? These, and many other questions, ought to be routinely asked by or on behalf of the clients during program planning.

Sessions for individuals who are retarded must group the individuals according to their ability to comprehend what they see and hear. Since it is not always obvious how much retarded individuals do comprehend, great care must be taken not to assume that their limitations are lower than they actually are. The

activities and programs developed should allow room for each individual to be exposed to new ideas and for each mind to stretch.

The informal aspects of individual sex education and counseling may well be more important than the structured situations. Respondents repeatedly stressed this idea and one respondent described sex education as ". . .on-going, long term, ideally done by staff who are there in the group home. When clients ask questions about sexuality, staff should be ready to take the time to answer and discuss." Informal conversations and experiences can be excellent opportunities for teaching. Watching movies which deal with sexuality in a healthy way can open up times for communication. There are games devised especially for persons with retardation which teach social skills including sexuality. Such games could be easily included in group home life. An accepting attitude on the part of staff is vital to this informal, individualistic approach. One respondent commented that when an open attitude to sexuality exists,

> . . . it's amazing what other things come up just because clients feel they can talk to you. It's a special time. We're saying that we see them as adults and as whole persons.

Staff Training and Support

Preparing and supporting the staff for sex education and counseling with the client population is

vital to any agency program. All sixteen respondents rated staff training and sensitization as a highly enabling approach. There is a consensus in the literature and in the research data that the staff members who know the clients best are in the best position to provide sex education and counseling. There is also a consensus, however, that "most staff feel inadequate and are professionally unprepared to deal with sexuality issues" (Appendix G, item II-T). Three concrete approaches can prepare and equip staff to fill the role of sex educator and counselor: 1) agency policy; 2) orientation of new staff members; 3) and on-going training.

Agency Policy

Rationale. Most individual staff members are only going to be as comfortable and confident dealing with sexuality as the agency as a body appears to be. If there is no agency policy regarding sexuality, staff members could easily perceive that the topic of sexuality is somehow off-limits. Consequently, they may well be hesitant and uncomfortable dealing with client sexuality. A well thought-out agency policy is a solid first step in establishing a positive atmosphere which would enable staff to provide systematic sex education and counseling. Considerations in policy development include participants, content, and values clarification.

Participants in developing an agency policy. Participants in policy development concerning the sexuality of the clients may well vary from agency to agency. Direct care-givers, supervisors, and administrators ought to be represented. The advisability of involving parents and board members depends on the interdynamics of their relationships to the agency and the clients and their attitudes towards client sexuality. For example, one respondent identified board members as a major obstacle to providing sexuality-related services and advised that developing such programs would be easier if board members were not involved. Another respondent described the board as including professional counselors and others who would provide excellent leadership in developing and implementing sex education and counseling programs. Similarly contrasting statements were made concerning parents. While board member and parental involvement is desirable, each agency must decide for itself if such involvement would be productive or counterproductive. Clients definitely ought to be involved in the process, to uphold the principles of self-advocacy and self-determination.

Content. What ought to be addressed in an agency policy concerning client sexuality? Several respondents cautioned that being too specific in policy statements

may create more problems than are solved. Broad statements, therefore, establishing a framework for providing systematic sex education and counseling, are sufficient for the policy. Important principles guiding the development of a policy statement include clients' rights to privacy, to information, to protection, and to self-determination at the appropriate level.

Values clarification. The highly sensitive and emotional nature of peoples' attitudes towards sexuality complicates the process of values clarification. The pluralistic nature of cultural attitudes towards the moral aspects of sexuality-related issues adds further complications. Defining values, nevertheless, is an important aspect of policy development. A definite statement of underlying values serves to unify and strengthen professionals in meeting resistance to the sexuality-related policies and programs of their agencies. If prospective staff and clients know the values out of which the agency functions, they can make an informed decision of whether or not to affiliate. The difficult process of values clarification can prevent problems and is therefore worth doing. Some values worthy of consideration are suggested by Gordon & Gordon (1983): enhancing the self-concept; understanding love as the basic component of a person's sexual

relationships; responsible decision-making based on a universal value of not hurting or using others; equal opportunity for males and females; and tolerance and appreciation for people who do not conform to traditional norms.

Orientation of New Staff Members.

According to the respondents, none of the sixteen agencies dealt systematically with client sexuality issues in the orientation of new staff members. This omission could well cause the same problem as ignoring sexuality in the policy statements of the agency might cause: staff have the impression from the outset that sexuality-related issues are awkward, negative, and off-limits.

The orientation process should include a positive and frank segment concerning client sexuality and agency policy and programs. The new staff member is thereby better equipped to assist in providing systematic sex education and counseling. There may well be some staff members who will disagree with the policies and programs and subvert them, either intentionally or unintentionally. Agency policy and orientation can provide a solid foundation upon which to deal with this problem if it should develop.

One respondent commented that the attitude of staff who are insensitive to clients' sexuality and sexual rights is usually generalized to their overall attitude towards the clients. The respondent went on to say that staff persons with this attitude usually do not "last too long" working with mentally retarded individuals. Clarity of agency expectations spelled out in policy statements and orientation programs may help persons unsuited for this type of work to screen themselves out.

On-going Training

The fact that nine of the sixteen responding agencies have provided in-service training events for their entire staffs which centered on client sexuality indicates an awareness of the importance of on-going staff training. Time and funds should be allotted for staff to attend occasional in-depth training sessions about teaching and counseling clients concerning sexuality. Discussion during regular staff meetings of matters concerning sexuality is another important and appropriate way of providing on-going education and training for staff.

The availability of resources is vital for the support of staff in providing sex education and counseling. A library or resource center could include audio-visuals and written or illustrated materials

designed for client use. Such materials developed for staff would aid in handling specific situations as well as approaching the area comprehensively. Anatomically correct dolls or mannequins and games designed for enhancing social skills are other types of materials that would be helpful. Current journals concerned with issues and developments in the field of mental retardation would give staff access to current thinking, best practices, and announcements of in-service opportunities. Providing staff time to use these resources needs to be considered along with providing them.

The assignment of a staff member to have responsibility for coordinating all aspects of sex education and counseling within the agency would help to insure a high quality of staff training and support in this area. Inherent to such an assignment is allowing a realistic amount of time in which to perform the responsibility. Ten agencies designated a staff person for this responsibility, but only three provided adequate time within the job description to perform the assigned responsibility. Since twelve of the sixteen respondents thought a staff position specifically given this responsibility and the time to do it would enable the agency to provide better programming, this recommendation seems to be appropriate.

Parental Involvement

In the case of adolescent children and adult clients who are legal wards of their parents, the desires of the parents regarding the sex education and counseling of their children must be honored. If parents are supportive of their adult or adolescent child's healthy sexual development, they can easily be involved with positive effect. When sexuality-related issues cause conflict between competent adult clients and their parents, however, the agency is bound by a commitment to clients' rights to be supportive of the client. Material in Appendix G, item II-A provides an excellent discussion of the complexities involved in being sensitive to parental feelings and trying to build trust with parents while also attempting to support competent adult clients in responsible decision-making and healthy sexual development. In all cases, the feelings and opinions of parents are dealt with best through sensitivity and respect.

To foster supportive parental attitudes toward sexuality in offspring with mental retardation, early sensitization and support should be offered by agencies. It is very difficult for parents who have denied their child's sexuality for many years--and indeed had very little support for any other attitude--suddenly to

recognize, understand, accept and support their adult child as a sexual person. Organizations like the Association for Retarded Citizens along with facilities which serve infants and young children who are mentally retarded could be supportive of families in helping their child to develop as a whole and healthy person.

Involvement of parents as advocates can be very effective. There are many parents who are accepting and supportive of their children as sexual persons. Eleven out of the sixteen respondents, in fact, could identify parents of their clients who might be willing to serve as advocates for the sexual needs and rights of persons who are retarded. Advocate parents who have experienced the challenges of having a child who is retarded would probably be able to communicate with other parents better than advocates who have not had that experience. Involvement of sensitive and informed parents in policy development and even program development and implementation may also be advisable. One respondent suggested that parents supportive of the sexual development of the client population might be willing to take clients on dates. Such activity would provide healthy role models as well as facilitate clients to develop socially. Staff often do not have time to provide this service.

It is important not to overestimate the negativity of parental attitudes toward the sexual development of

their children who are mentally retarded. Admittedly, the area of sexuality is one which parents of non-retarded children find awkward as well. When the issue is complicated by mental retardation, understandable consternation in dealing with it can exist. In the midst of this difficulty, parents need sensitivity to their feelings and support for their efforts in regarding their children as sexual persons, however gradual and limited their efforts may be. To challenge parents in a judgmental manner, to deny the validity of their feelings, or to prevent their involvement in their adolescent or adult child's programming (notwithstanding the issue of competent adult clients in conflict with parents previously discussed) is to invite major problems (such as the problems described by Kempton in Chapter II, p. 27).

Interagency Cooperation

There are two levels of interagency cooperation that are important to consider in attempts to provide systematic sex education and counseling to the client population. The first level is among agencies which serve the client population exclusively. The second level is between those agencies which serve the client population exclusively and community agencies available to the general public, including the client population.

Support for interagency cooperation was voiced by all sixteen respondents and is also stressed as vital to a strong sex education and counseling program in models found in the literature.

Ideas for cooperation among agencies which serve the client population include:

- purchasing program materials and maintaining a resource center;
- joint in-service programs;
- providing social events whereby clients from different agencies could meet each other and develop friendships;
- exchanging newsletters or having a joint newsletter;
- funding a staff position to coordinate and facilitate programs;
- supporting a pilot program to serve as a model;
- and establishing clear lines of communication between agencies who may serve common clients.

Efforts for interagency cooperation should strive to coordinate and maximize the use of already existing services and effective programs rather than duplicating services and programs. Interagency cooperation through some of the methods described above as well as others could well create a climate of mutual support that would enhance the sex education and counseling programs of each individual agency.

Cooperation between agencies serving the client population and agencies available to the general public

puts into practice the principle of mainstreaming. Assisting clients in utilizing community services will help integrate them into the wider community. In addition, clients can become more independent if they know how to utilize public services rather than being dependent upon services developed specifically for persons with retardation.

Utilizing community services is strongly recommended in the literature and by current authorities in the field. Most of the respondents are already practicing this type of interagency cooperation to some degree. Planned Parenthood, the Red Cross, and local mental health centers were cited as agencies who serve clients in various ways. Respondents described these community agencies as helpful allies in providing sexuality-related services to the clients.

Future Research

There are two important areas which would be appropriate foci for further research concerning sex education and counseling for persons who are mentally retarded: program evaluation and values clarification.

Program Evaluation

Sex education and counseling programs for persons who are mentally retarded are being developed and implemented more frequently than in the past. Evaluating

programs that have been in progress for two or more years is important. Searching for relationships between systematic sex education and counseling and statistics reflecting client behaviors would be informative. For example, the number of incidents of inappropriate behaviors or the pregnancy rate could be compared before and after the implementation of systematic sex education. In addition, program evaluation could help in improved program design.

Values Clarification

Clarifying the underlying values of sex education and counseling programs has been established as important yet difficult. Research focusing on underlying values could aid agencies in identifying and stating the values upon which their sex education and counseling programs are based. The development of a process for values clarification could arise out of such research. This topic is dealt with in-depth in the literature (Gordon & Gordon, 1983; Schur, 1988).

Summary

This research study centered on the question: What would enable the staff of agencies serving adults or adolescents with mental retardation to provide systematic sex education and counseling for their clients?

An in-depth review of literature addressing the sexuality of persons who are mentally retarded was made. In addition, professionals of sixteen agencies were surveyed about their experiences and ideas relevant to the research question. The findings in the literature and the results of the survey were combined with the ideas of the researcher to present recommendations.

Recognizing persons who are mentally retarded as whole persons must include recognizing and affirming them as sexual persons. Providing them with the sex education and counseling they deserve and need is not an easy task. Many barriers exist. This study suggests ways of reducing the barriers for the purpose of assisting persons with retardation in living healthier and fuller lives.

LIST OF REFERENCES

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Abramson, P., Parker, T., & Weisberg, S. (1988). Sexual expression of mentally retarded people: educational and legal implications. American Journal on Mental Retardation, 93, 328-334.

American School Health Association. (Currently in Press). Sexuality education within comprehensive school health education. Kent, OH

Bass, M. (1975). Sexual rights and responsibilities of the mentally retarded. Ardmore, PA: Medora S. Bass.

Bass, M. (1972). Developing community acceptance of sex education for the mentally retarded. New York: Human Sciences Press.

Bensley, L.B. (1988). A handbook establishing sexuality education programs in Michigan schools. Lansing: Michigan School Health Association.

Bernstein, N. (1985). Sexuality in Mentally Retarded Adolescents. Medical Aspects of Human Sexuality, 19, 50-61.

Blue, Roger. (1989). Lecture. ARC-sponsored workshop. Johnson City, TN.

Brantlinger, E. (1988). Teachers' perceptions of the parenting abilities of their secondary students with mild retardation. Remedial and Special Education, 9, 31-43.

Brantlinger, E. (1988). Teachers' perceptions of the sexuality of their secondary students with mild mental retardation. Education and Training in Mental Retardation, March, 24-37.

Brantlinger, E. (1985). Mildly mentally retarded secondary students' information about and attitudes toward sexuality and sexuality education. Education and Training of the Mentally Retarded, 20, 99-108.

Brantlinger, E. (1983). Measuring variation and change in attitudes of residential care staff toward the sexuality of mentally retarded persons. Mental Retardation, 21, 17-22.

Craft, A. & Craft, M. (1983). Sex education and counseling for mentally handicapped persons. Baltimore: University Park Press.

Craft, A. & Craft, M. (Eds.), (1978). Sex and the Mentally Handicapped. Boston, MA: Routledge & Kegan Paul.

Daniels, S., Chipouras, S., Cornelius, D., & Makas, E. (1979). Who Cares? A Handbook on Sex Education and Counseling Services for Disabled People. Washington, D.C.: Sex and Disability Project, George Washington University.

de la Cruz, F. & La Veck, G. (Eds.), (1973). Human Sexuality and the Mentally Retarded. New York: Bruner/Mazel.

" 'Disaster prevention' sex education ripped." (1990, March 28). Knoxville News Sentinel, p. A-8.

Evans, D. (1983). The Lives of Mentally Retarded People. Boulder: Westview Press.

Fischer, H., Krajicek, M., & Borthick, W. (1974). Sex Education for the Developmentally Disabled. Baltimore: University Park Press.

Furey, E., & Haber, M. (1989). Protecting adults with mental retardation: a model statute. Mental Retardation, 27, 135-40.

Giles, K. (1987). Sex education for pupils with severe learning difficulties. Research Supplement, Sept., 108-111.

Gordon, J., & Gordon, S. (1983). Raising a Child Conservatively in a Sexually Permissive World. New York: Simon and Schuster.

Grossman, H. (Ed.), (1983). Classification in Mental Retardation. Washington, DC: American Association on Mental Deficiency.

Handis, M. (1981). The impact of training in sex education on school and agency personnel's attitudes toward the sexuality of mentally retarded individuals Unpublished manuscript, Texas Tech University.

Hawkins, A. (1983). Sex education for the moderately retarded: parent-teacher attitudes and degree of student knowledge. Unpublished manuscript, United States International University.

Huntley, C. (1989). Sex Education with mentally retarded adults: a study in metropolitan Knoxville. Unpublished manuscript, University of Tennessee.

Johnson, P. & Davies, R. (1989). Sexual attitudes of members of staff. The British Journal of Mental Subnormality, 35, 17-21.

Johnson, W. (1975). Sex Education and Counseling of Special Groups: the Mentally and Physically Handicapped, Ill and Elderly. Springfield, IL: C.C. Thomas.

Johnson, W. & Kempton, W. (1981). Sex Education and Counseling of Special Groups. (2nd Ed.) Springfield, IL: C.C. Thomas.

Kaplan, R. (1989). Guest editorial. Theory into Practice, 28.

McCarthy, W. & Fegan, L. (1984). Sex Education and the Intellectually Handicapped. Boston: Adis Press.

Mims, A. (1981). The effects of a sex education workshop for teachers of the educable mentally retarded. Unpublished manuscript, University of Alabama.

Monat, R. (1982). Sexuality and the Mentally Retarded. Boston: Little, Brown & Co.

Plog, S. & Santamour, M. (1980). The Year 2000 and Mental Retardation. New York City: Plenum Press.

Selders-Powell, J. (1980). A survey of attitudes of parents, para-professionals, and professionals toward the sexuality and the sex education needs of moderately mentally retarded adults. Unpublished manuscript, University of Denver.

Scales, P. (1989). Comprehensive sex education in American society. Theory into Practice, 28, 174-181.

Schur, E. (1988). The Americanization of sex. Philadelphia: Temple University Press.

SIECUS/AAPHER. (1971). A Resource Guide in Sex Education for the Mentally Retarded. New York.

Taylor, M. (1989). Teaching parents about their impaired adolescent's sexuality. MCN, 14, 109-112.

Welbourne-Moglia, A. & Moglia, R. (1989). Sexuality education in the U.S.: what it is; what it is meant to be. Theory into Practice, 28, 157-164.

Wolfensberger, Wolf. (1982). Principles of Normalization. Toronto: National Institute on Retardation.

APPENDIXES

APPENDIX A

SEX EDUCATION SURVEY USED IN PILOT STUDY

Sex Education Survey

1. Name of Agency _____
2. Your Position Within Agency _____
3. Clientele Served (check all which apply)

   mildly retarded _____

   moderately retarded _____

   severely retarded _____

   profoundly retarded _____

   physically handicapped _____

   mentally ill _____

   male _____

   female _____

   other (specify) _____

4. Please check any of the sex education services listed below which you provide to your clients.

   formal classes offered on a regular schedule _____

   occasional sessions concerning sexuality issues _____

   response to individual situations or requests _____

   informal conversations on topics of sexuality _____

   crisis intervention with sex-related problems _____

   referral _____ If so, to whom? _____

   other (specify) _____

   number of clientele served _____

5. Would you like to receive the results of this survey? _____
6. Would you participate in a follow-up interview? _____

If yes to #5 or #6, please fill out:

Name _____

Mailing Address _____

Phone Number(s) _____

Thank you for your participation.

APPENDIX B

REVISED SEX EDUCATION SURVEY

SEX EDUCATION SURVEY

WORKING DEFINITION OF SEX EDUCATION AND COUNSELING: Systematic dissemination of information regarding physical sexual growth and development; and systematic attention to the physical, psychological and social sexual needs of each individual at his or her level with the goal of facilitating whole and healthy personality development.

---

1. Name of Agency _____

2. Your Position within Agency _____

3. Clientele Served

   total number of clients _____

   mentally retarded

   mildly to moderately _____%

   severely to profoundly _____%

   physically handicapped _____%

   mentally ill _____%

   gender

   male _____%

   female _____%

   mixed gender living arrangement(s) Yes or No

   NOTE: Percentages do not need to be exact. Since clients may fall in more than one category, the total may be more than 100%.

4. Sex Education and Counseling Services provided. Please check any which apply to your agency.

   systematic sex education & counseling (as defined above)_____

   classes concerning physical aspects of sexuality offered on a regular schedule (e.g. annually) _____

   sessions concerning psychosocial-sexual needs offered on a regular schedule (e.g. annually) _____

   occasional sessions concerning sexual issues _____

   response to individual situations or requests not of a crisis nature _____

   crisis intervention with sexuality-related problems _____

   referral _____If so, to whom?_____

   other (specify) _____

THANK YOU FOR YOUR PARTICIPATION

APPENDIX C

CHECKLIST OF POSSIBLE APPROACHES TO PROVIDING SEX EDUCATION & COUNSELING

WORKING DEFINITION OF SEXUALITY: The physical, psychological, intellectual and social aspects of sexual being.

Please check the items below which you think might enable your agency (or <u>has</u> enabled it) to move beyond present barriers to providing systematic sex education and counseling for your clients.

_____individual assessment regarding the sexuality of each client

_____individual plan of action regarding the sexuality of each client

_____agency policy regarding sexuality-related issues

_____staff training/sensitization

- _____information about physiological aspects of sexuality
- _____information about psychological and social aspects
- _____information about clients' sexual rights
- _____training in how to handle practical situations
- _____resource library of relevant curriculum materials, audio-visuals, magazine articles, books, etc.

_____parental involvement

- _____educational/sensitization event
- _____appointment to committee to develop sex education program

_____board member involvement

- _____educational/sensitization event
- _____appointment to committee to plan sex education program

_____involvement of interested public

- _____educational/sensitization event
- _____publicity relating to positive aspects of sex education for retarded persons

_____allocation in agency budget for "Sex Education"

_____interagency cooperation in developing and implementing sex education programs

THANK YOU FOR YOUR PARTICIPATION.

APPENDIX D

STRUCTURED INTERVIEW

I. What methods and evaluative tools could professionals use to assess the sexual needs of the individual client and to plan programming to meet those needs?

   A. Does your agency presently do a written assessment of the sexual needs and knowledge of each client at least annually?

   B. Are you familiar with any sexuality assessment instruments?

   C. Is each client's sexual needs and growth discussed in annual staffings?

   D. If you have been doing systematic sexuality assessment, describe the affect such assessment has had on your sex education and counseling program.

   E. If you are not presently doing systematic sexuality assessment, do you think such assessment would enable your agency to provide better sex education and counseling to your clients?

II. What methods could professionals use to sensitize parents, staff, and board members to the sexual needs and rights of children/clients?

   A. Does your agency have a written policy concerning the sexuality of the clients?

   If so, are staff and parents aware of the policy?

   B. Has your agency provided an in-service training event for the entire staff which centered on client sexuality?

      If so, in what ways did the event enable the agency to provide better sexuality programming?

   C. How does your agency deal with client sexuality issues in the orientation of new staff persons?

D. When and how do parents have an opportunity to discuss their child's sexual needs, desires, problems?

E. What has been the reaction of parents to any agency-initiated discussions of sexuality-related issues in the past?

F. Can you identify parents and board members who might be willing to serve as advocates for the sexual needs and rights of retarded persons?

How could such advocacy enable your agency to provide better services to meet your clients' sexual needs?

III. What resources do professionals need to provide better sex education and counseling for their clients?

A. Does your agency maintain an up-to-date library of resources pertinent to sex education and counseling with retarded clients?

How does or could such a library facilitate sex education and counseling with your clients?

B. Are you aware of persons knowledgeable in the field of sex education and counseling with retarded people whom you could use as resource persons?

How have you or could you resource such persons to enable your agency to better meet the sexual needs of your clients?

C. Does your agency's budget allocate money for sex education and counseling?

How does or could such an allocation enable your agency to provide sex education and counseling?

IV. What staff position within each facility researched can best be assigned major responsibility for tion and counseling?

Is there a staff position presently designated within your agency as having primary responsibility for overseeing sex education and counseling?

If so, is adequate time provided within the job duties of that position so that a quality sex education and counseling program can be pursued?

If not, do you think such a staff designation would enable the agency to provide a better sexuality program?

V. In what ways could interagency cooperation enable individual agencies to provide better sex education and counseling programs to their clients?

A. Have you experienced any interagency events or discussions or efforts which have enabled your agency to provide better sex education and counseling?

B. Do you think your agency would pursue sex education and counseling with more confidence and vigor if you knew that other agencies in the area were doing so?

C. What ideas do you have for interagency cooperation in this area?

APPENDIX E

COVER LETTER SENT TO PILOT PROJECT AGENCIES

THE UNIVERSITY OF TENNESSEE
KNOXVILLE

October 23, 1990

College of Education

Department of Special Services Education

Professional
Pilot Project Agency
Metropolitan Area
Knoxville, TN

Dear Professional:

Last spring your agency participated in a research project I am conducting in my graduate studies under the direction of Dr. Susan Benner. The information you provided about implementing sex education in your facility was most valuable. I am soliciting your help again as I continue my study in this most important area.

Previous data and discussion focused on the reasons which inhibit the delivery of systematic sex education and counseling with retarded adults. This phase of the study will seek to identify ways of moving beyond these barriers.

The enclosed "Checklist of Possible Approaches to Providing Sex Education and Counseling" is designed to gather your opinions and ideas, along with those of other professionals, and then to formulate solutions to frequently cited problems in this area. Please note the definitions at the top of the checklist. It is important for the validity of this study that we all use these understandings of "sex education and counseling" and "sexuality" as we discuss the topic.

After you have completed this checklist, I would like to conduct a thirty to sixty minute interview with you so that we can discuss your ideas in some depth. I will call you within the next two weeks to arrange a time to get together for that purpose.

As in the first phase of the study, all data will be analyzed on a group basis only. Confidentiality will thereby be maintained.

It is my hope that this project will be a positive step in the progress we as a professional community and as a society are making towards recognizing the sexual needs and rights of retarded persons. Such recognition must be followed by action to help meet those needs and protect those rights. Taking action is the subject of this study.

Thank you once again for your time and input which I deeply appreciate. I look forward to talking with you soon.

Sincerely,

Cristy Huntley

APPENDIX F

COVER LETTER SENT TO AGENCIES NOT INVOLVED IN PILOT PROJECT

THE UNIVERSITY OF TENNESSEE
KNOXVILLE

October 3, 1990

College of Education

Department of Special Services Education

Executive Director
Responding Agencies
East Tn Region
East Tennessee

Dear Executive Director:

I am gathering data for a graduate thesis under the direction of Dr. Susan Benner. The thesis is concerned with sex education and counseling with retarded adults. Because of your commitment to this client group, Mr. Fred Coe of Greene Valley Community Services identified your facility as an important participant in this study. I would greatly appreciate the participation of your organization and whichever individual therein is most qualified to provide the information.

The first phase of the study is the two enclosed survey instruments which can be completed in 3-5 minutes. Please note the definitions at the top of each of these instruments. It is important for the validity of the study that we all use these understanding of "sex education and counseling" and "sexuality" as we discuss the topic.

The second phase of the study involves an interview of thirty to sixty minutes to discuss in greater depth the possible ways of dealing effectively with the barriers to providing sex education and counseling with retarded adults. I will call you within the next two weeks to arrange a time to meet.

A summary of the results will be available to respondents. Data will be analyzed on a group basis only so that confidentiality can be maintained.

It is my hope that this project will be a positive step in the progress we as a professional community and as a society are making towards recognizing the sexual needs and rights of retarded persons. Such recognition must be followed by action to help meet those needs and protect those rights. Taking action is the subject of this study.

Thank you so much for your time and participation. Please call me at 482-6724 if you have any questions. I look forward to talking with you in the near future.

Sincerely,

Cristy Huntley

APPENDIX G

COMPOSITE OF DIRECT DATA

Agency code numbers used in tallying responses as reported below

FOLLOW-UP INTERVIEW DATA FORM

I. What methods and evaluative tools could professionals use to assess the sexual needs of the individual client and to plan programming to meet those needs?

A. Does your agency presently do a written assessment of the sexual needs and knowledge of each client at least annually?

No - 1 2 3 4 5 6 7 8 9 12 13 14 15 16
Yes, by a psychologist - 10
Not annually, but routinely upon entrance to the program - 11

B. Are you familiar with any sexuality assessment instruments?

No - 1 2 4 5 6 8 9 12 13 15 16
No, except there are related items on ABS - 3
Yes - 7
No, psychologist administers - 10
Use a self-developed assessment - 11
Somewhat - do not have any at agency - 14

C. Is each client's sexual needs and growth discussed in annual staffings?

If necessary/ when problems occur/ not routinely - 4 6 8 10 14 15

No, but are discussed annually at sex education event for clients where communication is encouraged - 2
Not always, but more and more frequently - 3
No - 5 11
Yes - 7 9 16
Yes, as needed - 12

D. If you have been doing systematic sexuality assessment, describe the affect such assessment has had on your sex education and counseling program.

Better able to provide services appropriate to each individual - 10 11

E. If you are not presently doing systematic sesuality assessment, do you think such assessment would enable your agency to provide better sex education and counseling to your clients?

Yes - 2 3 5 6 8 12 14 15 16
Qualified yes - 1 4 7
Unsure - 9

Difficult to assess needs of severe/profound - 2 4 9

II. What methods could professionals use to sensitize parents, staff, and board members to the sexual needs and rights of children/clients?

A. Does your agency have a written policy concerning the sexuality of the clients?

No - 1 3 5 6 8 13 14 15 16
Yes - 2 10 11
Yes, through adult rights - 7 9
Working on one - 12
Professional did not know - 4

If so, are staff and parents aware of the policy?

Staff - Yes, Parents - No - 2
Yes-10 11

B. Has your agency provided an in-service training event for the entire staff which centered on client sexuality?

Yes - 1 2 3 5 6 7 11 12 13 16
No, though individual staff have attended events elsewhere -4 8 14 15
Not yet, but are planning such an event - 8 9 10

If so, in what ways did the event enable the agency to provide better sexuality programming?

Sensitization to retarded persons as whole, sexual people - 1 3 6 9 11 12
Emotional desensitization, establish comfort in dealing with subject - 1 11
Learning practical approaches to specific situations/information - 5 10
Establish understanding, team approach - 9

C. How does your agency deal with client sexuality issues in the orientation of new staff persons?

Very little - 1 3 8 10 12 14
Through references to individual situations/ problems and how to handle them - 2 5 6 15
Through clients' rights - 7 12 13 14 16
Developing - 9
Read policies and procedures - 11
Train staff to be sensitive and open to clients' sexual needs and questions - 5

D. When and how do parents have an opportunity to discuss their child's sexual needs, desires, problems?

In response to problems--can bring it up at anytime - 1 2 4 5 8 9 10 11 14
Annual staffings, if desired - 3 4 5 8 9 14 16
Social workers communicate re. problems - 3
Parent group which meets monthly - 6
8-week staffing - 9
Orientation for new clients/families - 11 13

E. What has been the reaction of parents to any agency-initiated discussions of sexuality-issues in the past?

Mixed/individual - 1 4 10
Usually willing to work through problems - 1 3 5
Basically positive reaction - 2 9 11 16
Denial/"eternal child" viewpoint - 1 2 6 8 10 15
Uncomfortable, reluctant to discuss, threatened - 7 8 12 14 15
Minimal parental involvement (some clients are wards of DHS) - 12 13 16
Parents are not routinely involved if client is competent adult - 3 5 11 12
Parents are generally aware that teen-age children have normal, sexual feelings - 5
Parents rely heavily on staff to handle problems - 12

F. Can you identify parents and board members who might be willing to serve as advocates for the sexual needs and rights of retarded persons?

No - 1 3 5 7 10
Yes - 2 4 6 8 9 11 12 13 14 15 16
Board involvement would not be helpful - 12

How could such advocacy enable your agency to provide better services to meet your clients' sexual needs?

Education/sensitization to client sexuality - 2 9 12 14
Support/pressure agency to provide services - 3 13 16
Public education re. client sexuality - 4 6 10 14
Support/enlighten/involve other parents -6 10 11 15
Assist clients by giving them "permission" to be normal -7
Serve as role models for clients, take them on dates - 12

III. What resources do professionals need to provide better sex education and counseling for their clients?

A. Does your agency maintain an up-to-date library of resources pertinent to sex education and counseling with retarded clients?

Yes - 3 4 15
No - 6 8 10
Developing - 9 11
Individual staff have materials or access to materials - 1 2 5 7 10 12 14 16

How does or could such a library facilitate sex education and counseling with your clients?

Staff probably wouldn't have time to use - 1 4 5
Client education - 3
Staff development - 13 16
Resource for responses to individual situations - 3 8 11 15
Engender openness about the topic - 12
Keep up with current thinking, practice - 9
Materials for clients would help them be open - 10
Expense a problem - 7
Probably not used unless there is a program - 14

B. **Are you aware of persons knowledgeable in the field of sex education and counseling with retarded people whom you could use as resource persons?**

Yes - 1 2 3 4 5 6 8 9 10 12 13 14 15 16

How have you are could you resource such persons to enable your agency to better meet the sexual needs of your clients?

Programs/ Inservices - 1 2 4 5 6 8 9 11 14 16
Individual counseling with or concerning clients - 3 4 6 15(writes BIPs for agency)
Guidance in program development - 3
Written information/resources - 4 7
Phone consultation - 4 7
Alter/develop public perceptions - 12

C. **Does your agency's budget allocate money for sex education and counseling?**

Not specifically - 8 9 10 11 15
No - 1 3 5 6 7 13 14
Budgeted indirectly under "staff development", "resource materials", etc. - 2 4 12 16

How does or could such an allocation enable your agency to provide sex education and counseling?

Wouldn't matter because lack of funds is not a major problem - 1 2 3 4 5 6 8 9 10 11 12 13 15
More money = more systematic program - 6
Would help - 14
Could develop grant for pilot program in sex education - 3
Many materials are available at no cost - 7

IV. What staff position within each facility researched can best be assigned the major responsibility for sex education and counseling?

Is there a staff position presently designated within your agency as having primary responsibility for overseeing sex education and counseling?

Yes - 1 (health/recreation instructor) 8 (social workers, house managers) 13 (house managers) 16 (house managers) No - 4 5 6 11 14 15
Informally - 2 3 7 9 10 12

If so, is adequate time provided within the job duties of that position so that a quality sex education and counseling program can be pursued?

No - 1 2 3
Yes - 8 13 16

If not, do you think such a staff designation would enable the agency to provide a better sexuality program?

Yes - 2 3 4 5 9 10 12 14
More likely to accomplish - 2
Probably - 6 15
No - 7 11
Perhaps need coordinator in addition to above - 16
Medical person would be best, use clinical approach - 4
Team approach important - 9 11 12
Must be person who is comfortable - 7

APPENDIX H

COMPOSITE OF INDIRECT DATA

COMMENTS, QUALIFICATIONS AND ANECDOTAL INFORMATION CLASSIFIED ACCORDING TO THE FIVE SUB-QUESTIONS AND AN ADDITIONAL CATEGORY SIX FOR "OTHER MATERIAL"

Agency code numbers used in tallying responses as reported below

I. What methods and evaluative tools could professionals use to assess the sexual needs of the individual client at least annually?

A. Programs must be/are sensitive to individual needs, levels, etc. - 1 2 3 5 6 9 10 15 16

B. Assessment may not be necessary for every single client- depends on functioning level - 4

C. During sex education experiences, clients (adolescents) are embarrassed, giggly, have difficulty talking about their feelings. Sex education, therefore, needs to be on-going, long term, ideally done by staff who are there in group home. When clients ask questions about sexuality, staff should be ready to take the time to answer and discuss. Should be a mixture of formal and informal experiences. Should be "family-like" - 5

D. Much assessment is done "on-the-job" - 6 7

E. Individual situations can be very frustrating; what works with one person may not work with another - 8

F. Sexuality-related matters are usually a private matter for clients - 10

G. Clients need to be counseled as to right and wrong - 10

H. Competent adult clients have choice of whether or not to attend classes re. sexuality - 10

I. Sexuality is discussed in IEP under "social goals" - 16

J. AIDS and sexually transmitted diseases (STD) education for clients is extremely important, especially for clients living in independent or semi-independent living situations - 3 4 5 7 11 12 14

K. Efforts to support male adolescent clients in developing social relationships have not been highly successful. Difficult for clients to form friendships, especially with girls. Even when male-female relationship exists at school, invitations of outsiders to come to parties at group home are rarely accepted. Perhaps it is the stigma of the group home. Consequently, there are very few opportunities for intimacy. Higher functioning clients actively pursue girls, often talking of "going" with someone. Then they might say, "I don't want her anymore. You can have her." - 5

L. Dealing with sexuality may deal with seemingly unrelated behavior problems - 6 8

M. Stress responsibility, control over own body, importance of saying no, very important part of sex ed. - 7

N. Relationship between supportive employment and sexuality--retarded people relating to non-retarded co-workers - 8 12

O. Have identified PMS through individual assessment - 10

P. Emphasis upon social appropriateness - 7 10

Q. Relationships are the most important aspect of sex education and counseling that clients need. Clients are so institutionalized that many of them don't know how to love - 12

R. Increasing expressions of sexuality in residences so it must be addressed - 7

S. re. AIDS and STD education--"This [sex education] is not a luxury item, but a matter of life and death." - 14

T. Lack of opportunity for social and sexual relationships denies clients of their rights - 12

U. Adolescents have right to call house meeting whenever they wish - 16

V. Programs must be sensitive to the needs of the individual - 1 2 3 5 6 9 10 15 16

W. Don't want to stir up unnecessary problems through assessment - 1

X. Advising clients "not the proper time, not the proper place" is a cop-out if no appropriate situations are ever available to them - 8 4

Y. Dual-diagnosed folks have special problems in the area of sexuality - 9

Z. Policy of no dating between workshop employees/ clients yet this is not normal--policy needs updating - 10

a. Masturbation acceptance and instruction can be a cop-out if no other type of sexual expression is allowed - 12

b. Female client became involved with married man and when confronted responded, "But he said his wife treats him awful!" - 14

c. Possible "Bible belt" influence is an inhibiting factor with sex education and counseling - 1 4 8 14

d. Approach must be political, "walk gently," offer appropriate role models, deal with widely-accepted family/social concerns - 14

II. What methods could professionals use to sensitize parents, staff, and board members to the sexual needs and rights of their children/clients?

A. Initially, parents use a lot of denial when confronted with the sexuality of their child, but as time goes on and they listen to us more, and we relate details more to them and they begin to trust us more, I think they do accept it and ask us what to do about it. Then we give them guidance on how we handle particular issues with a lot of sensitivity to how they feel. . . The feelings of the parents play an important part in how we will respond to a certain situation.
Our clients are all adults and have individual rights beyond their parents telling them what to do. Occasionally, we will elect not to relate an incident to the parents. If we feel it would create problems between

the parent and the adult client, we just deal with it here. There is a lot of judgment involved--extended discussion by the team before a decision is made.

For clients who are declared mentally incompetent and have family who are legal guardians, we feel obligated to report any incident to the family. Parents are informed when clients enter the program that unless client has been legally declared incompetent, client will be allowed to make his/her own decisions. Sometimes parents are appalled at this. In all circumstances, we try to inform parents, build trust. If there is a conflict, however, the agency must side with the competent adult client. - 3

B. Normalization and adult right mandate sex education, counseling and rights for mentally retarded adolescents and adults - 2 3 4 7 9 10 11 12 16

C. On-the-job client behavior problems related to sexuality mandate sex education and counseling - 2 8

D. Some parents are more limited mentally than their children - 2 5

E. Sex education is not an issue in which either board members or parents want to be involved - 5

F. Many parents do not want to encourage sex education or social relationships and friendships, thinking such relationships will only cause problems - 6 7

G. Parents would deal with incidents as they occur than deal with the matter comprehensively - 4 8

H. Parents are biggest problem - 8

I. Parents are not a problem - 9

J. Parents object most strongly to birth control, thinking that by providing birth control, the agency is encouraging sexual activity/intercourse - 11

K. 80-year-old sister of client is advocate for clients' sexual rights - 12

L. Classic parental response--"Get it stopped!" - 15

M. Asking for problems if we don't communicate with parents - 2

N. Parents and board members saying "This is ok" would carry a lot of weight with those who are unsure about sex education and counseling with retarded persons - 2 5

O. Even the most liberal parents are pretty conservative on the issue of sexuality of their child - 3

P. Agency staff do well dealing with problems - 1

Q. There is a willingness/openness among professionals to deal with sexuality issue - 8

R. "We haven't ignored sexuality because we see the clients as whole human beings. It just isn't addressed directly until it is a problem." - 9

S. Staff who don't view clients as sexual and don't feel that they have sexual rights usually don't last long in this field. Usually, their attitude towards client sexuality carries over into other areas - 3

T. Most staff feel inadequate and are professionally unprepared to deal with sexuality issues - 5

U. Graphic presentation, language, need to be accepted, but are a major stumbling block for many staff - 5 6 7 8

V. "I don't understand it [client sexuality] yet. In all of my training--undergraduate and graduate--it was not taught." - 9

W. Staff turn-over a serious problem - 7 16

X. Parents object to agency raising issue, say "That's my job", but then neglect it - 10

III. What resources do professionals need to provide better sex education and counseling to their clients?

A. Many resource persons in sex education are not effective with retarded persons - 1 3

B. Have used resources of other agencies concerning sexuality issues (Planned Parenthood, Red Cross, local mental health agency) - 2 3 5 6 8 10 12

IV. What staff position within each facility researched can best be assigned the major responsibility for sex education and counseling?

If no one at agency feels adequate to do sex education and counseling, get an outside agency to do it; not an ideal arrangement, but better than nothing - 7

V. In what ways could interagency cooperation enable individual agencies to provide better sex education and counseling programs to their clients?

Suggestion - discuss sexuality topic at ARC meeting - 14

VI. Other material from responses which do not relate directly to the research sub-questions.

A. Group home stigma - sex crimes will result - 6

B. Public perception about sex education is that "If you tell them about it, they'll want to do it" - 6

C. Clients need to be encouraged to speak out - 8 12

D. Sexual preference should be accepted - 12

E. "If you start sex education, it's amazing what other things come up just because clients feel they can talk to you. It's a special time. We're saying that we see them as adults and as whole people." - 7

F. Difficult to respond to workshop situations because sometimes that is the only opportunity for male and female clients to see each other - 4

G. Other basic client welfare needs overshadow sex education although sex education is important - 2 14

APPENDIX I

ITEMS AND ISSUES CITED BY RESPONDENTS IN STRUCTURED INTERVIEW VALUED ACCORDING TO NUMBER OF CITATIONS

Value	Item or Issue
of vital concern (8-9 citations)	programs must be sensitive to the needs of the individual
	normalization and clients' rights mandate sex education & counseling
important to consider (5-7 citations)	AIDS and sexually transmitted diseases mandate sex education & counseling, especially for clients living somewhat independently
	there is a lack of social oppportunities, times for intimacy, build- relationships
	appropriate/inappropriate masturbation is common issue and frequently addressed with new staff
	have used resources of other agencies concerning sexuality issues
worthy of consideration (2-4 citations)	graphic presentation/language need to be accepted when providing sex education, but are major stumbling block for many staff
	on-the-job problems re. sexuality mandate sex education & counseling
	dealing with sexuality may deal with seemingly unrelated behaviors
	clients need to be encouraged to speak for themselves
	parents/bd. members saying, "This is ok" would carry a lot of weight with those unsure about sex ed. & couns. for retarded persons

Value	Item or Issue
worthy of consideration (2-4 citations)	some parents are more limited mentally than their children
	much assessment is done on-the-job
	many parents do not want to encourage sex ed. or social relationships, thinking such relationships will only cause problems
	advising clients "not the proper time, not the proper place" is a cop-out if no appropriate situations are ever available to them
	parents would rather deal with incidents as they occur than deal with sexuality systematically
	staff turn-over is a serious problem
	strong relationship between supportive employment and sexuality--retarded people relating to non-retarded people
	must be emphasis in sex ed. & couns. upon social appropriateness
	moral and ethical dimensions must be included in sex ed. & couns.
	many resource persons in mainstream sex ed. agencies are ineffective with retarded persons

VITA

CRISTY FOSSUM HUNTLEY

Ms. Huntley was born and reared in Ringwood, Illinois, the second oldest of eleven children, before the time when sex education was done much or even discussed. Her parents, Bobette and Gordon Fossum, nevertheless, passed on a healthy and open attitude towards sexuality.

Higher education began at Wartburg College in Waverly, Iowa. A B.A. degree with a major in English was granted by the University of Illinois, Chicago, in 1971. This thesis is part of a Master of Science program at the University of Tennessee to be completed in May, 1990.

Present employment is in agencies which provide services to adults who are mentally retarded and/or mentally ill. Future professional plans are to remain in this field.

Ms. Huntley is married to Harvey L. Huntley, Jr. (the Reverend) who is responsible for bringing her South. They live on the Beaver Creek in west Knox County with two lovely daughters, Elizabeth and Georgia, and several other creatures.