



What do mentally retarded individuals residing in group homes in a small western city desire in their sex education program?
by Robert John Ustby

A thesis submitted in partial fulfillment of the requirements for the degree of MASTER OF NURSING
Montana State University
© Copyright by Robert John Ustby (1977)

Abstract:

The problem of the study was to determine what mentally retarded individuals residing in group homes desired in their sex education program.

The author interviewed the mentally retarded population which consisted of six females and thirteen males that ranged in age from eighteen to sixty-two years of age. This population had spent from three to thirty-two years in institutions for the mentally retarded.

Ten members of the population were mildly retarded, five members were moderately retarded, and the intellectual status of four members was unknown.

The interview focused on a questionnaire developed by the author. The questions related to topics presently in use in sex education curricula for the mentally retarded and those topics suggested by authorities in the field.

It was found that: 1) These retarded individuals did have opinions, desires, and ideas about what they would like to talk and learn about in a sex education program. Most of the members (sixty-three to eighty-four percent of the population) indicated that they would like to talk or learn more about (a) handholding, (b) kissing, (c) dating, (d) love, (e) marriage, and (f) babies. About one-half of the participants indicated that they would like to learn or talk about (a) where a baby comes from, (b) caring for babies, and (c) the sexual parts of boys and girls.

2) These retarded individuals had varied interests, desires, attention spans, language problems, and cognitive abilities.

3) An individualized program and teaching on an individualized basis would be necessary when teaching sex education to these mentally retarded people because of their varied interests, desires, attention spans, language problems, and cognitive abilities.

The following recommendations were made: 1) That the mentally retarded be asked about what they would like to talk or learn about in a sex education program.

2) That the subject matter in sex education curricula for the mentally retarded include but not necessarily be limited to the questions, desires, and interests of the retardates.

3) That the sex education programs for the mentally retarded be individualized to meet the varying interests, desires, attention spans, language problems, and cognitive levels of these people.

STATEMENT OF PERMISSION TO COPY

In presenting this thesis in partial fulfillment of the requirements for an advanced degree at Montana State University, I agree that the Library shall make it freely available for inspection. I further agree that permission for extensive copying of this thesis for scholarly purposes may be granted by my major professor, or, in his absence, by the Director of Libraries. It is understood that any copying or publication of this thesis for financial gain shall not be allowed without my written permission.

Signature

Robert J. Utterby

Date

March 7, 1977

WHAT DO MENTALLY RETARDED INDIVIDUALS RESIDING IN GROUP HOMES
IN A SMALL WESTERN CITY DESIRE IN THEIR SEX EDUCATION PROGRAM?

by

ROBERT JOHN USTBY

A thesis submitted in partial fulfillment
of the requirements for the degree

of

MASTER OF NURSING

Approved:

Laura Walker PhD
Chairperson, Graduate Committee

Anna M. Shannon
Head, Major Department

Henry L. Parsons
Graduate Dean

MONTANA STATE UNIVERSITY
Bozeman, Montana

March, 1977

ACKNOWLEDGMENTS

The writer wishes to express his sincere appreciation to Dr. Laura Walker, Professor of Nursing and chairperson of the examining committee.

The writer also wishes to thank Dr. Barbara Hauf and Nancy Chandler of the Nursing Department.

A very special thank you is given to Dr. William Serdahely, Assistant Professor and health educator for his personal interest and concern in this study.

TABLE OF CONTENTS

	<u>Page</u>
VITA	ii
ACKNOWLEDGMENTS	iii
TABLE OF CONTENTS	iv
LIST OF TABLES	vi
ABSTRACT	viii
Chapter	
1. INTRODUCTION	1
Statement of the Problem	1
Need for the Study	1
General Procedure	2
Limitations and Delimitations	2
Definition of Terms	3
Summary	6
2. REVIEW OF LITERATURE	7
Mental Retardation - Prevalence and Causes	7
Education of the Mentally Retarded	12
Individualized Education - General Population	15
Individualized Education - Retarded Population	16
Language Difficulties Associated with Mental Retardation	18
Rights of the Retarded	20
Characteristics of the Subject Matter - "Sex"	23
Reasons For and Against Sex Education for the Mentally Retarded	24
Sex Education Levels for the Mentally Retarded	29
Sex Education Curricula	31
Summary Based on Review of Literature	35
3. PROCEDURES	39
Population	39
Method of Collecting Data	40
Questionnaire	44

	<u>Page</u>
Method of Organizing Data	47
Analysis of Data	47
Summary	47
4. RESULTS AND ANALYSIS OF DATA	48
Results of the Questionnaire	50
5. SUMMARY, FINDINGS, CONCLUSIONS, AND RECOMMENDATIONS	67
Summary	67
Findings	67
Conclusions	71
Recommendations	72
LITERATURE CITED	73
APPENDIX A. REACH, Inc. - Program Summary	79

LIST OF TABLES

<u>Table</u>	<u>Page</u>
1. Verbal Descriptions and Ranges in I.Q. Scores for Degree of Retardation	6
2. Risk of Mental Retardation in Children and Sibs of Retardates	10
3. Age Groupings of Population Members at the Time of the Interview	49
4. Intellectual Range of Population Members at the Time of the Interview	49
5. Would You Like to Talk or Learn more about Handholding?	52
6. Would You like to Talk or Learn more about Kissing?	53
7. Would You like to Talk or Learn more about Dating Girlfriends or Boyfriends?	54
8. Would You like to Talk or Learn more about Love?	55
9. Would you like to Talk or Learn more about Marriage?	56
10. Would You like to Talk or Learn more about Babies?	57
11. Would You like to Talk or Learn more about Caring for Babies? Would You like to See a Baby Being Born?	58
12. Would You like to Talk or Learn more about Where a Baby Comes From?	59
13. Would You like to Talk or Learn more about Sexual Intercourse?	60
14. Would You like to Talk or Learn more about Contraception, Venereal Disease, Masturbation, Homosexuality, and Abortion?	62

Table

Page

15. Would You like to Talk or Learn more about Sexual Body Parts of Boys and Girls?	64
--	----

ABSTRACT

The problem of the study was to determine what mentally retarded individuals residing in group homes desired in their sex education program.

The author interviewed the mentally retarded population which consisted of six females and thirteen males that ranged in age from eighteen to sixty-two years of age. This population had spent from three to thirty-two years in institutions for the mentally retarded. Ten members of the population were mildly retarded, five members were moderately retarded, and the intellectual status of four members was unknown.

The interview focused on a questionnaire developed by the author. The questions related to topics presently in use in sex education curricula for the mentally retarded and those topics suggested by authorities in the field.

It was found that: 1) These retarded individuals did have opinions, desires, and ideas about what they would like to talk and learn about in a sex education program. Most of the members (sixty-three to eighty-four percent of the population) indicated that they would like to talk or learn more about (a) handholding, (b) kissing, (c) dating, (d) love, (e) marriage, and (f) babies. About one-half of the participants indicated that they would like to learn or talk about (a) where a baby comes from, (b) caring for babies, and (c) the sexual parts of boys and girls.

2) These retarded individuals had varied interests, desires, attention spans, language problems, and cognitive abilities.

3) An individualized program and teaching on an individualized basis would be necessary when teaching sex education to these mentally retarded people because of their varied interests, desires, attention spans, language problems, and cognitive abilities.

The following recommendations were made: 1) That the mentally retarded be asked about what they would like to talk or learn about in a sex education program.

2) That the subject matter in sex education curricula for the mentally retarded include but not necessarily be limited to the questions, desires, and interests of the retardates.

3) That the sex education programs for the mentally retarded be individualized to meet the varying interests, desires, attention spans, language problems, and cognitive levels of these people.

Chapter 1

INTRODUCTION

The author was involved with parents of mentally retarded individuals while employed as a public health nurse in Wisconsin. During this time parents of the mentally retarded expressed an interest in learning more about sex education for their children. Since attending graduate school, this writer has become aware of the importance of individualized instruction in education. This study developed from an interest in individualized instruction and a concern about sex education for the mentally retarded.

Statement of the Problem

The problem of the study is to determine what mentally retarded individuals residing in group homes in a small western city desire in their sex education program.

Need for the Study

The study is important because the questions and topics most vital to the mentally retarded person's understanding of his/her sexuality may or may not be included in present day sex education curricula. Generally speaking, the curricula are expert, teacher, parent, or administration directed. Adults usually decide the content of sex education curricula for the mentally retarded. Mentally handicapped

people seldom contribute to or have input into decisions regarding curricula content.

General Procedure

The writer interviewed the mentally retarded population residing in group homes in a small western city. A tape recording was made of each interview which focused on the questions of the questionnaire included in Chapter 3. Permission for the interviews was obtained from the members of the population, the local chapter officials of The National Association for Retarded Citizens, REACH, Incorporated (see Appendix A for more information about REACH, Inc.), and the group home counselors. For reasons of confidentiality, the names of the persons interviewed and the city itself are not disclosed.

Limitations and Delimitations

It was necessary to individualize the questionnaire for each participant during the interviews. The writer was unable to follow the questions and phrase the questions of the questionnaire exactly the same for each interviewee because of language and communication problems. Some members of the population had difficulties dealing with incoming auditory information while others displayed difficulties in attention. At times, parts of the questionnaire had to be re-phrased, repeated, or explained using vernacular terminology. An

attempt was made to use language understood by the population members.

The size of the population in this study is a limitation. It may be misleading to apply implications from this study of a small number of mentally retarded individuals to the much larger population of all mentally handicapped people.

It is possible that some individuals of the study population have been rewarded for responding with "yes" answers. Yes responses may have been given by a participant out of habit when he/she did not really understand the question or topic. In order to determine if a participant was giving a yes response out of habit, a question such as, "Would you explain that a little more?" was asked after a yes response.

The study was delimited by the background of the population members and the geographical area. The population members were all living in group homes and had previously lived in an institution for the mentally retarded. The geographical area in which the population lived was of a rural nature.

Definition of Terms

The American Association on Mental Deficiency (AAMD) defines mental retardation as

. . . subaverage general intellectual functioning that originates during the developmental period and is associated with

impaired adaptive behavior. . . . Both criteria must be met before a person is to be considered mentally retarded. The criteria of intellectual functioning is measured by one or more standardized tests of intelligence and is considered sub-average when the obtained intelligence quotient (IQ) is greater than one standard deviation below the population of the mean at the age group involved. . . . The developmental period, although not precisely defined, is regarded as being approximately the first 16 years of life. . . . The criteria of impaired adaptive behavior is manifested in the areas of maturation, learning and social adjustment. Maturation refers to the rate of development in the self-help skills of infancy and early childhood. Learning refers to the ability of the individual to acquire knowledge as a result of his experience. Social adjustment is the degree to which the individual is able to maintain himself independently and to conform to personal, social, and vocational standards appropriate for his age group (Heintz, 1971:335).

Educable Mentally Retarded (EMR)

Although criteria for inclusion in classes for the EMR vary from state to state, a majority of school systems employ the following criteria:

(1) Retarded mental development. While the most commonly used IQ range is 50 to 75, there is a general trend toward aligning educational classification with the AAMD Classification. As a result there is a general move toward accepting an IQ range of 55 to 84 as the lower and upper extremes for inclusion in special classes for the EMR.

(2) Inability to profit substantially from regular education programs.

(3) Limited capacity for academic achievement.

(4) Limited capacity for independent social and occupational functioning (Heintz, 1971:335-38).

Trainable Mentally Retarded (TMR)

Mentally retarded children in school programs for the trainable usually fall into the IQ range of 30-50; however, as with EMR children, students vary from state to state, and the national range for children in programs for TMR extends from 25 to 60. Criteria for selection usually include capacity for development of self-help skills, personal and social adjustment in a restricted environment, and limited productivity in a sheltered employment center such as a common workshop for the severely handicapped. Trainable children are not expected to profit from traditional instructional programs; hence, academic instructional programs in the classical sense are not included in the curriculum (Heintz, 1971:338-39).

In Table 1 Heintz (1971:335) gives verbal descriptions and ranges in I.Q. scores for degrees of retardation (see page 6).

Group Home

A group home is a residential facility which provides supervision and training services to developmentally disabled adults. This definition was provided by the Director of REACH, Inc.

Table 1. Verbal Descriptions and Ranges in I.Q. Scores for Degree of Retardation

Degree of Retardation	Range of I.Q. Scores
Borderline	70 - 84
Mild	55 - 69
Moderate	40 - 54
Severe	25 - 39
Profound	25

Summary

A study of the desires of mentally retarded individuals concerning sex education curricula is important because the questions and ideas most vital to a person's understanding his/her sexuality may or may not be included in today's curricula. The needed data was obtained by using a tape recorder to record verbal answers to questions asked from a questionnaire administered by the writer to the mentally retarded individuals. The findings from this study should help parents, teachers, and administrators to know more about what mentally retarded individuals may desire in sex education curricula.

Chapter 2

REVIEW OF LITERATURE

This chapter presents information on mental retardation and education, including sex education. The review of the literature focuses on the following major areas:

Mental Retardation - Prevalance and Causes;

Education of the Mentally Retarded;

Individualized Education - General Population;

Individualized Education - Retarded Population;

Language Difficulties Associated with Mental Retardation;

Rights of the Retarded;

Characteristics of the Subject Matter - "Sex";

Reasons For and Against Sex Education For the Mentally Retarded;

Sex Education Levels for the Mentally Retarded; and

Sex Education Curricula.

Mental Retardation - Prevalance and Causes

Three percent of the total population in the United States is mentally retarded (President's Panel . . . 1963). Based on this figure, it is estimated that the number of mentally retarded individuals in this country is approximately six million people (Heintz, 1971).

Whaley (1974) states that intelligence, like stature, shows a continuous variation. Approximately seventy-five to eighty-five

percent of intelligence is contributed by the small additive effects of polygenes and the remainder by environmental factors.

Fraser and Nora (1974) report that if an individual with an I.Q. below seventy is arbitrarily defined as retarded, then some people will be retarded because they received an assortment of genetic and environmental factors that placed them in the lower portion of the normal distribution of the population without any factor in itself being abnormal. They further state that the causes of mental retardation fall into the same four categories as do congenital hip, heart malformations, and other common familial disorders: 1) mutant genes, 2) chromosomal aberrations, 3) major environmental insults, and 4) multifactorial etiology. Persons in the first three groups tend to be more severely retarded than those in the multifactorial group.

The most seriously affected retardates make up a small proportion of the total population of retarded persons. The most severely retarded have a high mortality rate (Matheny and Reisman, 1969). Mental retardates with an I.Q. below fifty-five exhibit a difference in gender. The sharp increase in the number of males in this group suggests the probability of an X-linked recessive gene effect. Severely retarded persons are almost always infertile (Whaley, 1974). Fraser and Nora (1974) report that intelligence of near relatives of those retarded persons with specific and, therefore, severe types of retardation is like that of the general population. However, the

intelligence of near relatives of children with nonspecific and, therefore, milder retardation tends to be lower than that of the general population.

Matheny and Reisman (1969) are concerned with the group that displays familial retardation. This group represents eighty to ninety percent of the total population of retarded people. Multifactorial or polygenic inheritance refers to genetic variations that are due to a number of genes held in common. The nature of the polygenic model suggests that mental retardation correlates with the degree of genotype similarity. Relatives of this group of retarded people have a higher incidence of mental retardation than that of the general population. Matheny and Reisman identify the following risk factors associated with familial retardation: If both parents are retarded, there is a fifty-five to sixty percent chance that the offspring will be retarded, a thirty-five to forty percent chance they will be borderline or slow, and a four percent chance they will be of average or better intelligence. If only one parent is retarded and the other parent has borderline or below intelligence, there is a thirty-five percent chance the offspring will be retarded and a ten percent chance they will be of average or better intelligence.

In another study of people with an I.Q. less than seventy, Fraser and Nora (1974:243) investigated the risk factors of mental

retardation for children and siblings. Their findings are presented in Table 2:

Table 2. Risk of Mental Retardation in Children and Sibs of Retardates

Parents	Children	Risk for child	Risk Percent
0	--	"	1
1	--	"	11
2	--	"	40
0	1	Risk for sibling	6
1	1	"	20
2	1	"	42

^aF. Fraser and J. Nora, Medical Genetics (Philadelphia and Febiger, 1979), p. 243.

Matheny and Reisman (1969) believe that it is important to point out that not all familial retardation is a result of heredity because often mental retardation can be attributed primarily to poor cultural or environmental factors. Most families with the familial form of retardation tend to be in the lowest economic and social class. Finally, they conclude that the majority of families with familial retardation will not avail themselves voluntarily to genetic counseling.

Jones et al. (1974) revealed a factor unknown to the general population that may increase the incidence of mental retardation. He found that women who were chronic alcoholics during their pregnancy had a high incidence of offspring with mental retardation. Forty-four

percent of the offspring in his study were determined to possess borderline to moderate degrees of mental deficiency.

The pollution of wastes containing mercury into the ocean by Japanese factories had contributed to an increase in mental retardation. Life and Health (1974) related that the residents who ate fish contaminated with mercury developed Minamata Disease. An increase in mental retardation was associated with Minamata Disease.

Infants who eat paint containing lead can develop lead encephalopathy and mental retardation (Begab, 1974; Marlow, 1973).

Bass (1974) reports that the President's Task Force on the Mentally Handicapped estimates that family planning could reduce congenital malformation by twenty percent and Down's syndrome by thirty percent. The Task Force recommends increased dissemination of birth control devices along with making sterilization and abortion more readily available.

In their paper, Anderson and Reed (1973) discuss several findings concerning mental retardation and birth rate figures.

1. There is no correlation between parents' I.Q. and family size.
2. Some retarded have very large families but more than half of them have no children. Thus, the average number of children per retarded individual is less than that produced by a non-retarded individual.

3. Retarded parents produce about seventeen percent of all retarded children.

In response to Anderson and Reed, Murphy (1973) states that the gene pool has long been in a state of near equilibrium with a slow trend toward improvement of the genetic stock. A conservative estimate is that ninety-five percent of all people carry harmful genes; a more reasonable estimate would be ninety-nine point nine percent. The majority of these genes are genes for recessive traits and difficult to detect. Murphy (1973:129) states, "If the human is to reproduce from unsullied stock only, a minute fraction of the population is going to be very busy indeed." He advises that nothing can be done about the gene pool without imperiling adaptability and points out that the carrier state of Tay-Sachs disease is associated with a lower than average risk of tuberculosis. He warns that any interference with the dynamics of the gene pool may cause problems.

Education of the Mentally Retarded

Gunzberg (1974:628) believes that education for the mentally retarded should be modest but realistic, and enable them to function as unobtrusively and competently as possible through the teaching of social competence. It is essential that education ensures, first of all, that the retarded person is adequately prepared for his role in the community. Gunzberg adds that there is considerable concern about

the mentally retarded person's social inadequacy, which makes him a social liability, but nearly all educational work concentrates on his academic weaknesses even though the community tolerates scholastic weaknesses quite well. Gunzberg points out that in normal education the order of emphasis is: academic proficiency, occupational competency, and competency in social adjustment. In the case of the mentally retarded the order of emphasis should be: social competency, occupational or vocational competency, and academic proficiency.

For a long time children with an I.Q. score above fifty were given education and those with a score below fifty were given training. This served as an administrative convenience but also determined the quality of education given them. Gunzberg (1974) reports that in Great Britain the Education (Handicapped Children) Act of 1970 abolished this line of division between educable and trainable retardates. It established that all children, regardless of their mental deficiency, were now the responsibility of the education authorities.

However, there is difficulty in agreeing on the definition of mental retardation. The American Association on Mental Deficiency recognized the need to achieve greater uniformity and developed the interdisciplinary definition the writer used in Chapter 1 (definition of terms). The definition differed from some earlier terms and these differences are important. The definition clearly states that sub-average intellectual functioning must be accompanied by impairment in

adaptive behavior. It also states that the term is descriptive of the individual's current intellectual and adaptive behavior. This is very important because the individual may meet the criteria of mental retardation at one time and not at another.

Labeling may be an important factor in determining whether an individual receives training or education even if the label is inappropriate. Kurtz and Wolfensberger (1974) report that once a label is attached to an individual, those who deal with him often assume that the label is a legitimate characterization of his condition. This may be true even when there is little or no evidence supporting the appropriateness of the label. Whalen (1973:238) reports, "Once labeled, individuals lose their individuality. The mentally retarded are construed as members of a homogeneous group with a standard set of characteristics and deficiencies." Edgerton (1973:245) adds, "One central finding from the studies of mildly and moderately retarded is that through being labeled mentally retarded, such persons suffer an acute loss of self-esteem." As would be expected, this diminished self-esteem is a fundamental problem for the retarded and for all those who must interact with them. Begab (1974) feels mental retardation is not necessarily a permanent legitimate characterization of an individual; for certain groups, especially the so-called cultural familial group, "cure" through behavior change is possible.

The use of I.Q. tests may also contribute to labeling and be a factor in determining whether an individual receives training or education. Murphy (1973:129) discredits the use of I.Q. tests which are often used as tools for labeling the mentally retarded.

They do not lend themselves to any of the classical statistical techniques, such as discriminant analysis or multiple regression, because there is no agreed variable against which they can be validated; if there were, we could use the outcome variable and not the test. If there is nothing to appeal to for validation, then inevitably the construction, the weighting, and the interpretation of the tests must be colored by the standards of the psychologists, for the most part middle-class males of European stock and academic cost. If the birds constructed such tests, we would doubtless get low marks in building nests, hatching eggs, flying, and catching worms. We would be labeled hopeless imbeciles and perhaps be compulsorily sterilized by our well meaning rulers.

Individualized Education - General Population

Bolvin and Glaser (1971:270) remind us that in 1925 the National Association For Study of Education declared, "It has become palpably absurd to expect to achieve uniform results from uniform assignments made to a class of widely differing individuals." Individualized instruction emerged to deal with the problems mentioned by the National Association For Study of Education. There has been a movement in education in recent years toward individualized instruction (Deshaw, 1973; Bishop, 1971; Dunn, 1971).

Individualized instruction provides a program for each student that is based on his/her characteristics as a learner and includes

his skills, abilities, interests, learning styles, motivation, goals, rate of learning, self-discipline, problem-solving ability, degree of retention, participation, strengths, weaknesses and prognosis for moving ahead in various curriculum areas and projects.

(Dunn, 1971:31). For many people it implies instruction segregated from the rest of the class, for others independent study. Still others believe it implies one child and a tutor or one child and a machine. This is not the case according to Bolvin and Glaser. Individualized instruction is instruction that is adapted to an individual's needs, characteristics, and interests and may include the use of small group instruction, teaching machines, programmed instruction, tutoring, project work, or independent study. Seigel (1967) reports that for instruction to be most effective, it must be tailored to the needs, capabilities, and histories of individual learners.

Conley and O'Rourke (1973:591) believes that instruction might be improved by a process of obtaining baseline data on students involved in sex education courses; they state,

In educational circles, it is axiomatic that an assessment of students' needs and interests should proceed instruction efforts. This assignment should help in obtaining desired educational outcomes. Too often, instructors assume a prior knowledge of the student wants without validating such assumptions.

Individualized Education - Retarded Population

Weisgerber (1974:33) wrote,

Much has been written about the principles and practices employed in individualized learning for regular students and

for the most part these systematic procedures are equally appropriate for handicapped students. The handicapped child warrants individual attention and educational experiences adapted to meet his unique needs.

Gunzberg (1974:653) when speaking of education for the retarded states, "It would be a retrograde step if education for all were interpreted as meaning the same education to different degrees. The guiding principle is to each according to his needs."

Gunzberg believes that education should respect the choices, wishes, and desires of retarded people. Mentally subnormal people are seldom encouraged to participate actively in decisions and arrangements concerning them though normal people claim the right of having a say in issues relating to them.

Shindell (1975) believes that all instructional procedures for the retarded must be geared to the level of the individual, including sex education.

Borthick, Fisher and Krujicek (1973) believe that when teaching sex education to the mentally retarded, eliciting information is just as important as giving information. They believe that the first and most important step in making available sound sex education for the developmentally disabled person is to talk to that individual. By talking with an individual one can gain insights to his developmental level, needs, interests, questions and concerns. Mattison (1973) suggests that before teaching sex education to the mentally retarded

it is important to listen to them and find out where they are in their own psychosexual development, their emotional level, interests, and questions.

Language Difficulties Associated with
Mental Retardation

Mittler (1974) reports that for language functioning to be effective, the subject has to:

1. be able to receive stimuli produced in sequential order;
2. maintain a sequential impression of the message so that its components can be integrated into a pattern;
3. scan the pattern from within to categorize the data and compare it with an existing store; and
4. respond differentially to perceptual impression.

According to Mittler these are the very disabilities that have been shown to be severely impaired in the mentally subnormal. They have particular difficulties in dealing with incoming sensory information, and many of their learning difficulties can be regarded as stemming from a disorder in attention. Information processing of auditory material is particularly difficult, but it is also seen in dealing with visual material. Mittler (1974:535) states that the subnormal

Frequently lack the social and behavioral skills which would allow them to indicate to the speaker that he was not being understood, thus depriving the speaker of the kind of cues which would enable him to modify his utterance accordingly.

A normal child learns as he gets older to give signals that he does not understand something by frowns, puzzled looks, or asking for something to be repeated. Mittler feels these are essential social skills in a communication situation which a child may acquire without conscious effort but which may need to be taught to the mentally retarded child.

Muller and Weaver (1964) studied the psycholinguistic abilities of institutionalized and non-institutionalized trainable mental retardates. They found that institutionalized people were inferior in language development.

Spren (1965) documents the relationship between I.Q. and both speech and language disorders. He reveals that the frequency of language disorders is one hundred percent in those with an I.Q. below twenty, around ninety percent in the I.Q. range twenty-one to fifty, and about forty-five percent in the mildly retarded group.

Johnson (1973) sees the retarded as having a language barrier when dealing with sex education. First of all, they face the frustration of being unable to decode some important verbal messages because of the unfamiliar vocabulary or the complex style in which it is used. The retarded are not skilled in medical terminology. He thinks the reluctance of the educator to use vulgar language is another barrier. Chadsey and Wentworth (1970) in the Gosset Webster Dictionary define vulgar as common or ordinary. This language is understood by all, but

its use is not accepted. Money (1973) supports the use of pictures and films for explicit teaching to the mentally retarded, but observes that our culture has a great inhibition to pictures of sexual organs.

Rights of the Retarded

The Mental Disability Law Reporter (1976) reveals that Florida recently enacted a "Bill of Rights of Retarded Persons" (Chapter 75-259, approved June 29, 1975), which spells out and guarantees basic rights for the clients of the state mental retardation system. The clients' rights enumerated in the new law (effective July, 1975) include dignity, privacy, and humane care; religious freedom; an "unrestricted" right to communication and visitation; possession and use of personal belongings and clothes; education and training services (though not at any particular level), including sex education; behavioral and leisure time activities; physical exercise; humane discipline; and compensation for labor in accordance with applicable federal regulations.

Public Law 94-142 (1975) deals with the educational needs of the more than eight million handicapped children in the United States. Some of its important provisions are:

1. assurance of an effective policy guaranteeing the right of all handicapped children to a free, appropriate public education, at no cost to parent or guardian;

2. assurance of special education being provided to all handicapped children in the "least restrictive" environment;
3. assurance of regular parent or guardian consultation; and
4. assurance of the maintenance of an individualized program for all handicapped children. (The emphasis is not in the original copy.)

In the definitions of this law, it states

The term "individualized education program" means a written statement for each handicapped child developed in any meeting by a representative of the local educational agency or an intermediate educational unit who shall be qualified to provide, or supervise the provision of, specially designed instruction to meet the unique needs of handicapped children, the teacher, the parents or guardian of such child, and, whenever appropriate, such child, which statement shall include (A) a statement of the present levels of educational performance of such child, (B) a statement of annual goals, including short-term instructional objectives, (C) a statement of the specific educational services to be provided to such child, and the extent to which such child will be able to participate in regular educational programs, (D) the projected date for initiation and anticipated duration of such services, and (E) appropriate objective criteria and evaluation procedures and schedules for determining, on at least an annual basis, whether instructional objectives are being achieved.

Burt (1973) reports there are several kinds of state laws that limit the freedom of those labeled mentally retarded to engage in sexual relations, to marry, and to rear children. In a number of states, "mentally retarded" individuals can be compulsorily sterilized, denied marriage licenses, or lose the custody of their children. However, in recent years these laws have rarely been invoked. Burt firmly

believes that any law that singles out "mental retardates" for special restrictions in sexual or family life violates the United States Constitution.

Goodman (1973) reports on the legality of providing contraceptive information to all people. The public welfare provisions of the Social Security Act Title IV amended in 1967 maintains that states must make available on a voluntary basis family planning information to any person of child-bearing age asking for it, regardless of marital status or age, including the mentally retarded.

The Wisconsin Association for Retarded Citizens Board of Directors adopted the following resolution on sexuality on November 8, 1975, as reported in the Wisconsin ARC News, March, 1976.

RESOLUTION ON SEXUALITY

WHEREAS, persons who are mentally retarded have the same sexual feelings, thoughts and needs that other people have, and
WHEREAS, factual and accurate information on human sexuality decreases the incidence of sexual problems and inappropriate behaviors, and
WHEREAS, persons who are mentally retarded are in need of special training and education in their learning process, and
WHEREAS, non-mentally retarded adults have the right to freedom and privacy in expressing themselves sexually, and
WHEREAS, non-mentally retarded persons have the right to obtain birth control devices and/or to birth control methods,
THEREFORE, persons who are mentally retarded have the right to privacy, to sexual expression that does not impinge upon the rights of others and that is within legally defined limits, to sex education and information, and to information and training in the use of effective birth control, and to obtain such birth control devices.

THEREFORE, WARC seeks to ensure the rights of person who are mentally retarded by encouraging legislation which protects their rights, by recognizing their sexual rights, by promoting the gathering together of sex education resource materials for families and educators, by supporting the training of persons in the field of human sexuality and by encouraging the implementation of sex education programs.

Characteristics of the Subject Matter - "Sex"

Warren Johnson (1973) feels that the prime characteristic of the subject matter of sex education is that it is different. It is not treated as educational subject matter in the same sense as chemistry or nutrition. No polling is done of the public or school officials to determine whether mathematics or history should be taught in the schools. The strange taboo system of sexual morality and attitudes present in today's society was laid down by Old Testament Jews. The early Christians added to the Jewish regulations a frank hatred of sex and women. Johnson (1973:61) states,

The influential St. Augustine wrote that the gateway to hell lay between a woman's thighs; and it was he who permanently fixed the sex-in-guilt association in the Christian mind.

Tradition plays an important factor in our society. An example of this, according to Johnson, is the disavowal of the report of the President's Commission on Pornography and Obscenity which found no evidence that pornography produces ill effects on the beholder, child, or adult. Johnson (1973:62) concludes,

Historical, moral, legal, and linguistic traditions profoundly affect all efforts at sex education and often hinder attempts to educate in this area. Especially impeded, perhaps, are any efforts to educate the mentally retarded.

Deisher (1973) reports that there has been a progressive change in public awareness of the importance of sex in people's lives.

Reverend Tyrer (1973:xii) states,

We of this generation are living in an hour of transition from the day when sex was considered as something to be hidden, something that had undefined relation to impurity . . . , to the cleaner sweeter day that is dawning . . . , it will be exalted as the most important thing in the world.

Reasons For and Against Sex Education for the Mentally Retarded

Maddock (1974:374) feels the heart of the issue of sex education for the retarded is found in this question,

At what ages, under what circumstances, with whom, and in what forms shall genital activity be considered appropriate for the person with special needs--and with what consequences for the individual and for society?

Maddock gives reasons of why people oppose sex education for the mentally retarded: (1) fear of uncontrolled reproduction; (2) fear of an undisciplined sex drive; and (3) denial of the sexuality of the retarded person. Hoyman (1974) reports that some people feel that sex education will lead their children toward premature sexual permissiveness. Hoyman does not specifically mention retarded children, but speaks of children in general.

Maddock (1974) points out the obvious by saying that the sexuality of the retarded is a fact. Shindell (1975) reports that retarded and normal individuals have similar sex interests and desires.

Hammer, Jensen, and Wright (1967:625) concur, "According to parental observations, the sex drives, curiosity, and interests of this group of mildly defective children differed little from that of their normal siblings and age mates." Gebhard (1973) in his study reports that the retarded with I.Q.'s of fifty or less experienced less heterosexual and homosexual activity than those with higher I.Q.'s but orgasm in sleep was more prevalent for the former group. Johnson (1973) reports that like the so-called normal person, the retarded person is likely to, but not necessarily, have a strong interest in sex. He feels the mentally handicapped, like most people, are interested in sex primarily for its potential sensual gratifications and that it may have little or nothing to do with a motivation to procreate or form a permanent relationship.

Deisher (1973) recognizes that society has increasingly recognized the rights of the retarded to be educated, to work and to fit into society in a way commensurate with their abilities. But, society has almost entirely neglected the rights of the retarded to be sexual individuals, to enjoy sexual pleasure, and to experience feelings that are of a sexual nature.

Kempton and Forman (1971:Forward), in referring to the mentally retarded, declare,

Until their parents, the professionals working with them, and members of the community face the fact that all handicapped persons are sexual beings, and until programs are developed to help them understand their sexuality and enjoy it appropriately, we have not truly progressed in our efforts to help them, nor indeed have we acknowledged their rights.

Maddock (1974) believes that many people who feel the exceptional person should be protected from knowing what normal people know about sex are in a way protecting themselves from the sexuality of the retarded person.

Sex education for the mentally retarded may help to decrease the incidence of venereal disease among the mentally handicapped. Kempton, Bass, and Gordon (1971), in their book Love, Sex, and Birth Control for the Mentally Retarded, relate that a child is more likely to have sexual problems when he/she does not know much about sex and that there is less promiscuity and venereal disease among those with more information. Levine (1967) portrays sex education as a possibility for reducing the incidence of venereal disease because gonorrhea and pregnancy rates decrease when sex education is introduced into public schools.

The incidence of this disease is growing. According to Baker (1974), gonorrhea has the greatest incidence of any communicable disease required by law to be reported; syphilis is number four. An

added difficulty is that eighty percent of the women and fifteen percent of the men with gonorrhea have no symptoms. Subak-Sharp reveals that there are at least two hundred and fifty thousand and perhaps as many as one million cases of the venereal disease herpes simplex II in the United States. As of yet there is no proven cure for this disease. Bass (1974) reports that venereal disease is three times higher in the retarded than in the normal population.

The incidence of venereal disease nationwide, the prevalence of this disease among the retarded, and the fact that sex education may help decrease the incidence of venereal disease, are important reasons which support sex education for the mentally handicapped.

Maddock (1974) gives other justifications for sex education for the retarded:

1. The role of the body in human development is important and sex education can provide an opportunity for the retarded to focus attention on their body and physical expression.

2. The interpersonal aspects of sex must not be forgotten. The retarded often lack an opportunity for sexual expression (physical, interpersonal, and symbolic) and this leads to less effective social, emotional, and intellectual functioning.

3. Parents desire help in the sex education of their retarded offspring.

Barker, Hall, and Morris (1973) in their research on sixty-one non-institutionalized mildly and moderately retarded adolescents show that in certain areas (contraception, conception, and venereal disease) the adolescents were lacking in accurate information, and parents were unsure of the knowledge their children possessed. The mentally retarded adolescent had a more liberal attitude than expected by the parents. Sex education was not being given in the home. The parents expressed concern that assistance be given in this area. Social class, race, and religion did not correlate with the test measures, and this suggests the need for sex education for the mentally retarded is demonstrated in all strata of society.

Hammer, Jensen, and Wright (1967) in their study of fifty retarded adolescents reported that parents felt more comfortable about coping with sex education for females than males. The onset of menarche helped to initiate sex education for the females. However, because physical changes were not as demonstrative for the males, the parents tended to delay or avoid sex education for their sons. Parents indicated they would only answer questions when asked, and if none were asked this was interpreted by the parents as a lack of interest in the topic by their children. Goodman, Bunder, and Lesh (1971) found that parents with retarded children living at home have limited knowledge of sexual functions and make only minimal efforts to give sex instruction.

Presently there is a movement to return institutionalized mentally retarded people back to the community. Shindell (1975:88) states that "no normalization process can be considered complete and/or successful without consideration for its socialization component." Gordon (1975) predicts that there will be a great move back to the institutions if no sex education and contraceptive education is given to the mentally retarded. Gunzberg (1974) states that in the past the relationship of the sexes had been considered only in terms of keeping them apart but now people realize that this task has to be dealt with through preparatory training. No normalization program can be successful without dealing with the topic of sex education.

Sex Education Levels for the Mentally Retarded

Kempton (1971:65) reports that when teaching sex education to the trainable mentally retardates (TMR) one should remember the following:

1. The TMR group does not have as rational an approach in expressing their sexuality.
2. Many TMR people have difficulties in expressing themselves to the opposite sex, and do not express their feelings in an "organized" manner.
3. The sexual behavior of many TMR persons may be auto-erotic.

4. Learning for this low level is best accomplished visually, accompanied by short simple statements with simple pictures or hand demonstrations. Experimenting with new methods may also be helpful.

5. Most trainable retardates cannot discuss facts rationally so the education process may be acting out a simple social situation to demonstrate what is appropriate.

Alcorn (1974) reports that there is a tendency to generalize the sexual attributes of the trainable mentally retarded or exclude TMR people from any discussion of program needs. He reports TMR children as showing little inclination toward sexual activity and minimal curiosity about sex, those having done so being more likely to demonstrate interest in the manner of a normal preadolescent who talks about a boyfriend or girlfriend at school and who might hold hands with a partner at a party. He quotes a parent as saying,

Retarded children vary in their abilities to comprehend situations and interpretation of sexual matters, and, like any other thing, sex education must be geared to their level of understanding. Some, like ours, can not even comprehend simple concrete things without difficulty, and sex education is not a prime consideration.

Kempton (1971) believes that sex education for the educable mentally retarded people should be much the same as for the normal population, but it should be more simply and concretely stated and with much more repetition. Meyers (1972:1) states, "The sex education

needs of the educable mentally retarded are basically the same as those individuals of normal intellectual ability."

Sex Education Curricula

There are those who question the validity, adequacy, and nature of sex education curriculum for the mentally retarded. Balester (1971) pointed out that very little research is available concerning the structure, content, and results of sex education programs. Blom revealed the neglect of sex education in special education:

While guidelines and curricula exist at various grade levels for sex education, there is some question about the adequacy of many of them. My impression is that most of the curricula have been based on what adults think children want to know, or should know at different ages; less often on what is known about the psychology of children--their interests, questions and cognitive capacities (Blom, 1976:360).

The sex education programs for the retarded are, for the most part, teacher-directed, not student-directed. The mentally retarded students do not decide what they will study because it has already been decided for them by experts, parents, teachers, or administrators.

Meyers (1972: Table of Contents) in his curriculum guide for teachers incorporates three levels of sexual and social development for the educable mentally retarded. There are primary, intermediate, and advanced levels and lesson plans for each area.

Lesson Plans

Primary

- | | |
|--------------------------------------|--------------------------|
| 1. Realistic Body Image | 7. Sexual Encounters |
| 2. Proper Toilet Habits | 8. Growth |
| 3. Differences between Men and Women | 9. Differences in People |
| 4. Male and Female Roles | 10. Negative Feelings |
| 5. Self Concept | 11. Living Things |
| 6. Love | 12. Human Reproduction |

Intermediate Level

- | | |
|--|-------------------------------------|
| 1. Embryo and Fetal Development | 4. Facial and Body Hair, Acne |
| 2. Sociograms and Peer Relationships | 5. Reproductive Organs |
| 3. Adolescent Physical and Emotional Changes | 6. Menstrual Hygiene for Girls |
| | 7. Sexual Feelings and Masturbation |

Advanced Level

- | | |
|--------------------------|--------------------------------|
| 1. Personality | 5. Dating |
| 2. Feelings and Emotions | 6. Premarital Sexual Relations |
| 3. Authority | 7. Heredity |
| 4. Peer Groups | 8. Environment |

- | | |
|---|----------------------|
| 9. Planning for Marriage
and Family Life | 14. Sexual Deviants |
| 10. Motivation for Marriage | 15. Venereal Disease |
| 11. Family Planning | 16. Alcohol |
| 12. Communication in Marriage | 17. Smoking |
| 13. Meeting Conflicts in
Marriage | 18. Drug Education |

Gordon (1973) suggests that the retarded (and perhaps normal people) do not need to know many facts about sex. The information given to them can be done in a few minutes, though it must be repeated many times, and for different levels of understanding. According to Gordon (1973:69) the only concepts which need to be taught to the mentally retarded are:

1. Masturbation is a normal sexual expression no matter how frequently it is done and at what age. It becomes a compulsive, punitive, self-destructive form of behavior largely as a result of suppression, punishment, and resulting feelings of guilt.
2. All direct sexual behavior involving the genitals should take place only in privacy. However, since institutions for the retarded are not designed or operated to ensure privacy, the definition of what constitutes privacy in an institution must be very liberal. Bathrooms, one's own bed, the bushes, and basements are private domains.
3. Any time a girl and a boy who are physically mature have sexual relations, they risk pregnancy.
4. Unless both members of a heterosexual couple clearly want to have a baby and understand the responsibilities involved in child-rearing, they should use an effective method of birth control.

5. Until a person is about 18 years old, society holds that he or she should not have intercourse. After that age, the person can decide for himself.
6. Adults should not be permitted to use children sexually.
7. The only way to discourage homosexual expression is to risk heterosexual expression.
8. In the final analysis, sexual behavior between consenting adults (regardless of their mental age and of whether their behavior is homo or hetero) should be no one else's business --providing there is little risk of bringing an unwanted child into this world.

Consideration should also be given to achieving greater acceptance of 1) abortion as a safe, legal, and moral alternative to bringing an unwanted child into this world, and 2) voluntary sterilization as a protection for those retarded persons who could function well in a marriage if they did not have children.

Kempton, Bass, and Gordon (1971) in the book, Love, Sex, and Birth Control for the Mentally Retarded--A Guide for Parents, include the following chapters:

Preparing for Puberty	Contraceptive Methods
What About Masturbation	Vasectomy and Tubal Ligation
What are the Merits of Dating	Abortion
Sexual Intercourse	What About Marriage
Venereal Disease	What if She Wants Children
Birth Control	

Kempton, Bass, Gordon, and Meyers specify the curriculum to be studied.

However, there are some authorities who suggest that the mentally retarded should be included in deciding the sex education

program content. Gunzberg (1975) believes that education should respect the choices, wishes, and desires of the mentally retarded. Mentally subnormal children are seldom encouraged to participate actively in decisions and arrangements concerning them though normal people claim the right of having a say in issues relating to them.

Borthick et al. (1973) report that much literature is available about the sexual development of the mentally handicapped, and curricula are available that list the prescribed sequence in which the handicapped individual is expected to learn facts and concepts about sexuality. He believes suggestions for eliciting information from the mentally retarded is just as important as suggestions for giving information. He suggests using a picture book and talking with the mentally retarded person to gain information on their sexual feelings, desires, and interests and knowledge levels. Mattison (1973) suggests that before teaching sex education to the mentally retarded, it is important to listen to them and find out where they are in their own psychosocial level and what they want to know.

Summary Based on Review of Literature

Three percent of the total population in the United States are mentally retarded. Those people with specific causes of mental retardation tend to be more severely retarded, but the vast majority of

retardates have a multifactorial etiology and are not as severely retarded as the former group.

The topic of sex has many traditional taboos, values, and preconceived opinions. Only recently have we arrived at the point where we can talk and think about sexuality as something which is a normal part of human behavior, and which, perhaps, deserves the same study and research as many other types of human behavior.

The retarded are sexual individuals with the same feelings, thoughts, and needs that are possessed by other people. Factual and accurate information on human sexuality decreases the incidence of sexual problems. Sex education aids in helping people gain a wholesome attitude toward sex and an understanding of sexual attitudes, roles, and relationships.

For a long time children with an I.Q. score above fifty were given "education" and those with a score below fifty were given "training." The term, "mental retardation," is a descriptive term of an individual's present intellectual and adaptive behavior. The individual may meet the criteria of the definition at one time and not at another. However, all too often, a label is attached to an individual, and those who deal with him often assume that the label is a legitimate characterization of his condition, even when there is little, if any, evidence supporting the appropriateness of the label.

Public Law 19-142 provides that all handicapped children have a right to a free, appropriate, public education at no cost to the parents or guardian. It does not say for all those with an I.Q. above fifty. It applies to all handicapped children. It also stipulates the maintenance of an individualized program for all handicapped children.

Individualized instruction has gained popularity in the field of education. Individualized instruction provides a program for each student that is adapted to the individual's needs, characteristics, and interests. It may include small group instruction, teaching machines, programmed instruction, tutoring, project work, or independent study. The handicapped person surely warrants individual attention and educational experiences adapted to meet his unique needs. All instructional procedures must be geared to the level of the individual, including sex education.

It is important when teaching sex education to elicit information from the retarded that indicates their desires, interests, needs, questions; and cognitive levels. When eliciting information, one must remember that the retarded are often faced with a language barrier. Often the retarded have not learned the social skills that allow them to indicate to the speaker that they do not understand something. Oftentimes the material is presented in a complex way or by using

medical terminology not understood by the retarded. Vulgar terms are understood by most persons, including the retarded, but there is a reluctance on the part of educators to use vulgar terms.

Adults often think they know what should be taught to children or what interests them, but this is not often a true representation of the situation. Blom (1970) sees most curriculum as being based on what adults think children should know or want to know about sex, rather than on the expressed interests and questions of the students. This leads to the question to be dealt with in the next chapter: What do the retarded desire in a sex education program?

Chapter 3

PROCEDURES

This chapter outlines the procedures used in investigating the question: "What do mentally retarded individuals desire in a sex education curriculum?" The following sections are included in this chapter: population, method of collecting data, questionnaire, method of organizing data, analysis of data, and a summary.

Population

One distinct population was involved in the study which took place in a small western city during the fall of 1976. All mentally retarded persons, regardless of age, sex, or I.Q., residing in group homes in this city were considered for possible inclusion in this study. Nineteen out of a total population of twenty-one individuals were included in the study. Two individuals declined to participate. All people in the study population were involved with Recreation, Education, and Adult Counseling for the Handicapped (REACH), Incorporated.

REACH, Inc. is a legally recognized, non-profit organization which is currently providing services to developmentally disabled adults in this small western city. A more detailed description of REACH, Inc. is included in Appendix A.

Method of Collecting Data

The writer had the good fortune of belonging to the National Association for Retarded Citizens (NARC) and had been involved with this organization for two years before the study was begun. This enabled the writer to gain valuable insight into the lives of retarded people, their families, and those associated with them.

The author became a member of the local chapter of NARC in the city where the study took place. Through the help of this organization and the people the writer met at the local chapter meetings, the population for this study was identified.

Permission to interview the population was obtained from the local chapter of NARC, REACH, Inc., the group home counselors, and the retarded individuals involved in this study. For reasons of confidentiality, the city and the names of the people involved in this study have been withheld.

A questionnaire to be used during the interview was developed by the writer. The questions relate to the topics presently in use in sex education curricula and those topics suggested by authorities in the field. The writer also discussed the questionnaire content with Dr. William Serdahely (health educator who teaches sex education), REACH, Inc., and various people involved with the local chapter of NARC.

