

**PARENTAL OPINIONS REGARDING PROTECTIVE  
SERVICES FOR THE MENTALLY RETARDED  
IN UTAH 1971**

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PROTECTIVE SERVICES  
FOR THE  
MENTALLY RETARDED  
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## ABSTRACT

### Purpose

The purpose of this study was to provide some initial research in four general areas of concern related to the mentally retarded in Utah.

The first and chief area of consideration was *guardianship*. The purpose here was to determine whether the parents of mentally retarded children, who were either residents or who had pre-admission status at the Utah State Training School, were interested in guardianship provisions for their children.

A second area was *sterilization*. The purpose related to this subject was to elicit and analyze attitudes and opinions on the subject by the same above identified parents.

The other two areas which were considered in the study were *marriage of the mentally retarded*, and the *quality of care provided by the Utah State Training School for the mentally retarded*. The purpose for these two was also to obtain opinions and attitudes from the parents.

## Methodology

The data were obtained from 42 interview schedules developed by four graduate students. The students administered the schedule to parents of mentally retarded children who were either Utah State Training School residents, or who had pre-admission status at the school. The names of the parents were selected from two files at the State Training School; a pre-admission file, and an active file. The interview schedule, which dealt with questions developed for the study, was given in the home of the retardate's parents. The data obtained from both the parents of pre-admission children, and of resident children, were transferred to tally sheets. Percentage tables, comparisons and analyses were made from the collected data.

## Conclusions

It was found that the parents of mentally retarded children who were residents at the Utah State Training School were less concerned about problems relating to their child's future, than parents of retarded persons not yet admitted to the

state facility.

The study also showed that most parents from the sample drawn were concerned about future guardianship needs for their mentally retarded children. These parents knew little about guardianship, but favored guardianship of person and money when need was called to their attention.

It was found that parents were divided in their opinions about whether or not the mentally retarded should be allowed to marry. Many comments were given supporting the opinions on this subject.

Regarding sterilization, the study showed that parents were not unified in their answers regarding whether or not their mentally retarded child should be sterilized. Almost all of the parents commented and gave reasons for their answers.

A majority of the parents of both pre-admission and resident children had positive feelings about the service that was provided by the Utah State Training School.

### Recommendations

It is suggested that parents of children who reside at the Utah State Training School or who have pre-admission status, be provided more education pertaining to guardianship. It is recommended that Standby Guardianship, Limited Guardianship, Lifetime Guardianship, and Public Guardianship all be considered as possible areas for additional enabling legislation in Utah.

It is suggested that the decision to sterilize a mentally retarded person remain a highly individualized matter, since there are numerous differing attitudes held by the families of these persons.

It is recommended that mentally retarded persons should not be denied opportunity for marriage solely on the basis of mental retardation.

## CHAPTER I

### INTRODUCTION

#### General Statement

The mentally retarded throughout time have seldom been afforded the same rights and protections under the law as have those in the prevailing majority. Consequently, we are just now beginning to realize that we carry a responsibility for constructive change in this area. The Protective Services constitute one general area where emphasis needs to be placed in order to correct some of these deficiencies. This is the primary focus of study that is to be undertaken here. Other areas to be considered in somewhat lesser detail include the questions of marriage and sterilization for the mentally retarded person, as well as a discussion of parental opinions regarding the quality of services provided by the Utah State Training School.

Guardianship, and the need for adequate guardianship provisions, are key components in the protective services. Traditionally, guardianship of a child has extended until the time that the

child has reached majority age, usually 21 years, and has resided with either the parent or a legally appointed guardian. The implicit assumption of course has been that by this age the person will have become mature enough to conduct his own affairs, in other words, to take on the usual adult responsibilities. However, in the case of the mentally retarded person this is not always true. More often than not, it is not true. This person may have little understanding of or appreciation for what it means to handle sizable sums of money, to contract for certain goods and services, and so forth. Thus, it would seem essential that any legislation respective of the rights of these individuals would include some provisions directed towards insuring that help be given them in these areas.

At the present time it appears that legislation in the various states, as a whole, is not adequate to provide for these services, nor is it a simple matter for parents to make arrangement for this. Perhaps Utah needs to consider the advisability of additional legislation. This is the most important question that is being asked in the study.

### Statement of the Problem

There are approximately 30,000 mentally retarded persons living in Utah, each with a varying degree of retardation. At the present time, most of them are cared for by their families. But family members are subject to disablement and death, and may no longer provide direct care for their retarded children. Thus, there is a need for legal protective controls, in line with parental wishes and legislative process. There is a trend in Utah, and in the nation, to enable social living, educational and employment or partial employment opportunities for the mentally retarded through the community resources. This trend is in contrast to the continuation of the system of large state institution custody or care. What do parents see as the needs to be met? This is the main problem to be dealt with in the study.

### Purpose of the Study

The purpose of this study is to examine, analyze, and compare the opinions of two groups of parents of retarded children in regard to:

1. Guardianship
2. Marriage

3. Sterilization
4. Services provided by school

#### Hypotheses

Hypotheses were developed in regard to the four areas of concern. They are as follows:

1. Guardianship - *Pre-admission parents will be more concerned about advance planning for guardianship than will residents' parents.*
2. Marriage - *Pre-admission parents will be more accepting of the possibility of marriage for their mentally retarded children than will residents' parents.*
3. Sterilization - *Residents' parents will be more in favor of sexual sterilization for mentally retarded persons than will pre-admission parents.*
4. Service Provided by School - *Pre-admission parents will have a more favorable opinion of the of the service provided by the Training School than will residents' parents.*

#### Delimitations of the Study

There were 60 parent names drawn by a systematic random sampling method from the active and inactive files at the Utah State Training School for the purpose of this study. It was possible to interview parents of only 42 of those drawn.

The data collection task was shared by four interviewers, each with his own unique style of

interviewing and differing attitudes, personality, and experience. This had some effect, despite efforts to standardize.

#### Definition of Terms

- Guardianship:** *"A legally recognized relationship between a specified, competent adult and another specified person, called a ward" (Boggs, 1970b, p. 2). For a further discussion of the types of guardians and the functions of each see Chapter II—Review of Literature.*
- Pre-admission:** *Refers to an individual on whose behalf admission to the Utah State Training School has been requested.*
- Pre-admission parents:** *Refers to those parents of individuals for whom admission to the Utah State Training School has been requested.*
- Protective Services:** *Refers to those services provided either privately or publicly to protect the mentally retarded in the areas of guardianship, marriage, and sterilization.*
- Resident:** *Refers to an individual currently residing at the Utah State Training School.*
- Residents' Parents:** *Refers to those parents of individuals who reside in or at the Utah State Training School. They may also be called "Parents of residents."*
- Rural:** *Those areas exclusive of urban or suburban areas.*
- Sterilization:** *Rendering one incapable of procreation.*
- Suburban:** *Areas adjacent to Salt Lake City, Ogden, and Provo.*

**Urban:** *Refers to Salt Lake City, Ogden, and Provo.*

**Utah State Training School:** *The residential facilities in American Fork, Utah. For the purpose of this study, it may also be referred to as: the Training School, the School, the State Training School, or USTS.*

## CHAPTER II

### REVIEW OF LITERATURE

The purpose of this chapter is to provide a brief summary of some of the past provisions concerning guardianship of the mentally retarded, and to review some of the present proposals regarding mental deficiency and guardianship. Also, a short section will be devoted to sexual sterilization and marriage of the mentally retarded. Although much has been written about mental disorders and their effect on criminal responsibility and on certain civil law problems, relatively little has been written on the subject of guardianship of the mentally retarded. This chapter is an attempt to view some of the more recent literature concerning this subject.

#### History of Guardianship

Guardianship provisions for the mentally impaired are to be found in the earliest recorded laws. The Roman law of the Twelve Tables provided for a familial curator for the furiosus. Later, Pretorian law extended this protection to all persons mentally incapacitated. Early English law

provided for guardianship of the property of "lunatics" and "idiots." In the case of the "lunatic," or mentally ill, the property was taken over and administered by the guardian until such time as the person recovered. In the case of the "idiot," or mentally retarded, the lands were seized by the guardian and used by him to support the ward until his death, at which time the guardian took personal possession of the estate (Allen, 1968, pp. 2-3).

Down through the years the primary concern of guardianship provisions has been that of the protection of property. In the past, it was assumed that the guardian would look after the well-being of the ward's person and would have the ward's best interests at heart. It is only recently that the concept of guardianship of the person has been differentiated from that of guardianship of the property (Boggs, 1970b, p. 2; Hormuth, 1963, p. 29). Even now the main focus of guardianship seems to be on the property rather than on the person (Allen, 1968a, p. 3; Allen, 1969, p. 2; Boggs, 1966, pp. 418, 421; Davidson, 1965, pp. 250-253).

In the United States, the first provisions for guardianship were initiated during the Colonial period. In 1650, Maryland passed a law authorizing the appointment of guardians for feeble-minded children. By the time of the Revolution, some of the colonies had allocated funds for certain individuals to care for the feeble-minded children of the towns. In other cases, these children were auctioned to the highest bidder who used them for manual labor in exchange for their care (Baumeister, 1970, p. 4). Today the question of guardianship is left up to each separate state.

#### The Meaning of Guardianship

*Guardianship refers to a legally recognized relationship between a specified, competent adult and another specified person, called a ward, who because of his tender age or some significant degree of mental disability, which is judicially verified, is considered to lack the capacity to exercise fully some or all of the rights pertaining to adults generally... (Boggs, 1970b, p. 2).*

The guardian has legal authority over his ward and has the right to make decisions for him. In the case of the child, the parents hold the authority for natural guardianship. In the case of the incom-

petent adult, the guardian is appointed by the court as an agent of that court.

*In many respects, guardianship and parenthood carry similar responsibilities. Like the parent, the guardian becomes responsible for the care, custody, and control of the child. He is entrusted with authority to make important decisions regarding the well-being of his ward that may affect the individual's whole life. These decisions may involve medical care, employment, consent to marriage, and entry into the armed forces—all of which may be considerations for many of the retarded and problems about which they cannot be expected to exercise sound judgment.*

*Judicially appointed guardians, on the other hand, are subject to certain limitations to which parents are not subject. These stem from various legal aspects of guardianship. Guardianship—where minority is the basis for appointment—automatically terminates when the child attains his majority. This does not apply in cases based upon mental incompetency. In any case, while the guardianship is in force, the relationship is subject to continuing supervision and review by the court (Begab, 1970, p. 589).*

In the past, guardianship served to protect society from the mentally retarded person rather than serving the retardate. The major emphasis was on keeping the incompetent person from making decisions that would be harmful to others. He was kept from making contracts, holding property and receiving large sums of money. He was also kept

away from other people as much as possible and definitely not allowed to marry or raise a family. From these conditions has arisen a stigma for the word "guardian." It has become associated with incompetency and financial mismanagement (Allen, 1968a, p. 37; Allen, 1968b, p. 637). Because of this stigma, the parents of many retarded persons have neglected to plan for guardianship. The main course to take has been to institutionalize the retardate (Begab, 1970, p. 587). Another popular alternative is to keep the retardate at home and treat him as an eternal child. Neither of these options allows the mentally retarded the chance to protect his own future. According to Begab (1966, p. 82)

*Guardianship is one of the least often employed, yet perhaps most effective protection of the retarded person's future.*

The issue of guardianship is presently a growing concern. There are two reasons for this according to Boggs (1966, pp. 423-424). The first reason is that in the past the institution has played the "quasi-guardianship" role. With the advent of modern medicine, more retarded persons

are living past infancy than in previous years. These larger numbers will not all be able to be institutionalized. The second reason for the growing interest is that more opportunities, with their inherent decisions to be made, are being presented to the retarded. The need for a "legal personality" with the authority to help make these decisions in the best interest of the person is evident.

#### Functions of Guardianship

Traditionally, the functions of a guardian have been defined under one of three areas: guardianship of property, guardianship of person, and general guardianship (Begab, 1970, p. 587). More recently in proposals made by the National Association for Retarded Children, NARC, (and in provisions of the Louisiana and, recently, the New York state laws) guardianship has further been defined under categories of life time guardianship, standby guardianship and limited guardianship (National Association for Retarded Children, 1970, henceforth cited as NARC). Following is a discussion of each of these categories:

### Guardianship of Property:

In some states called a conservator, the guardian of the property or estate is responsible for the management of the property and the financial and business affairs of the incompetent (Allen, 1968; Davidson, 1965, p. 253). This has been the most universally recognized concept of what guardians do. And, since most mentally retarded persons seldom have many possessions, their parents usually do not plan for the appointment of a guardian (Boggs, 1966, pp. 418-420).

### Guardianship of Person:

The guardian of the person is responsible for providing necessary care, food, shelter, clothing, medical attention, and even diversion (Allen, 1968). He also has the power to request for his ward, commitment to or release from a hospital (Davidson, 1965, p. 253). The President's Panel on Mental Retardation 1963 recommended that guardianship of the person be differentiated from that of guardianship of property (Hormuth, 1963, p. 29). This would help bring it back

into the realm of a service that would allow the retardate at least a "*substitute means of personal expression*" (Boggs, 1966, pp. 419-420).

#### General Guardianship:

One who performs the functions of both the guardian of the person and guardian of the property is called a general guardian. Begab (1970) suggests that since the mentally retarded do not usually have much property and since they need close personal attention, a general guardian best suits their situation.

#### Lifetime Guardianship:

In most states guardianship terminates upon the majority of the ward. A separate court procedure to declare incompetency is usually necessary to reinstate the guardian or keep his guardianship in force. A proposal for lifetime guardianship would give statutory authority to keep the guardianship in force after the ward achieves his majority. This would alleviate the additional expense and embarrassment to the ward of having to hold a court hearing to declare him incompetent

as an adult. A periodic court review would insure that the need for the guardian continued to exist (NARC, 1970).

Standby Guardianship:

In many cases upon the death of the parents or guardian there is a long delay before another guardian is appointed. In some cases, one is never appointed (Boggs, 1966, p. 420). Standby guardianship would allow for an alternate guardian (or guardians) to be appointed without his having to post a bond until it became necessary, through the death or incapacitation of the parents or existing guardian, for him to perform his functions as guardian. This would guarantee continuity in care for the ward. It would also allow parents the opportunity to appoint a guardian (and successor guardian if they wished) during their lifetime (NARC, 1970).

Limited Guardianship:

Many retarded persons are able to live in the community, earn a living, and manage their affairs with a minimum of external controls. Present laws provide the only

alternative to complete self-reliance as that of guardianship with full control of the retardate's estate and/or his person. Limited guardianship would set a situation where the retarded person would manage his own affairs and be able to contract himself for up to a certain dollar amount (one year's wages in Louisiana, \$300 or one month's wages, whichever is greater, in New York). The guardian would have to sign any contracts larger than this. Also, he would manage any funds over and above the normal wages and earnings of his ward (NARC, 1970).

The President's Panel on Mental Retardation recommended that limited guardianship be incorporated into the "*legal spectrum*" (Boggs, 1966, p. 413; Hormuth, 1963, p. 29). The Utah State Department of Health Advisory Committee on Mental Retardation (1965, p. 74) recommended that Utah adopt this proposal.

Guardian ad litem:

This is a term sometimes confused with those discussed above. It means a guardian appointed by the court to represent a minor

or an incompetent person during judicial proceedings (Begab, 1970, p. 587). In Utah a guardian ad litem may be appointed even though the ward is under the jurisdiction of another guardian (UTCA, 1953, 75-13-8). The guardian ad litem is dismissed upon the termination of the court proceedings.

Natural Guardianship:

This refers to the authority held by parents as guardians of their children (NARC, 1968, p. 7).

Types of Guardianship

There are two general types of guardianship: private guardianship and public or collective guardianship.

Private Guardianship:

Under private guardianship, the function of guardian is carried out by an individual such as a friend or relative and in certain instances by the trust officer of a bank. Friends and relatives are usually appointed as guardians when the family estate is small or when the emphasis is desired on

guardianship of the person (Davidson, 1965, p. 252). In instances where there are large estates or when actions taken need to be on rational grounds without sentimental factors entering in, a bank trust officer is often appointed (Davidson, 1965, p. 252).

#### Public or Collective Guardianship:

*As has been seen, private guardianship does not always meet the needs of the mentally impaired and their families, and a number of devices—of greater or lesser efficacy—are employed to fill the gap (Allen, 1968a, p. 99).*

Because of some of the problems inherent in private guardianship (i.e. the expense of paying the guardian and the emphasis on property) and because of the increasing alternatives in the community to institutionalization (i.e. vocational rehabilitation, sheltered workshops, day care centers) the various forms of public guardianship are being "actively explored" (Katz, 1968, p. 201). Some of the forms that public guardianship and collective guardianship have taken are:

- 1-Public agency directors as guardians  
Both Minnesota and California

have plans where the director of one or more state agencies may be empowered to be a guardian in certain cases (for a further discussion, see the section entitled "*States' Provisions for Guardianship*").

2-The director of institutions that care for the mentally retarded

In some states the director of an institution becomes the guardian of those committed to that institution (Begab, 1970, p. 587). In other cases the director plays the role of "*de facto*" guardian (Boggs, 1970a, pp. 596-597).

3-Private, non-profit organizations as guardians

In some states organizations (such as the Massachusetts Association for Retarded Children, MARC) have set up trust funds and guardianship plans that help provide "*a continuing personal interest in the child.*" They are usually set up with a board of

trustees who make disbursements from a general fund made up from membership dues, gifts, and bequests. In some cases the board will administer an individual fund for a designated person (NARC, 1970, p. 8).

Boggs (1966, p. 426) warns that in the public and collective agencies that the "*service of guardianship*" may easily be over-looked.

#### States' Provision for Guardianship

Numerous states now have guardianship laws that deal specifically with the mentally retarded. In this section, some of the provisions in the California, Louisiana, Minnesota, and New York state laws will be discussed. The guardianship provisions in the Utah law will also be reviewed briefly.

#### California and Minnesota

California and Minnesota are two states that provide for public guardianship of the mentally retarded. Minnesota became the first state to provide this type of program when it enacted a guardianship law in 1917. The law makes the provision that the Commissioner of Public Welfare is

to be named as guardian of the person of all individuals found to be "mentally deficient" through a hearing in the probate court (Allen, 1968a, pp. 101-102).

Allen explains the authority of the Commissioner is

*equal to that traditionally given to private guardians of the person: he must consent to the ward's adoption; he may hold limited sums of the ward's benefit; under some conditions the commissioner may be able to arrange a 'mentally deficient' ward's sterilization; and a ward cannot marry without the commissioner's permission. He is also permitted to control his ward's environment. The protective functions of the commissioner are those usually associated with the role of a personal guardian (Allen, 1968a, pp. 102-103).*

These functions are carried out by social caseworkers employed by the county welfare boards.

The Minnesota plan is presently being reviewed and changes are being recommended. Boggs (1966) explains that the recommendations are that more recognition be given to parental guardianship and less emphasis be put on early commitment to state guardianship.

In California the Director of Public Health may be named as:

*Either the guardian or conservator of the*

*person and estate or person or estate of any mentally retarded person who is eligible for the service. To qualify the retarded person must either first be (1) eligible for the services of a regional center, or (2) a patient in any state hospital, and who is admitted to such hospital from a county served by a Regional Center (Dinkelspiel, 1969, p. 222).*

The Director performs his functions as guardian through the regional centers. The type of services provided by the centers include:

(1) diagnosis, (2) counseling on a continuing basis, (3) provide state funds to "vendors of service" to the mentally retarded, (4) maintain a registry and case records, (5) follow-up, (6) assist in state hospital placement, (7) call the public attention to unmet needs, (8) maintain an adequate staff (Dinkelspiel, 1969).

The Director of Public Health may be appointed guardian through a court hearing or by a will. He may also be nominated by the parents before their death. When this happens, he will either accept or reject this nomination in writing. His acceptance becomes binding on him and his successors (Dinkelspiel, 1969). This last provision sets up a de facto arrangement for standby guardianship.

More recently provisions have been made where the Director of the Department of Mental Hygiene can be appointed as "guardian of the estate of a mental patient where there is no other guardian" (Boggs, 1966, p. 414).

#### Louisiana and New York

Louisiana has in its guardianship laws provided for lifetime guardianship, standby guardianship and limited guardianship (see previous section for explanation). These provisions were accepted by the National Association for Retarded Children and sent out in 1970 to all the states's Associations for Retarded Children under the title of NARC Guardianship Recommendations. At that time, New York was in the process of passing these proposals into law. It was said of the proposals,

*The Committee feels that by recognizing the unique status of retarded individuals, these proposals will enable parents to better protect the future of their children at a saving in legal proceedings and expenses and will allow the retarded in the community the flexibility to manage their own earnings and purchases with necessary limitation and safeguards (NARC, 1970).*

New York also passed a law that would allow a non-profit organization such as the state Associa-

tion for Retarded Children to act as the guardian of the person only of a retarded individual (NARC, 1970).

#### Utah Guardianship Law

The Utah Guardianship law is found in Chapter 13, Section 75 of the Utah Code. This law provides for general guardians (UTCA, 1953, 75-13-29), guardians of property (UTCA, 1953, 75-13-32), and guardians of person (UTCA, 1953, 75-13-31). One of these guardians may be appointed either by parental desires through a will or by the court when there is no will. There are no provisions for limited guardianship or standby guardianship (except in the special case where the court may appoint joint guardians for a person already needing a guardian).

Also lacking is any provision to establish a system of public guardianship. In a report by the Department of Health Advisory Committee on Mental Retardation (1965, p. 74) recommendation #60 states,

*The state should establish a system of public guardianship where an agency could act as guardian or joint guardian of mentally retarded persons.*

In explaining this recommendation, the committee goes on to say,

*This recommendation would need legislative authority. The whole problem of guardianship should be reviewed and a system established to protect the retarded in their activities in the community, as well as in institutions. With the development of full community programs, this becomes very important. Such things as limited guardianship, guardianship of property as differentiated from the person, and periodic reviews of all guardianship matters will be necessary to the proper operation of such a system (Utah State Department of Health Advisory Committee on Mental Retardation, 1965, p. 74).*

#### Looking Ahead

Two broad factors are influencing the need for more guardianship protections for the mentally retarded. (1) The modern antibiotics are helping many of the retarded children, who previously would have succumbed to fatal illnesses, to live healthy lives (Boggs, 1966, p. 423). This is going to put a bigger demand on the already overcrowded institutions with the results being that the more severely retarded will be institutionalized and the less severely retarded will have to find alternatives <sup>to</sup> institutionalization (Baumeister, 1970). (2) With the recent upsurge of egalitarianism the mentally retarded have received new opportunities in the

communities (Begab, 1970, p. 587; Katz, 1968, p. 201; Weihofen, 1965). Guardianship is seen as a means to enable the retarded to enjoy the rights and freedoms to which they have always been entitled (Allen, 1969, pp. 2-5; Begab, 1970, p. 589; Boggs, 1966, pp. 407-420; Boggs, 1970b, p. 2; Katz, 1968, p. 200). Following are some of the proposals that have been made to meet these needs.

In 1963, the President's Panel on Mental Retardation called for

*a differentiation between guardianship of the property of a retarded person and guardianship of the person. The development of a limited guardianship of the person is called for together with periodic review by the courts of the need of continuation of any form of guardianship. Judicial review every two years, of the need for continued institutional care for all retarded adults is recommended (Hormuth, 1963, p. 29).*

These proposals have been acted on by various states, some of which were mentioned in this study. Other states are presently considering these recommendations.

Other suggestions have been made by some of the authors concerned with guardianship. Boggs, (1970b, pp. 597-598) suggests that the process for

appointing a guardian be made easier. She explains that many of the parents of mentally retarded children are confused by the procedures that are currently necessary. Boggs (1970a, p. 5) also suggests that in the area of public and collective guardianship, voluntary bodies be coupled with the public agencies set up to perform the guardianship role. Begab (1970, p. 591) explains about the different groups that can be called on to perform volunteer duties. He suggests as possibilities: parents who have had retarded children, professionals who have been concerned with the retarded and members of the local bar associations. Boggs (1970a, p. 5) suggests that future guardianship provisions be made flexible so that they can change to leave more options open to the retardate.

The major area of concern seems to be that guardianship come to serve the needs of the ward more adequately. Boggs (1966) suggests certain means, such as more consultation and supervision for the guardians to ensure "*more enlightened guardians.*" She also suggests that more emphasis be placed on the "*service of guardianship.*" This is especially necessary in guardianship of the person.

### Sterilization

Most of the material in regard to sexual sterilization was written in the 1920's and 1930's, as a culmination of the eugenics movement. Most of this literature reflects a theme of "*sterilization for human betterment*" (Laughlin, 1922). As an example, the frontispiece of a book by Laughlin (1922) called, Eugenical Sterilization in the United States, depicts a family consisting of a father, mother, and three children. The caption beneath the picture is, "*Keep the life stream pure.*" It is obvious that eugenics was a main consideration in the adoption of sterilization practices of that time (practices still reflected in present laws). For instance, in the introduction to Laughlin's book Eugenics, Harry Olson, a well-known Supreme Court Justice in Illinois at that time, states,

*Professor Irving Fisher (another noted authority of the time) stands against the forces which work for racial deterioration, and for improvement and vigor, intelligence and moral fiber of the human race. It represents the highest form of patriotism and humanitarianism... By Eugenic measure, for instance, our burden of taxes can be reduced by decreasing the number of degenerates, delinquents, and defectives supported in public institutions (Laughlin, 1922, p. v).*

Similarly, Landman writes,

*Society has brought to a greater realization than ever of the evils that attend the presence of the growing number of one socially undesirable people in our population. The mentally diseased, the feeble-minded, the idiots, the morons, and the criminals are regarded as the Nemeses of our civilization and the prohibition of their propagation is considered the salvation of society and the race. On the other hand, the encouragement of the fecundity of the superior stocks of our population is envisaged as one of the panaceas for our social ailments (Landman, 1932, p. vii).*

Landman (1932) goes on to explain that his book deals with "the process of human sterilization as a means of restricting the multiplication of our socially inadequate people in society." The mentally retarded, presumably, were included in the category of "socially inadequate people," although the term "mentally retarded" was not used in those days. "Mental deficiency" or "mental defective" were terms more often used. In the biggest share of the early literature three main reasons are outlined as justification for the sterilization of "mental defectives":

- 1-Protection of society from these individuals
- 2-Protection of the individuals themselves
- 3-Restriction of propagation of the defective type

Court cases of this period reflected similar attitudes. The prevalent feeling was perhaps best summed up by Chief Justice of the United States Supreme Court, Oliver Wendell Holmes in his opinion in the landmark Buck vs. Bell case (47 Supreme Court Rep. 584, 274 U.S. 200). He ended his brief opinion in favor of sterilization practices with, "*Three generations of imbeciles are enough.*"

Writers such as Gosney and Popenoe (1931, p. ix), although favoring sterilization for the mentally defective, moderated their statements somewhat by writing such things as "*Eugenic sterilization of the hereditary defective is a protection, not a penalty, and should never be made a part of any penal statute.*" The authors were reporting on the results of 6,000 sterilization operations which were performed in California during the 20-year period from 1909 to 1929. The ideas of these men are more or less where we stand today with regards to sexual sterilization.

Some of the more contemporary literature, though, questions and in some cases directly attacks the principle of involuntary sterilization. Allen (1968b, p. 638) explains, "*The first general*

principle declared by the Task Force on Law (President's panel on Mental Retardation) is to minimize intervention by the law insofar as possible." He goes on to say that eugenic sterilization is an example of the law in a coercive role. He cites the fact that there are 26 states in which eugenic sterilization may be performed—in 23 of these it is involuntary. Allen sums up his argument by saying,

*We have been unable to find persuasive scientific proof either of the inheritability of the defects for which sterilization is now being imposed or of the fact that a child—even of normal intelligence—will be seriously handicapped by the fact of being reared by a retarded parent. With the increasing availability of improved supervision and protective services and of birth control devices far less drastic and irrevocable than surgical procedures, it is our finding that there is no sound basis for sanctioning the continuance of involuntary sterilization—under whatever euphemism it may be applied (Allen, 1968b, p. 642).*

In his book, Bernstein also talks out against eugenic sterilization,

*Forced birth control and eugenic sterilization are nothing more than selective breeding based on a universal value: Some individuals are worth more to society than others. A value judgment of this nature may be questioned and is a dangerous precedent.*

*Scientific knowledge has put the heredity factor of retardation in perspective. If the problem of retardation is to be diminished, genetic problems will need continuing attention, but a major first step should be to eliminate poverty, not just to limit offspring. In the ghettos chronic illness exists, obstetrical and prenatal care is abysmal, families are disorganized, education is meager and poverty rampant. These factors are the greatest causes of retardation (Bernstein, 1970, p. 111).*

Marriage of the mentally retarded is another subject being looked at by contemporary authors. Presently these marriages are prohibited in most American jurisdictions. Utah, Nebraska, and North Carolina make an exception to this prohibition if the person is sterilized (Allen, 1968a, p. 299-302).

Katz (1968, p. 15) points out studies by Jastak that show that the frequency of separation and divorce of the mentally retarded in Delaware was not significantly different from the non-retarded. He goes on to say that *"there is ample evidence from studies that there are many mentally retarded adults who do marry and make a good adjustment."*

### Summary

Guardianship, sexual sterilization, and marriage of the mentally retarded are being looked at with more interest in view of some of the present trends. With more mentally retarded persons surviving birth, alternatives other than institutionalization are being planned. With more of these persons out on their own, the necessity for guardianship provisions for them will have to be explored. The President's Panel on Mental Retardation recommended that changes be made in the guardianship laws as they existed. Lifetime guardianship, stand-by guardianship, limited guardianship, and differentiation of guardianship of the person from that of guardianship of the property are some of the answers to these recommendations. Also a movement to set up public and collective guardianship services has been an out-growth of these recommendations.

Sexual sterilization for the mentally retarded is being questioned on the grounds of whether it really is accomplishing what it was supposed to do—help stop the multiplication of "mental defectives." The question is being asked if the legal authorities

have the moral right to deprive anyone of the right to bear children. These and other questions regarding eugenic sterilization and marriage of the mentally retarded will no doubtedly be asked more frequently from now on.

## CHAPTER III

### METHODOLOGY

#### Introduction

This study was planned with the aid and cooperation of the Utah State Training School at American Fork. A home interview schedule was designed to gain information concerning the attitude and present knowledge of the parents of mentally retarded children in regard to guardianship. Other areas were also included such as: sterilization, marriage, and general questions to give characteristics of the sample.

#### Authorization

Authorization for the study was obtained from Mr. Paul Sagers, Superintendent of the Utah State Training School, Mr. William H. Long, Utah State Training School, Social Services Director, and the Graduate School of Social Work, University of Utah represented by Mr. H. Donald Selin. The Superintendent, writers, and others working with the mentally retarded in Utah saw a need for the study to determine what the parents see as their

needs in dealing with present and future guardianship laws in this state.

#### Selection of Sample

The sample was selected from the two main files at the Utah State Training School. One file consists of all resident cases. The second file contains pre-admission cases. These two files include all persons referred to or residing at the Training School.

The resident file is in order of date of admission. The pre-admission file is alphabetically listed. To draw a sample of persons who were most likely to have either one or both parents living, no active cases were drawn with admission dates before 1950. Pre-admission files are kept current.

A systematic sampling method was used in the actual drawing of the sample. In the resident case file, every 30th file was drawn. In the pre-admission file, it being smaller in number, every 5th case was drawn.

The sample drawn consisted of 30 resident cases and 30 pre-admission cases. No attempt was made to limit the sample to a specific area in the state of Utah.

### Technique for Collection of Data

A home interview schedule was developed which would answer the questions dealt with in this study. (See appendix 1). A letter explaining the study was sent to the family. (See appendix 2). Each of the researchers involved in the study then made a telephone call to set up an appointment to visit the parents. The researcher then visited the home in a structured interview setting. Responses were recorded on the interview schedule.

The interview schedule had two parts. The first part contained sample characteristics and the other consisted of questions regarding guardianship, marriage, sterilization, and care. The same interview schedule was used for the pre-admission group and resident group. This was done to measure the difference in attitudes and opinions in the question part of the schedule.

### Tabulation and Analysis of Data

The data concerning both groups was transferred from the interview schedule to tally sheets. From the tally sheets, percentage figures were constructed to show specific information in the two

sections. Comparisons were made in both the characteristic and question sections to show possible dichotomies. Results were analyzed as to their similarities and differences between the pre-admission parents and the parents of residents now at the Training School. A breakdown between the two groups was done in the sample characteristic section. Results are shown in Chapter IV. Both groups were then combined in the presentation of that data.

CHAPTER IV  
PRESENTATION AND INTERPRETATION OF DATA

Introduction

Chapter IV consists of two parts. The first part contains characteristic information about the retarded person and his family. The results are seen in Figures 1-10. The second part of this chapter contains questions related to four general areas of concern in regard to the mentally retarded. They are:

1. Guardianship - Questions 1-5
2. Marriage - Question 6
3. Sterilization - Question 7
4. Services Provided by School - Question 8

After each section that is outlined above there appears a hypothesis in regard to expected findings in each area.

The last section of the questionnaire provides for an evaluation of the interview by both respondent and interviewer. However, the results were not tabulated, since both reflected bias and did not appear to be relevant to the study. Thus

this part of the questionnaire is not covered in the figures.

Although questions 9 and 10 asked for a declarative response from the interviewee, it was found that in many cases this type of response was not elicited. Instead many responses were in fact questions on the part of the parent or parents being interviewed. This is shown in Figures 19 and 20 and is elaborated on in the analysis which follows these figures.

#### Characteristics of the Sample

In this part of the study a breakdown between the resident parents and the pre-admission parents was completed. In that breakdown of the two sample groups, there appeared to be no areas where the two groups differed. Therefore, the percentage shown in the figures is presented as both groups together.

#### INFORMANT

The informant, or the individual who responded most often to the interview schedule, was the mother. Of the 42 completed interviews, the mother alone was the informant of 66.66% of them, while the father alone was the informant of 16.66%. The two

parents together responded to 14.28% of the interview schedules, and those other than parents (relatives and friends) were informants of 2.38% of the schedules. Figure 1 shows this information.

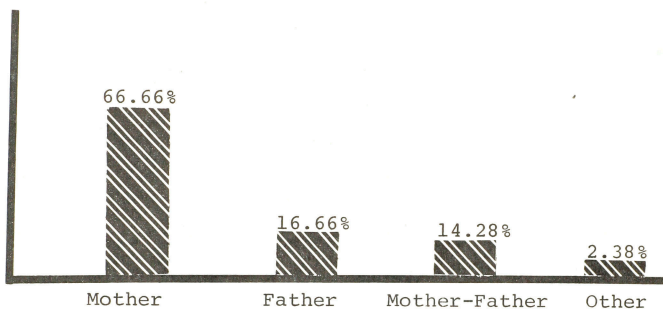


Fig. 1 - *Informants giving information for the 42 families interviewed in this study.*

It is very possible that the major reason for the mothers informing the most often was because many interviews occurred during the daytime hours when the fathers were away from the home. There is a slight indication that a small number of the fathers chose not to participate in the interview, since a few were in the home during the interview, but did not appear for the communicative interchange regarding the study.

#### AREA IN WHICH PARENTS OF THE RETARDED PERSON RESIDE

Figure 2 shows that 57.14% of the parents live in suburban places. There are 23.80% who live in urban areas, and only 19.04% who live in rural communities.

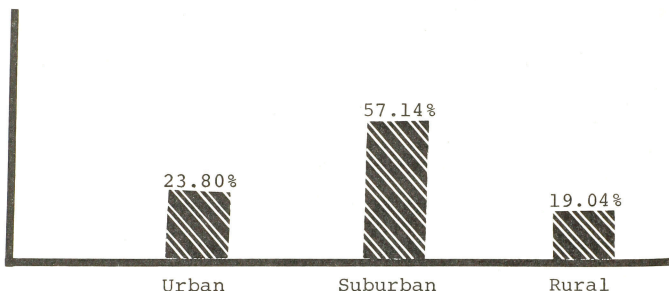


Fig. 2 - Area in which the parents of the 42 mentally retarded persons reside.

#### AGE AND NUMBER OF MOTHERS AND FATHERS INVOLVED IN THIS STUDY

The average age of the mothers in the study was 44.46 years. The youngest was 27 years old and the oldest was 67 years old. There were 41 living mothers and one deceased mother.

The average age of the fathers in the study was 45.45 years. The youngest was 28 years old, and the oldest was 77 years old. There were 33 living fathers and nine deceased fathers.

#### NUMBER AND AGE OF SIBLINGS IN THIS STUDY

There was a total of 196 siblings in the 42 families. There is an average of 4.67 of them per family. The average age of all siblings was 17.72 years. The oldest sibling was 40 years old. The youngest was one year old.

#### MARITAL STATUS OF PARENTS

The largest number of parents involved in this study were married. Figure 3 shows 61.90% of them to be thus, while only 14.28% were divorced. This could indicate that the suspicion that mentally retarded children are chief contributing factors in marital dissolution is highly questionable. That which suggests the opposite, or that mentally retarded children may help maintain marital bonds, is favored, according to the study. There were 21.42% of the parents who were widowed and 2.38% who were separated.

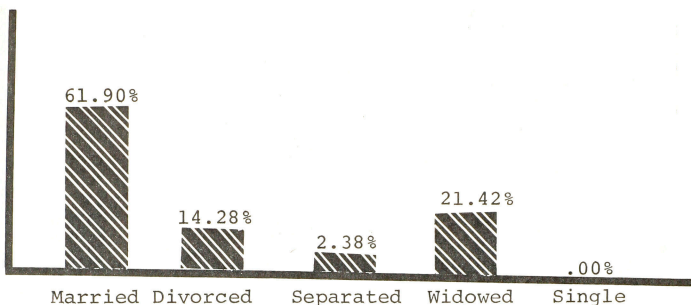


Fig. 3 - *Marital status of the parents of the 42 mentally retarded in this study.*

#### SOURCE OF FINANCIAL INCOME OF THE FAMILY UNIT

The major source of income for the families in the study was employment. This source was 66.66% of all possible sources listed in the interview schedule. Social Security was next, accounting for 16.66%. In comparison to employment (66.66%), welfare, which was 7.14%, represented a small percentage, ranking third. Fourth was pension which was 4.76%. Savings and unemployment were the same; each being 2.38% of the total possible income sources listed. Figure 4 shows this information.

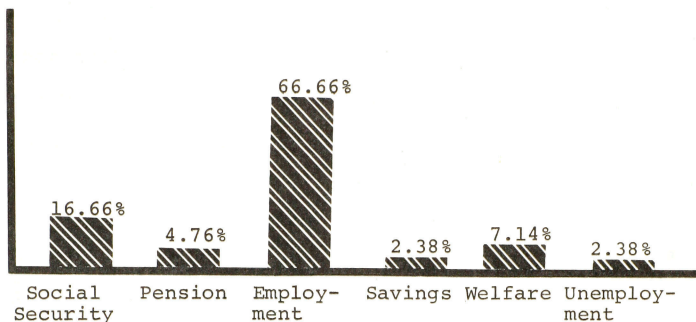


Fig. 4 - Source of financial income of the 42 family units in this study.

#### MONTHLY INCOME OF FAMILY UNIT

Figure 5 shows the monthly income of the family unit in this study. There were families in all categories. One family was using savings for family existence.

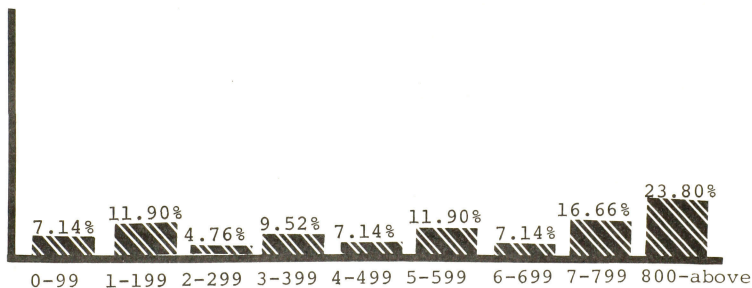


Fig. 5 - Monthly income in dollars of the 42 family units in this study.

Of the total, 61.90% of the informants said that their income met the needs of the family unit. The percentage of those who felt it did not meet their needs was 38.09%. Figure 6 indicates this information.

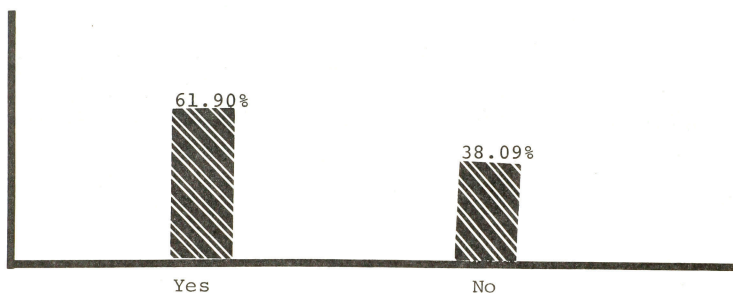


Fig. 6 - Responses of the 42 family units as to adequacy of income.

#### FORMAL EDUCATION OF FATHERS

More than 1/3 of the fathers in the study completed formal education through grades 10-12 (35.71%). The percentage of those who had some college was 23.80%. College graduates amounted to 7.14%, while postgraduates came to 9.52%. Figure 7 shows this information. The percentage of those fathers with education ranging from Kindergarten through the sixth grade was 7.14%, and of those who

had completed education from grades seven through nine was 16.66%.

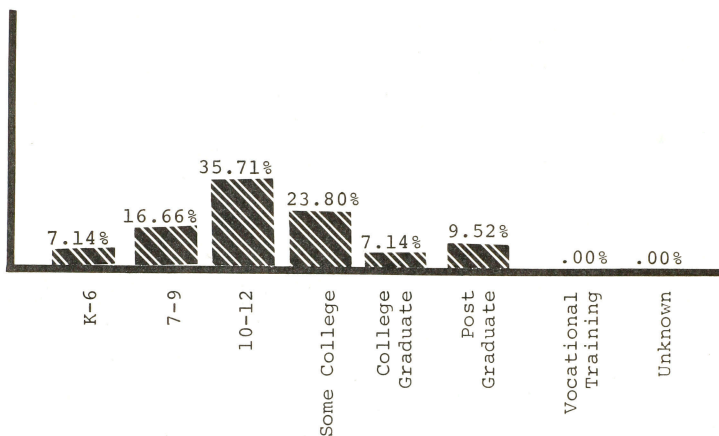


Fig. 7 - *Formal education of the fathers of the 42 mentally retarded persons in this study.*

#### FORMAL EDUCATION OF MOTHERS

Most of the mothers in the study (61.90%) obtained formal education to grades 10-12. The percentage of those who completed education from Kindergarten through grade six was 9.52%, and for those achieved from grades seven through nine, it was 16.66%. 9.52% of the mothers had some college, 4.76% were college graduates, and 2.38% were post-graduates. The percent of mothers whose formal

education was unknown was 2.38%. None of the mothers in the study had Vocational Training. Figure 8 shows this information.

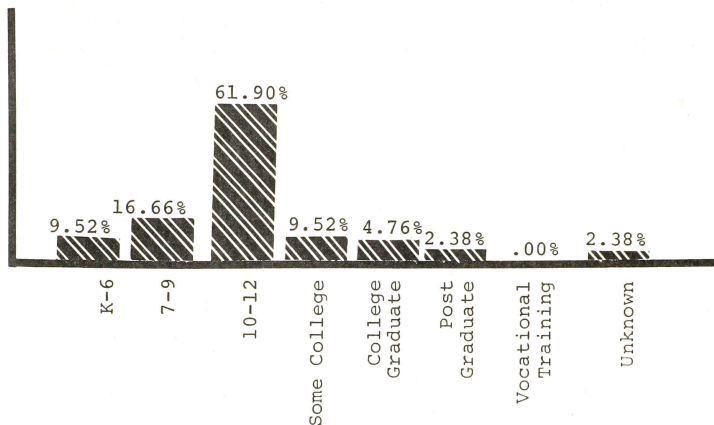


Fig. 8 - Formal education of the mothers of the 42 mentally retarded persons in this study.

#### WHERE RETARDED PERSON RESIDES

One half of the retarded people involved in the study reside at the State Training School. The next largest number live with their natural parents. These amount to 35.71%. Only 4.76% live with the natural mother alone, and 2.38% live in foster homes. The percentage who live in nursing homes amounts to 11.90%. Figure 9 gives these percentages.

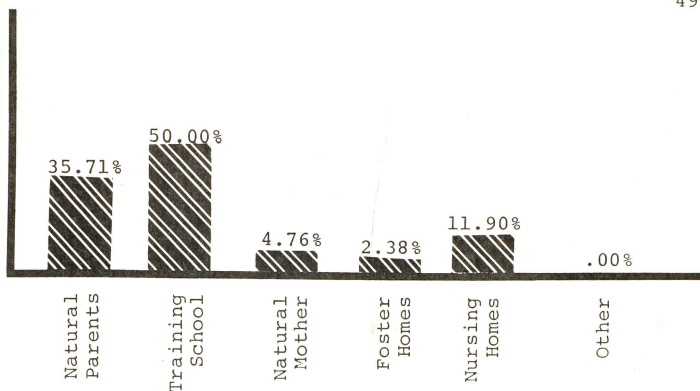


Fig. 9 - *Place of residence of the 42 mentally retarded persons in this study.*

#### PARENTAL VISITS

The largest percentage of parents who do not have the retarded child at home, visit him once a month. This is 23.80%. 38.09% of the parents have their children living with them at home. The percentage of those who visit the child biweekly and those who visit yearly is the same. It is 11.90% for both. 14.28% visit weekly. None of the parents in the study answered, "*We never visit our child.*" Figure 10 shows this information.

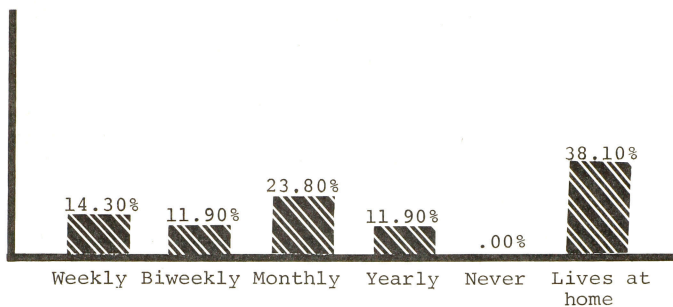


Fig. 10 - Parental visits with the 42 mentally retarded persons in this study.

Evaluation of Data

Guardianship

QUESTION #1

*During the past year, how many hours have you spent thinking about what would happen to your mentally retarded child if you and your spouse should die?*

Of the total sample, 42 responses were obtained; Figure 11 shows the results.

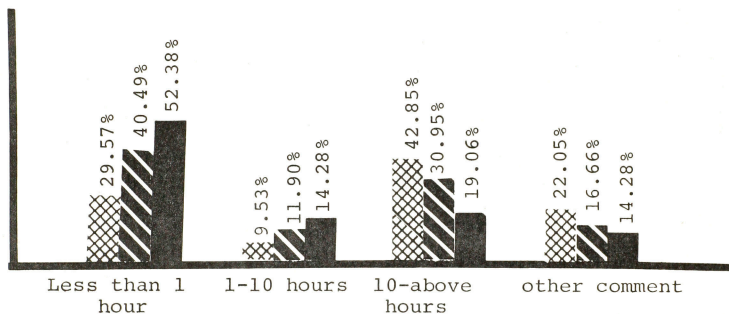


Fig. 11 - Hours spent thinking of what would happen to the mentally retarded person should the parents die. Pre-admission Parents Average Resident Parents

Comments where no response was given mainly consisted of such statements as "It is difficult to estimate exactly how much time you spend thinking about this," or "It's in the back of your mind all the time," etc.

A plurality (40.47%) of the people interviewed said that they had thought about it less than one (1) hour during the past year. However, the majority (59.52%) said they had thought about it either between one and ten hours, or over ten hours, or had thought about it constantly.

In the breakdown between pre-admission and residents, the two groups of parents interviewed showed a considerable difference in the amount of time that they said they had thought about what would happen to their child in the event of their deaths. For example, while 9 or 42.85% of the parents who are waiting for their children to be admitted to the Training School stated that they had thought about this more than ten hours during the past year, only four, or 19.04%, of the parents whose children were already in the Training School said they had thought about it over ten hours.

On the other hand, 11, or 52.38%, of parents of residents stated that they had thought about this question less than one hour during the past year. Only six, or 28.56% of parents of pre-admissions stated that they had thought about this less than one hour during the past year.

Of the parents interviewed, this would seem to indicate more conscious thought on the part of the parents of pre-admissions than on the part of those parents who already have placed their children in the Training School.

QUESTION #2

*Would you be interested in appointing someone to be responsible for your mentally retarded child so that if you and your husband died there would be someone to look after him/her?*

Of the total sample, 38 responses were obtained. Four did not respond because they knew of no one whom they could appoint. They are included in the figure making a total of 42 responses. Figure 12 shows these results.

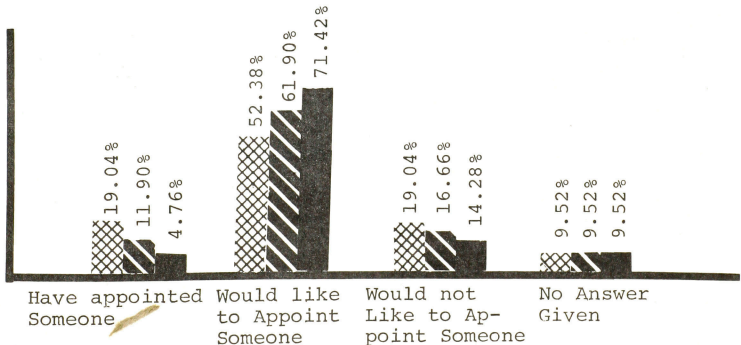





Fig. 12 - Responses of the parents of the 42 mentally retarded persons regarding interest in appointing someone guardian should they die. Pre-admission Parents  Average  Resident Parents 

The majority of both sets of parents would like to appoint someone as a guardian for their child. There were 52.38% of pre-admission parents and 71.42% of resident parents who stated they would like to appoint someone. However, as can be seen, a somewhat higher percentage of parents of children who were already in the Training School indicated that they would be interested in appointing someone to be responsible for their child in the event of their death. This was usually listed as a guardian.

Generally, where someone had already been appointed, it was done through a will.

#### QUESTION #3

*Assume that you and your husband died during the next year, what would happen to your child?*

The responses were broken down into these three general areas:

- a. Family members or other relatives would take care of them.
- b. They would stay at the Training School or the state would provide care.
- c. Other comment.

The responses are shown in Figure 13.

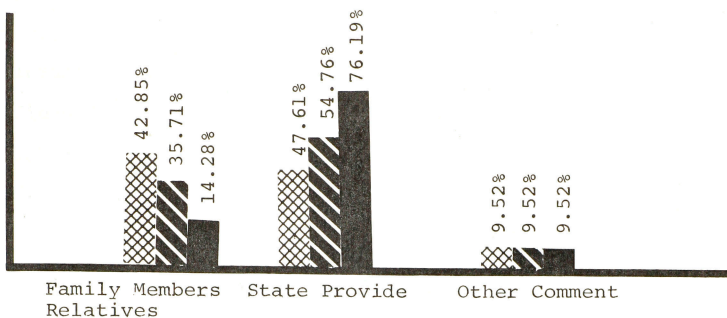





Fig. 13 - Breakdown of what would happen to the 42 mentally retarded persons should both parents die during the next year. Pre-admission Parents  Average  Resident Parents 

Considerably more parents whose children are residents reported that if something happened to them, their children would either (a) stay at the Training School, or (b) the state would provide for them. This probably reflects the fact that they are already being taken care of by the state. Conversely, only 3, or 14.28% of all parents of residents contacted said that family members or other relatives would probably take care of the retarded child. In comparison to this, 9, or 42.85% of the parents of pre-admission children stated that they would expect family members or other relatives to assume the responsibility.

The other category which was selected by two of the parents of residents included (1) a life

insurance program which was set up to provide financially for the child, in one case, and (2) the other family said that their child would stay in the nursing home where the child now resides.

The two families who did not respond had pre-admission children, and said they could not respond because "their child was able to take care of himself."

#### QUESTION #4

*Do you think that the legislature of Utah should pass a law that would make it easier for you to appoint a guardian for your child?*

The responses called for were simply "yes," or "no." These results are shown in Figure 14.

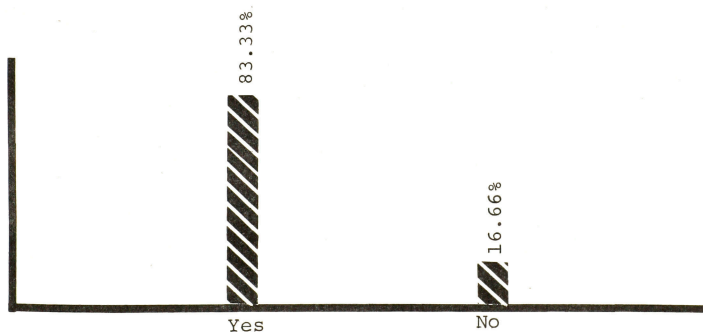


Fig. 14 - Response of the parents of the 42 mentally retarded persons regarding whether or not Utah should pass legislation that would make it easier to appoint a guardian for their child.

Results were similar between the parents of pre-admissions and parents of residents. An overwhelming percentage of both groups answered "yes" to this question, indicating that they favor legislation in Utah which would make it easier for them to appoint a guardian for their mentally retarded child.




The parents who did not favor it, in both groups, usually stated that this should be left up to the family to decide, that it was not the state's business, or comments similar to this. However, it is not known whether they fully understood the meaning of "enabling legislation," which could have influenced their answer.

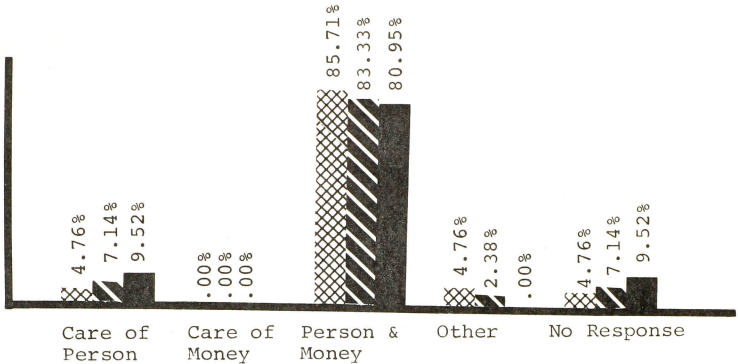
QUESTION #5

*If you favor guardianship, what have you hoped it would provide for your child?*

Results of this question can be found in

Figure 15.

Fig. 15 - Breakdown of what parents of the 42 mentally retarded persons hoped guardianship would provide. Pre-admission Parents  Average   
Residents' Parents 



As can be seen, both groups strongly favored guardianship which would provide for both the person and his/her money or financial matters. All persons interviewed were asked to respond to this question regardless of their response to question #4 (i.e. even if their answer to question #4, "Do you think the Utah legislature should pass a law, etc.?" was "No"). Only a total of seven families in both groups favored something different, which would seem to indicate strong approval for a guardian who would look after both the retarded individual's person and also their money.

Of the four who did not respond to this question by answering either with a, or c, one, who answered d, or "other", commented that their child

was capable of looking after himself, while the three who did not respond at all exhibited a seeming lack of interest in this area of consideration.

Interestingly, no responses were received in category b, which was "care of money" only. This might lead one to conclude that parents feel that if the guardian were not interested in the child's person, that he should not or could not be responsible for the child's money. One person did indicate, however, that he did not feel it should be the same person who would care for both the person and his money. In other words, he felt that an attorney or an executor of an estate might be in a better position to handle the person's financial matters, while a relative or family member could take care of the retardate's other needs.

#### HYPOTHESIS REGARDING GUARDIANSHIP

*Pre-admission parents will be more concerned about advance planning for guardianship than will residents' parents.*

This hypothesis was substantiated by the findings. The most obvious manifestations of greater concern on the part of pre-admission parents were seen in questions 1 and 3. Question 1

asked about time spent during the past year thinking about what would happen to their child if they should die. Among the parents contacted in this study, over twice as many pre-admission parents interviewed stated they had thought about this over 10 hours as did residents' parents. Considerably more residents' parents, on the other hand, responded that they had thought about it less than one hour during the past year. This would seem to bear out the hypothesis that pre-admission parents are more concerned about advance guardianship planning for their children than are resident parents.

Evaluation of Data

Marriage

QUESTION #6

*An area of some concern to many families of mentally retarded persons is marriage and the responsibility of child rearing. Do you feel that mentally retarded persons should be allowed to marry?*

Results of this question can be found in

Figure 16.

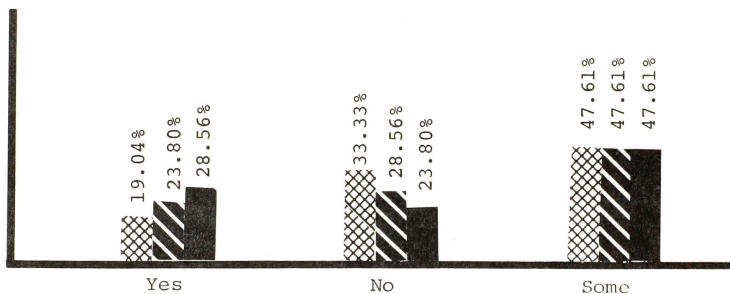




Fig. 16 - *Feeling of the parents of the 42 mentally retarded persons regarding marriage for mentally retarded persons. Pre-admission Parents Average*  *Resident Parents* 

On this question, there was very little difference between the responses given by parents of each group. About half (47.61%) in each case thought that some retarded persons should be allowed to marry.

Although it was not provided for in the questionnaire, there were a number of comments given in regard to this question. Most of them concerned a definition of "some." For example, a number of parents stated that "some should be allowed to marry." Others said that it depends on their capabilities, what and how much they can do for themselves, the degree of their retardation, and whether their condition is such that they can assume the responsibility of marriage and family.

Ten, or about one fourth of the parents interviewed said flatly, "Yes, the person should be allowed to marry with no restrictions placed on him." Twelve responded just as emphatically in the negative, that "No, a retarded person should not be allowed to marry under any circumstances." The exact meaning of the term "retarded person" was left up to the interviewee to decide as to his own definition of the term.

Of the sample, about the same number favored allowing marriage for retarded persons as were against it. About twice as many said that "some" should be allowed to marry, while enumerating the conditions or circumstances under which they would permit it.

HYPOTHESIS REGARDING MARRIAGE

*Pre-admission parents will be more accepting of the possibility of marriage for their mentally retarded children than will be residents' parents.*

This hypothesis was not substantiated by the findings. Both parent groups responded similarly to the question, as was reflected in the earlier discussion of the findings.

Evaluation of DataSterilization

## QUESTION #7

*How do you feel about sexual sterilization of mentally retarded persons?*

Results of this question can be found in Figure 17.

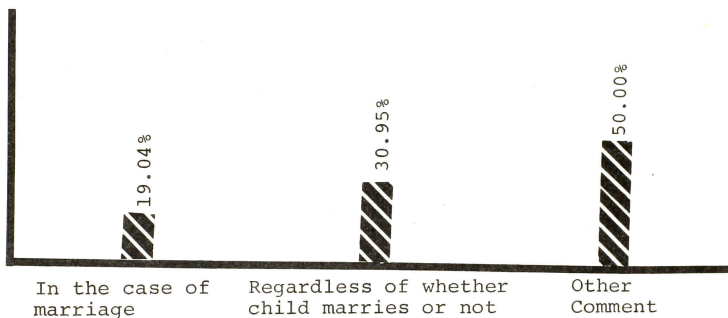


Fig. 17 - *Feelings of the parents of the 42 mentally retarded persons regarding sexual sterilization of the mentally retarded.*

The responses to this question were also fairly consistent between the two groups. About half of each group, and therefore half of the total, could or would not answer the question by using either responses a or b. Most had some comment that they needed to make in order to answer the question.

A number of them had difficulty in relating the question to their particular situation. This was because many of them felt that their child's mental and medical condition precluded the necessity for sterilization. Many stated their children showed no interest in sex (or the opposite sex) and questioned the need for any action at all. Several answered in the hypothetical case, saying that were their child able to marry, they would like or would not like them to be sterilized.

For many this question did not seem to apply directly. It therefore created some confusion for those parents whose children's conditions had some effect on the nature of their answer.

#### *HYPOTHESIS REGARDING STERILIZATION*

*Residents' parents will be more in favor of sexual sterilization for mentally retarded persons than will pre-admission parents.*

This hypothesis was not substantiated by the findings. Responses were very similar among both groups.

Evaluation of Data

Services Provided by School

QUESTION #8

*How do you feel about the service that has been provided for you and your child by the Training School?*

Responses were tabulated on the basis of whether they were generally positive (+), generally negative (-), or contained elements of both (in which case they were tabulated as an "o"). Where no response was given, they were also recorded as (o). This is shown in Figure 18.

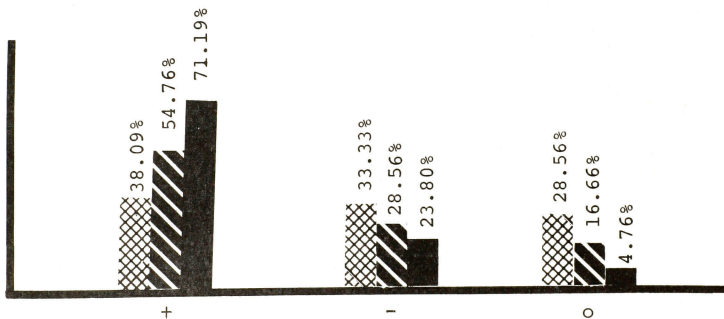


Fig. 18 - Feelings of the parents of the 42 mentally retarded persons regarding service provided by the Utah State Training School.

Whereas all but one, or 20 of the parents of the residents responded to this question, 15 of them

favorably, six of the "pre-admission parents" did not respond at all. This may have indicated some hesitancy on the part of parents of pre-admissions to respond due to concern that if they did respond it might affect the status or possibility of their children being admitted to the Training School. An overwhelming percentage (71.42%) of residents' parents gave positive responses to this question. Only 5, or 23.80% gave a negative response. The negative responses were largely related to "lack of adequate staff at the Training School" as they saw it.

#### *HYPOTHESIS REGARDING SERVICE PROVIDED BY SCHOOL*

*Pre-admission parents will have a more favorable opinion of the service provided by the Training School than will residents' parents.*

This hypothesis was, if anything, contradicted by the findings. Most (71.42%) of the residents' parents gave generally favorable responses, whereas several pre-admission parents did not respond at all. Of those who did, only 38.09% gave generally favorable responses.

Evaluation of Data  
Possible Guardianship

QUESTION #9

*What questions do you have  
about possible guardianship?*

The majority of parents interviewed had no further questions. Whether it had been covered adequately or whether the parents' anxiety level was such that nothing occurred to them, is a question for further study. Figure 19 shows figures for this question.

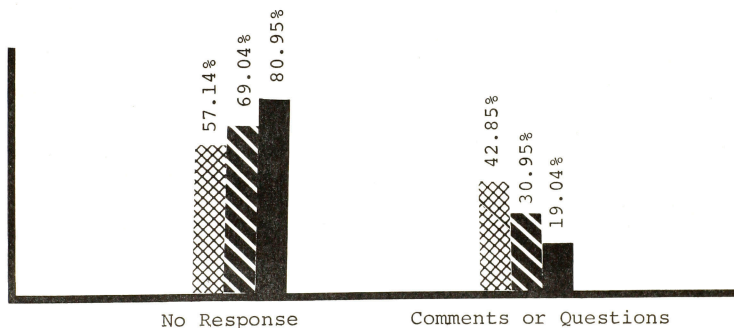


Fig. 19 - Additional responses of the 42 parents of the mentally retarded in this study.

More parents of residents had no comments or questions, as evidenced by the findings in Table 19.

Seventeen out of 21, or 80.95% of the parents of residents studied, indicated they had no further

questions or comments about guardianship. Among the parents of those awaiting admission to the Training School, 12, or 57.14%, similarly had no questions at all. Of those who did, nine, or 42.85% had no questions but did want to make some type of comment. This seems to be related to opinions that were stimulated during earlier parts of the interview but were not expressed until this point. Only four, or 19.04%, of the parents of residents interviewed had any further questions or comments.

The findings would seem to indicate that parents who already have their children placed at the Training School are less concerned about or have had their questions about guardianship for their children answered.

#### QUESTION #10

*Are there some other questions  
you have concerning what we have  
talked about?*

Results were quite similar between the two groups. Fifteen out of 21 of the pre-admissions parents interviewed said they had no further questions, while 17 of the 20 residents' parents said they had nothing further to ask or comment on. This information can be found in Figure 20.

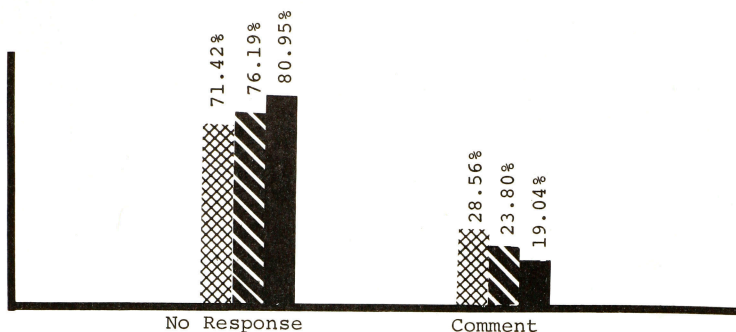





Fig. 20 - Other questions concerning areas of this study as asked by the 42 parents of the mentally retarded persons. Pre-admission Parents  Average  Resident Parents 

As with the previous question, comments were much more prevalent than questions. A total of 10 responses were obtained. Interestingly, the same number in the resident group (4) responded to this question as did in the previous question asking about guardianship, etc.

It appears that by this time, most people interviewed were satisfied that they had been asked sufficient questions to cover the topic of guardianship. Another possible explanation for their general lack of response could be that a level of anxiety was induced which inhibited a further expression of feeling.

## CHAPTER V

### SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

#### Purpose

The purpose of this study was to provide some initial research in four general areas of concern related to the mentally retarded in Utah.

The first and chief area of consideration in the study was *guardianship*. The purpose here was to determine whether the parents of mentally retarded children, who were either residents or who had pre-admission status at the Utah State Training School, were interested in guardianship provisions for their children.

A second area was *sterilization*. The purpose related to this subject was to elicit and analyze attitudes and opinions on the subject by the same above identified parents.

The other two areas which were considered in the study were *marriage of the mentally retarded*, and *the quality of care provided by the State Training School for the mentally retarded*. The purpose for these two was also to obtain opinions and attitudes from the parents.

### Methodology

The data for this study were obtained from 42 interview schedules that were developed by four graduate students. The students administered the schedule to parents of mentally retarded children who were either Utah State Training School residents, or who had pre-admission status at the school. The names of the parents were selected from two files at the State Training School: a pre-admission file, and an active file. The interview schedule, which dealt with questions developed for the study, was given in the home of the retardate's parents in a structured interview setting. The data obtained from both the parents of pre-admission children, and of resident children, were transferred to tally sheets. Percentage figures, comparisons, and analyses were made from the collected data.

### Characteristics of the Sample

Those areas which provide general information about the sample are summarized as follows:

There was 57.14% of the sample who lived in suburban areas. Urban areas included 23.80%, and 19.04% of the families lived in rural places.

Of the sample, there were 41 living mothers and one dead. There were 33 living fathers and nine dead. There were 196 siblings in the 42 families interviewed. The percentage of parents married was 61.90%. That for those divorced was 14.28% and for those widowed was 21.42%.

Those families having employment as the major source of income was 66.66%. Social Security provided for 16.66%, Welfare, 7.14%, Pension, 4.76%, and Savings and Unemployment were each 2.38%. There was 23.80% of the sample whose income was \$800 and above per month. The lowest income which was 0-\$99 was secured by 7.14% of the sample. There were 11.90% who received \$100-\$199 per month; 4.76% received \$200-\$299; 9.5% received \$300-\$399; 7.14% received \$400-\$499; 11.90% received \$500-\$599; 7.14% received \$600-\$699; and 16.66% received \$700-\$799. There was 61.90% of the sample who felt that their income was adequate to meet the needs of their families, and 38.09% who felt that the income was not adequate to meet their needs.

The percentage of fathers in the study who had formal education from K-6 was 7.14%. There was 16.66% with education from 7-9; 35.71% with education

from 10-12; 23.80% with some college; 7.14% who were college graduates; 9.52% who were post graduates, and none of the fathers had vocational training. The percentage of mothers in the study who had formal education from K-6 was 9.52%. There was 16.66% with education from 10-12; 9.52% with some college; 4.76% who were college graduates; 2.38% who were post graduates; 2.38% who did not know how much education they had obtained; and none of the mothers had vocational training.

There was 35.71% of the retarded persons in the sample who resided with their natural parents. 50.00% resided at the State Training School; 4.76% with their natural mother; 2.38% in foster homes; and 11.90% in nursing homes. The percentage of parents in the sample who visited their retarded child weekly was 14.28%. For those who visited biweekly, it was 11.90%; monthly was 23.80%; yearly was 11.90%; and none of the parents stated that they never visited their child. The percentage of retardates in the sample who lived at home was 38.09%.

#### Findings and Conclusions

Conclusion 1. *Parents of residents were less concerned about problems related to their child's*

*future than parents of retarded persons not yet admitted to the state facility.* This conclusion was supported by the following evidence:

There was 42.85% of the pre-admission parents who spent ten or more hours thinking about problems related to their child's future if both parents were to die. Only 19.06% of the resident parents group said that they had thought about this subject for ten or more hours in the past year.

Additional supporting evidence would be that 52.38% of parents of residents stated that they had thought about this subject less than one hour during the past year. Only 29.57% of parents of pre-admissions stated that they had thought about this for that amount of time.

There was 19.04% of the pre-admission parents who said they had already appointed someone who would be responsible for their mentally retarded child if they were to die, and only 4.76% of the resident parents said that they had arranged for some form of guardianship.

Considerably more resident parents than pre-admission parents reported that if something happened to them, their children would either stay at the Training School, or the state would provide for them.

Conclusion 2. *Most parents were concerned about future guardianship needs for their mentally retarded children.* This conclusion was supported by the following evidence:

An overwhelming majority of the parents in the study indicated that they would favor the passage of legislation in Utah which would make it easier for them to appoint a guardian for their mentally retarded child.

There was 83.33% of the parents interviewed who stated that they favored legislation in this area. Only 16.66% answered that they did not favor the passage of this type of legislation.

Of the 42 responses obtained, 52.38% of the pre-admission parents stated that they would like to appoint someone who would

be responsible for their mentally retarded child in the event of their deaths. There was 71.42% of the parents of resident children who stated that they would like to appoint someone.

Conclusion 3. *Most parents knew little about guardianship, but favored guardianship of person and money when need was called to their attention.* This conclusion was supported by the following evidence:

There was 85.71% of the pre-admission parents who favored care of person and money, and 80.95% of the resident parents favored this type of guardianship.

Conclusion 4. *Parents were divided in opinions about whether or not the mentally retarded should be allowed to marry.* This conclusion was supported by the following evidence:

There was 47.61% of the pre-admission group who felt that some retarded persons should be allowed to marry. The percentage for the resident group who felt this way was also 47.61%.

Conclusion 5. *Parents were not unified in their answers regarding sexual sterilization for their mentally retarded child, but gave differing and varied answers and comments because of the highly individualized nature of this subject in its application. This conclusion was supported by the following evidence:*

About half of each group, and therefore half of the total, could or would not answer the question by favoring it in (a) the case of marriage, or (b) regardless of whether the child marries or not. They felt a need to comment. There was 19.04% who favored sterilization in the case of marriage, and 30.95% who favored it, regardless of whether the child marries or not.

Conclusion 6. *A majority of the parents of both pre-admission and resident children had positive feelings about the service that was provided by the Utah State Training School. This was supported by the following evidence:*

There was 54.76% of both parent groups who expressed positive attitudes about the service that was provided. An

average of 28.57% of the two groups expressed negative opinions about the service.

#### Recommendations

1. It is suggested that parents of children who reside at the Utah State Training School or who have pre-admission status, be provided more education pertaining to guardianship.
2. It is recommended that Standby Guardianship, Limited Guardianship, and Lifetime Guardianship all be considered as possible areas for additional enabling legislation in Utah.
3. It is recommended that consideration be given to establishment of Regional Centers for mentally retarded persons in Utah to enable improved services and more adequate use of existing resources.
4. It is suggested that the decision to sterilize a mentally retarded person remain a highly individualized matter, since there are a myriad of differing attitudes, feelings, beliefs, and opinions held by the families of these persons.
5. It is recommended that mentally retarded persons should not be denied opportunity for marriage solely on the basis of mental retardation.

APPENDIX

## APPENDIX 1

## SCHEDULE

**Instructions:** *It is probable that many more mentally retarded persons could lead satisfying lives if there were adequate programs to help safeguard their personal rights and interests. The extremes in responding to a retarded person, such as over-protection, or a lack of interest, do not assist them in actualizing these satisfying lives.*

*There are laws in a number of states which enable guardianship protection for children or persons who are declared physically, or mentally incompetent to manage their own affairs. These are sound tested laws which have worked well for the purposes intended, but these could possibly be improved by some statutory ammdements. If it is determined that family and friends see value from additional enabling legislation, then perhaps further provisions may be made in this area.*

*Your answers will help us to know whether the extensive work that is required to effect changes is a desire of parents who have mentally retarded children.*

*Keep in mind that throughout this questionnaire there are no right or wrong answers.*

Demographic Information

1. Informant \_\_\_\_\_
2. Relationship \_\_\_\_\_
3. IQ of retarded person \_\_\_\_\_
4. Area in which parents of the retarded person reside:
  - a.  Urban
  - b.  Suburban
  - c.  Rural
5. Age of family members:
  - a.  Father
  - b.  Mother
  - c.  Siblings

\_\_\_\_\_

6. Age of retarded person: a. \_\_\_
7. Sex of retarded person: a. \_\_\_
8. Where the retarded person now resides:
- a. \_\_\_ with natural parents
  - b. \_\_\_ at the training school
  - c. \_\_\_ with natural mother
  - d. \_\_\_ with natural father
  - e. \_\_\_ adoptive (explain):
  - f. \_\_\_ other (explain):
9. Marital status of parents:
- a. \_\_\_ married
  - b. \_\_\_ single
  - c. \_\_\_ divorced
  - d. \_\_\_ separated
  - e. \_\_\_ other (explain):
10. Formal education of parents:
- | <u>Father</u>                | <u>Mother</u> |
|------------------------------|---------------|
| a. ___ sixth grade and under | a. ___        |
| b. ___ seventh-ninth         | b. ___        |
| c. ___ tenth-twelfth         | c. ___        |
| d. ___ some college          | d. ___        |
| e. ___ college graduate      | e. ___        |
| f. ___ post graduate         | f. ___        |
| g. ___ vocational training   | g. ___        |
| h. ___ unknown               | h. ___        |
11. Source of income:
- a. \_\_\_ Social Security
  - b. \_\_\_ Pension
  - c. \_\_\_ Employment
  - d. \_\_\_ other (explain):

12. Monthly income of family unit:
- a.  0-99
  - b.  100-199
  - c.  200-299
  - d.  300-399
  - e.  400-499
  - f.  500-599
  - g.  600-699
  - h.  700-799
  - i.  800-above
13. Do you feel that this income is adequate to meet the needs of your family?
- a.  Yes
  - b.  No
14. How often do you visit your mentally retarded child?
- a.  weekly
  - b.  monthly
  - c.  yearly
  - d.  other (explain):

### Questions

1. During the past year, how many hours have you spent thinking about what would happen to your mentally retarded child if you and your spouse should die?

Comment:

- a.  less than one hour
- b.  1-10 hours
- c.  10-above

2. Would you be interested in appointing someone to be responsible for your mentally retarded child so that if you and your husband died there would be someone to look after him/her?
- a. \_\_\_ have appointed someone already  
b. \_\_\_ would like to appoint someone  
c. \_\_\_ would not like to appoint someone
3. Assume that you and your husband died during the next year, what would happen to your child?

Comments:

4. Do you think that the legislature of Utah should pass a law that would make it easier for you to appoint a guardian for your child?
- a. \_\_\_ Yes  
b. \_\_\_ No
5. If you favor guardianship what have you hoped that it would provide for your child?
- a. \_\_\_ care of person  
b. \_\_\_ care of money  
c. \_\_\_ care of person and money  
d. \_\_\_ other (explain):

6. An area of some concern to many families of mentally retarded persons is marriage and the responsibility of child rearing. Do you feel that mentally retarded persons should be allowed to marry?
- a.  Yes  
b.  No  
c.  Some
7. How do you feel about sexual sterilization of mentally retarded persons?
- a.  in the case of marriage  
b.  regardless of whether the person marries or not  
c.  other comment:
8. How do you feel about the service that has been provided for your child by the training school?
- Comments:
9. What questions do you have about possible guardianship?
- Comments:
10. Are there some other questions you have about what we have talked about?
- Comments:



## UTAH STATE TRAINING SCHOOL

AMERICAN FORK, UTAH 84003

PAUL S. SAGERS, Superintendent

## APPENDIX 2

Dear

The Utah State Training School and its Social Service Department is currently involved in a research project designed to gain a more complete understanding of the future needs of the mentally retarded person and his family. Such information is necessary and helpful in planning for future programs.

We are requesting your permission for one of the graduate social work students affiliated with our Social Service Department to talk with you about your feelings and needs regarding your child. No names or other identifying information will be used in this study.

You will be contacted by Mr. \_\_\_\_\_ for an appointment. Your cooperation and participation is encouraged. It is important to have as complete participation as possible.

Sincerely,

Paul S. Sagers  
Superintendent

William R. Long, M.S.W.  
Director, Social Service Department

WRL/mm

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## BIBLIOGRAPHY

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 N. J.: Scarecrow Press, 1968.

*This book includes a study of assault and the resultant need for sterilization statutes in the law.*

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*This book includes writings by 25 authors concerning clinical issues inherent in the present body of knowledge about prevention, treatment and rehabilitation of mental retardation. Many of the chapters were presented at a symposium sponsored by the Department of Psychology at the University of California School of Medicine, San Francisco, in November 1964. This article concerns the responsibilities of the family with regards to the mentally retarded.*

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*This book is a broad survey of the field of Mental Retardation, particularly as it relates to Social Work. This article reviews each of the types of guardianship. It makes recommendations as to volunteer guardianship services.*

Berstein, M. D. (Ed.) Diminished people: problems and care of the mentally retarded. Boston: Little, Brown & Co., 1970.

*This book was written mainly for the professional who plans to work with the mentally retarded person and his parents. It includes writings by 15 authors. The book is divided into two parts: social issues and clinical issues. This article is about techniques that can be used in parents' groups.*

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