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# Effect of social and psychological pressures on siblings of mentally retarded individuals

Thomas B. Madsen

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THE EFFECT OF SOCIAL AND PSYCHOLOGICAL PRESSURES  
ON SIBLINGS OF MENTALLY RETARDED INDIVIDUALS

by

THOMAS B. MADSEN

A thesis

submitted in partial fulfillment

of the requirements for the degree of

Master of Science in Health Services Administration

Cardinal Stritch College

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## Abstract

# THE EFFECT OF SOCIAL AND PSYCHOLOGICAL PRESSURES ON SIBLINGS OF MENTALLY RETARDED INDIVIDUALS

THOMAS B. MADSEN

The researcher surveyed fifty families within the Shawano County, Wisconsin, area who have a mentally retarded member and at least one sibling whose age is between 7 years and 20 years or 30 years and 45 years. The purpose of this project was to ascertain what stress, both sociological and psychological, was felt by the siblings of a mentally retarded individual. The second purpose of the project was to ascertain what inference mainstreaming<sup>1</sup> may have had on the generational age groups.

The researcher attempted to identify the problems the sibling of a mentally retarded person felt in regard to social pressures, misconceptions, understanding the disability, and other ramifications which may have affected the sibling's attitude toward the mentally retarded individual. The researcher also surveyed and interviewed area professionals to determine what problems were encountered when dealing with the siblings of the mentally retarded.

The researcher found, through surveys and selected interviews, that there are, indeed, pressures felt by the sibling. These pressures appear to stem from within and without the immediate family.

The 7 to 20 year old group appeared more willing to discuss their sibling's disability and also appear less anxious. After further interviews with members of this age group and after discussing the findings with local school teachers, it was assumed by the researcher that the concept of mainstreaming had a great bearing on the findings of the initial interviews. This is not to discount youthful naivete, however, the findings appeared to be convincing.

The 30 to 45 year old age group appeared more anxious, and although willing to talk, not as open as their youthful counterparts. When asked about mainstreaming, a majority didn't know what it meant and appeared disinterested when advised of its meaning. More on these findings can be found in Chapter Three of this project.

Approval

This thesis has been approved

by the following committee:

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Project Advisor Date

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## Table of Contents

Chapter	Page
1. Problem Statement and Methodology . . . . .	1
Purpose and Title of the Project . . . . .	1
Problem Statement . . . . .	2
Project Location and Duration . . . . .	5
Objectives . . . . .	6
Developmental Objectives . . . . .	6
Evaluation Objectives . . . . .	7
Evaluation Methodology . . . . .	8
Limitations of the Project . . . . .	10
Budget . . . . .	12
Timeline . . . . .	13
Notes . . . . .	14
2. Review of the Literature . . . . .	15
Introduction . . . . .	15
(Major Issue #1) . . . . .	16
Historical Foundation . . . . .	16
Philosophical Foundation . . . . .	19
Psychological Foundation . . . . .	21
Sociological Foundation . . . . .	23

Chapter	Page
(Major Issue #2, etc.) . . . . .	24
Historical Foundation . . . . .	25
Philosophical Foundation . . . . .	29
Psychological Foundation . . . . .	30
Sociological Foundation . . . . .	32
Summary . . . . .	35
Notes . . . . .	37
3. Findings, Conclusions, and Recommendations . . . . .	40
Purpose of the Project . . . . .	40
Research Methodology . . . . .	40
Description of Findings . . . . .	41
Analyses of Findings and Conclusions . . . . .	55
Summary/Recommendations . . . . .	58
Bibliography . . . . .	62



## CHAPTER ONE

### Problem Statement and Methodology

#### Purpose and Title of Project

##### Purpose

The purpose of this project was to ascertain what problems (psychological and sociological) the siblings of mentally retarded individuals encounter. The researcher divided the siblings into two age groups. The first group was made up of siblings of mentally retarded individuals whose age fell between 7 years and 20 years; the other group was an older set of siblings, whose ages were between 30 years and 45 years. The reason for the age difference coincided with the second question, which the project addressed: What effect has the concept of mainstreaming had on the two age groups? The researcher assumed the older group of siblings were unaware or ignorant of the basic concept of mainstreaming, while the younger group had been exposed to it for many years. In other words, the younger generation of siblings grew up in an environment where mainstreaming was the common tool for integrating the disabled population into the "mainstream" of society, especially in regard to school programs.

The findings of the research should assist health care professionals in dealing more effectively with families of the mentally retarded individuals they serve. The purpose of this project was a better understanding of how professionals interact

with siblings of mentally retarded persons. Such understandings are important when one considers at least one sibling assumes a decision-making role in the life of the mentally retarded individual by becoming legal guardian, conservator, or by assuming power of attorney.

### Title

"THE EFFECT OF SOCIAL AND PSYCHOLOGICAL PRESSURES  
ON SIBLINGS OF MENTALLY RETARDED INDIVIDUALS"

### Problem Statement

#### Statement of the Problem

It is difficult growing up in an ever-changing society. The adjustment from childhood to adulthood can be traumatic, even for those from the most secure household environment. Sibling rivalry is one component which may cause stress between children. However, growing up and attaining responsible adulthood can be even more difficult when one of the children is mentally retarded, as noted by Margaret E. Adams: "The unit of society that bears the initial brunt of social stress stemming from mental retardation is the nuclear family . . . the presence of a retarded child in the family impinges also on the normal children, creating adjustment problems for them in turn."<sup>2</sup>

The purpose of this project was to assess and analyze the effects of having a mentally retarded individual as a sibling. In addition, the researcher attempted to distinguish what effect the

concept of mainstreaming of the early 1970's and 1980's had on the attitudes of the adult sibling of the mentally retarded individual.

### Background Information

In the early 1970's, the federal government mandated that persons residing in state or federal institutions for the mentally deficient should have the opportunity to function as normal members of society.<sup>3</sup> The doors of the mental institutions opened, thus implementing the concept of mainstreaming.

Although this phase of deinstitutionalization has not been considered completely successful by some health care professionals, it did pave the way for more open services to be provided to the developmentally disabled population. Over the years, the developmentally disabled population, which includes the mentally retarded, along with other disabilities, such as the chronically mentally ill, was supported by legislation which mandated that they should be living in the "least restrictive setting."<sup>4</sup> In other words, if handicapped could cope living in society, with the proper support systems, they were protected by law.

With this in mind, the responsibility was placed back on the family to furnish as much support (emotional, financial, etc.) as possible. For instance, instead of a severely mentally retarded person being sent off to live in an institution, the family kept him or her at home with governmental supports or within the community at a licensed foster care home or a community-based residential facility.

Legislation also mandated integrated school curriculum for those students classified as having an exceptional educational need. Mainstreaming became a factor in schools, and it is here where the researcher decided to ascertain what differences may occur between the two aforementioned generational groups.

### Need for the Project

Professionals and writers have researched extensively the effect a mentally retarded sibling has on a normal child. Margaret E. Adams and Frances Kaplan Grossman have both examined this problem. Adams did her research in 1969, previous to the advent of mainstreaming, while Grossman worked on the problem in 1972, as deinstitutionalization and mainstreaming were just coming into being. More recently, Thomas H. Powell and Peggy Ahrenhold Ogle dealt extensively with this problem in their 1985 book entitled, Brothers and Sisters - A Special Part of Exceptional Families.

Most of the material found by the researcher dealt with east coast families, whose culture may be different from rural east central Wisconsin. Social services differ a great deal, as do other socio-economic features of the population. Also, from the available material, the researcher found very little research on how the effects of mainstreaming may differ between the two generational groups. Be that as it may, some material did reflect differences in attitudes, but none attributed to the concept of mainstreaming. Therefore, the researcher decided to explore the effects of mainstreaming and, considering the apparent lack of material

dealing with upper midwest farming communities, to center the research in Shawano County, where the researcher had access to lists of possible research participants.

### Project Location and Duration

#### Location

The research project setting was the rural and urban areas of Shawano County, Wisconsin. Because Shawano County was almost exclusively rural, the emphasis was placed in that setting, although the City of Shawano, population 7000, also encompassed a good portion of research.

Shawano County had a population of almost 36,000 people. It was bordered by Brown County (Green Bay) on the East, Outagamie County (Appleton) on the Southeast, Marathon County (Wausau) to the West, and Menominee County and Reservation to the North. Shawano's largest industry was dairy farming, with wood products and tourism as significant secondary others.

#### Duration

This project began on October 15, 1985. The researcher sent initial questionnaires (devised to assess the effects of having a mentally retarded sibling) out on October 16, 1985, to a target group of 20 individuals. The researcher then conducted respondent interviews during the final two weeks in October, 1985, and sent out remaining questionnaires on November 4, 1985, after the initial questionnaire was validated, with tabulations and calculations being completed by the first week in January, 1986.

## Objectives

### Developmental Objective #1

By October 1, 1985, the researcher revised and had approved for distribution the initial questionnaire for the sample target groups.

#### 1. Implementation Activities

- a. Developed a questionnaire for both generational groups with the assistance of professional colleagues and the Research Advisor.
- b. Obtained approval from Project Advisor as to the validity of the questionnaire and validity tool.
- c. Obtained approval from Unified Health Services Developmental Disabilities Coordinator and Case Managers for use of client lists.
- d. Interviewed target group.

2. Evidence of Completion - an approved questionnaire with 80 percent correspondence of the target group between both oral and written forms.

### Developmental Objective #2

By November 4, 1985, the completed questionnaire was prepared for distribution.

1. Implementation Activities
  - a. Developed a cover letter to be sent out by Developmental Disabilities Case Managers.
  - b. Prepared a mailing list devised from names and addresses provided by Developmental Disabilities Case Managers.
  - c. Mailed the questionnaire to the remaining 30 individuals.
2. Evidence of Completion - the questionnaire was mailed out and a return rate of 66 percent was realized by January 8, 1986.

Evaluation Objective #1 was to ascertain what percentage of the 30 to 45 year old population of siblings of a mentally retarded individual did not understand the concept of mainstreaming, did not philosophically believe in mainstreaming, and continued to harbor ill feelings toward society and the mentally retarded sibling due to feelings of guilt, contempt, or hatred because of the presence of a mentally retarded person in the immediate family. A secondary objective was to distinguish how 30 to 45 year old siblings felt about services and rights of the mentally retarded population on federal, state, and local levels.

Evaluation Objective #2 was to find if the 7 to 20 year old age group appeared more accepting of the mentally retarded sibling because of the inception of mainstreaming. The researcher wanted to compare the results of this group to the older group of siblings.

## Evaluation Methodology

### Target Population and Sampling Methodology Used

The researcher sought out 50 families within the Shawano County area who had at least two children, with one of those children diagnosed as mentally retarded. After the initial procedure to ascertain questionnaire validity, the researcher mailed the questionnaire to the remaining 30 siblings. The 50 families encompassed the initial validation group of 10 people from each age group and then 30 after the questionnaire was validated. In all, there were fourteen 7 to 20 year olds and nineteen 30 to 45 year olds participating. The researcher did not allow for the severity of retardation, in that he chose to encompass all spectrums of mental retardation. The target group consisted of normal siblings of mentally retarded individuals within the age spectrum of 7 years to 20 years and 30 years to 45 years.

### Research Design and Procedures

The researcher employed the Likert Method of question design in the questionnaire and evaluated it through percentages of results. The percentages from each age group were cross referenced to find the differences between them and to assist the researcher to ascertain the feelings and beliefs of each group.

The researcher hand delivered the initial questionnaire and interviewed a target group of ten persons from each generational group. The interview helped the researcher find out the validity of the questionnaire. This group came from a list of siblings from



each age group provided by Developmental Disabilities Case Managers. The researcher required 80 percent correspondence between the written and oral report. Those questions that failed to yield 80 percent coherency were not used and a list of backup questions employed. The researcher used backup questions only if they corresponded with the 80 percent rule.

### Materials and Instruments

The researcher used a fifteen point questionnaire, which was derived with the assistance of Shawano County Developmental Disabilities professionals. The researcher developed the questionnaire with the assistance from area professionals and an intensive literature search.

### Data Collection Methods

The researcher hand delivered the target group questionnaire and established a structured interview process. The interview process consisted of the researcher asking the target group members the same questions as in the questionnaire. The researcher also interviewed the target group to assure sincerity and reliability. The researcher wanted an 80 percent correspondence between the written and oral questions, to assume validity of the questionnaire. After 80 percent correspondence was found, the remaining 30 questionnaires were mailed to the normal siblings.

### Summary Data Analysis Methods

The survey was used to determine what percentages of the two ages groups appeared to accept their mentally retarded sibling, harbored ill feelings toward society in general, and the sibling in particular and how the two age groups felt about rights and services for their siblings.

### Limitations of the Project

#### Definitional

The researcher found it difficult to assess the attitudes of the respondents which hindered the process of defining the results. The researcher also found a difference between the validation group and the actual survey participants. For reasons unclear to the researcher, the two groups did not correspond. The researcher will address this point further in Chapter Three.

#### Methodological

Some returned questionnaires were incomplete or had statements indicating a lack of understanding of the questions. These questionnaires were not incorporated within the survey. Also, the small number of survey participants limited the external validity of the survey.

### Implementation

One major constraint was the availability of validation group participants. Scheduling, travel time, and participant skepticism hindered the validation process.

BudgetDirect Costs

1. Survey Typing . . . . .	\$ 20.00
2. Copies of Surveys . . . . .	10.00
3. Envelopes . . . . .	7.50
4. Postage . . . . .	36.40
5. Report Typing . . . . .	150.00
6. Paper . . . . .	<u>45.00</u>
Total Direct Costs	\$ 268.90

Indirect Costs

1. Researcher Time - 240 hours x \$20.00/hour . . .	\$4,800.00
2. Mileage \$.28 per mile x 114 miles . . . . .	<u>31.92</u>
Total Indirect Costs	\$4,831.92
Total Costs	\$5,100.82

Timeline - 1985-1986

<u>Research Project/Thesis Process</u>	<u>SEPT.</u>	<u>OCT.</u>	<u>NOV.</u>	<u>DEC.</u>	<u>JAN.</u>	<u>FEB.</u>
Step 1 - Submitted Project Concept Form for Approval	*-----*					
Step 2 - Formulated and Distributed Project Questionnaire to Target Group		*-----*				
Step 3 - Submitted Initial Chapter One for Approval			*-----*			
Step 4 - Distributed Questionnaire			*-----*			
Step 5 - Questionnaires Returned at a Rate of 66 Percent				*-----*		
Step 6 - Survey Completed; Revised Chapter One Submitted for Approval					*-----*	
Step 7 - Chapter Two Submitted for Approval						*-----*
Step 8 - Analyzed Data						

## Notes From Chapter One

1. Grossman, Herbert J., M.D. et al. Classification in Mental Retardation. American Association on Mental Deficiency, Washington, D.C. 1983. p. 183.
2. Adams, Margaret E. "Siblings of the Retarded: Their Problems and Treatment", Management of the Family of the Mentally Retarded. Wolfensberger, Wolf and Kurtz, Richard. eds. Follett Educational Corp. 1969. pp. 445-446.
3. Rugg, Anne V. Children of Misfortune. The Wisconsin Council on Developmental Disabilities. Madison, Wisconsin, 1983. p. 60.
4. Grossman, p. 182.

## CHAPTER TWO

### Review of the Literature

#### Introduction

As stated in Chapter 1, the researcher designed the project to assess what psychological and sociological pressures were felt by two different age groups of siblings of mentally retarded individuals living in Shawano County. The project design was to ascertain what, if any, the concept of mainstreaming, associated with Public Law 94-142, may have had to promote differences of opinions and beliefs between the two age groups. The two age groups in question were siblings of mentally retarded individuals between the ages of 7 and 20 years and 30 and 45 years.

The researcher's literature review centered around magazine articles, professional papers, theses, professional journals, books, and other publications dealing with families of the mentally retarded. Also included in the literature review were articles, books, and professional journals dealing with Public Law 94-142 and the concept of mainstreaming. The researcher also interviewed several Shawano County social workers, teachers, and administrators of programs for the mentally retarded.

The purposes of the literature review was to assist the researcher in understanding the difficulties attributed to having a mentally retarded sibling, and also to assist the researcher and

the reader to further understand the four foundations behind the concept of mainstreaming.

The two major issues reviewed by the researcher addressed the four perspectives: historical, philosophical, sociological, and psychological. First, what negative or positive effects were encountered by having a mentally retarded sibling? Second, have the concepts of Public Law 94-142 and mainstreaming had an effect on the siblings of mentally retarded individuals, and is there a distinct difference in philosophy between generational age groups because of the onset of mainstreaming?

#### Major Issue #1: The Effects of Having a Mentally Retarded Sibling

In this issue, the researcher addressed the ramifications of growing up in America with a mentally retarded sibling. No matter what the living environment, the burden of having a mentally retarded brother or sister could be traumatic. Therefore, what were the effects of having a mentally retarded sibling, especially considering the philosophical attitude and, as previously stated, the generation of the normal child?

#### Historical

Like many families with a mentally retarded sibling, society has, within the past twenty-five years, begun to recognize the plight of the normal sibling. It is no coincidence that this was first brought about during the onset of the 1960's.<sup>1</sup>

The Association for Help of Retarded Children in New York



became aware of the problems being faced by siblings of mentally retarded children when references were made to social workers by parents in 1962.<sup>2</sup> Up until that time, very little attention was paid to the normal brothers and sisters of retarded persons.

However, the first person of that era to initiate published reports on the effects of having a mentally retarded sibling was Bernard Farber in his article, "Effects of a Severely Mentally Retarded Child on Family Integration", published in 1959. In this article, Farber discussed the effects on the normal brother, as compared to the normal sister, and how much those effects are differentiated by the presence of the retarded sibling. Farber also discussed how the presence of a mentally retarded sibling impacts on the entire family structure.<sup>3</sup>

Other experts in the study of siblings of mentally retarded individuals included Wolf Wolfensberger and Richard Kurtz, who are best known for their collaborative studies, which include, Management of the Family of the Mentally Retarded and A Theoretical Framework for Management of Parents of the Mentally Retarded, both published in 1969. Mary Feely, Meyer Schreiber, and Margaret E. Adams also contributed to Wolfensberger's and Kurtz's works. The major issue addressed in these articles dealt primarily with the concept of social service agencies intervening with families of mentally retarded individuals, especially in regard to self-help and encounter groups for siblings of the mentally retarded.

In regard to present day experts, Thomas H. Powell, Ph.D., and Peggy Ahrenhold Ogle, Ph.D. appear to stand out as the

leading authorities. Their book, Brothers and Sisters - A Special Part of Exceptional Families (1985) has become one of the most authoritative works to cover the subject of siblings of mentally retarded individuals. Not only did Drs. Powell and Ogle discuss the ramifications of having a mentally retarded sibling, they offered suggestions and advice as to the various therapeutic and clinical alternatives.

Over the past twenty-five years, as the American society became more aware and tolerant of its disabled population, the effects of having a disabled family member on the immediate family also came into focus. Previous to 1960, most mentally disabled people were shipped off to institutions, or as they were called in Wisconsin, training schools or colonies.<sup>4</sup> With no supports from the community, governments or legal systems, families had no choice but to either do what they could at home or send the disabled child to an institution.

In 1962, President John F. Kennedy mandated that society could no longer turn its back on this population, and organized the President's Panel on Mental Retardation. In that same year, the panel issued a report entitled: "National Action to Combat Mental Retardation."<sup>5</sup> This report ". . . insisted that state institutions upgrade the quality of their services and encouraged local governments to provide comprehensive, community-based facilities and services."<sup>6</sup> With this report came the advent of federal involvement and fiscal aid to states in regard to the mentally retarded population. Also with this came the involvement

of family members, all family members, with the care and responsibilities toward the mentally retarded individual.

Since that time, Wisconsin has seen a myriad of community-based services geared toward the mentally retarded population. As the needs of the retarded became more visible to society, so did the needs of their families. It was only natural that the siblings and their problems would come to light. Support groups were organized through social service agencies and benevolent organizations. While many of these support groups remained small and informal, some grew as the realization of the needs of the normal sibling grew.

In Wisconsin, a statewide support group was founded and called "Sibling Support System." Other innovations included a state-wide sibling conference which was held on November 6-7, 1981, as a part of a family support seminar.<sup>7</sup> It appeared that as the awareness of the disabled population grew, so did the public's awareness of that population's brothers and sisters.

### Philosophical

Many human service workers, the researcher included, have encountered many people unaware or totally ignorant of the ramifications, issues, or causes of mental retardation. Many people fail to comprehend, much less recognize, the needs of the mentally disabled population.

Education was one factor that may have assisted the public in understanding mental retardation and the effects it has had on the

family. However, it was most difficult to "educate" or even "legislate" philosophical concepts.

Be that as it may, this nation attempted to eradicate negative beliefs toward mental retardation through presidential commissions and legislation.<sup>8</sup> Supplemental Security Income, Social Security Disability Income, Medicaid, and other federally mandated benefits have assisted the mentally disabled to integrate more effectively into society. With these benefits and the protection of the courts, many mentally disabled individuals have crossed that barrier that separated the normal population from the abnormal. However, these mandated services could not sway individual beliefs.

Many siblings were caught in a double philosophical bind: They were born into a family where there was a mentally retarded sibling. They may not have liked this person and wished he or she would simply go away forever. Yet, the family was dedicated to this person, which was contrary to the normal sibling's beliefs. The normal sibling must insulate his or her own beliefs and tolerate the mentally retarded individual when his personal philosophy was against it.

Sol Gordon, in his book Living Fully discussed what siblings may experience: ". . . it is normal to have negative thoughts about your handicapped brother or sister: wishing they were dead; would go away; were never born, and so on . . ." <sup>9</sup> What Gordon and other writers and professionals espoused was the concept that there is nothing wrong with having certain feelings or maintaining a certain attitude.

However, of late, many siblings have taken it upon themselves to write of experiences, both good and bad, about their mentally retarded brother or sister. It was this philosophy of acceptance that had permeated the trend toward the needs of normal siblings.

For instance, Julia Ellifritt, writing in The Exceptional Parent writes about her Down Syndrome sister, ". . . My biggest problem in dealing with Bonnie has been guilt. I had not been able to forgive myself for the things I had done."<sup>10</sup> Yet, Ms. Ellifritt went on to discuss her change in attitude when adulthood and the ensuing responsibilities arose. This does not appear to be an isolated case. Of late, there were many articles and books on this new philosophical trend.

Perhaps it could have been the value of learning about the respect for life. Perhaps it was because siblings of mentally retarded ". . . have specific needs in regard to respect and understanding . . ." <sup>11</sup> that their own philosophies on life must witness more changes than the norm permits.

### Psychological

As this nation's philosophical attitude had changed toward the mentally disabled population, so, too, had the psychology behind it. For instance, giving attention and counseling to siblings of the mentally retarded was a relatively recent occurrence.<sup>12</sup> Yet, it signifies a change in attitude toward the mentally retarded population and their families.

While mental retardation may be considered a total family handicap, recent studies have indicated that the psychology behind this "family disability" is one of no longer placing the blame on any one family member.<sup>13</sup> This attitudinal change was attributed to the fact that normal siblings were now becoming more vocal in regard to their own needs and frustrations.<sup>14</sup> Also taken into consideration was the open attitude of the public at large about various disability groups, including the mentally retarded.

The federal government also assisted in this attitudinal change. The advent of deinstitutionalization and the enactment of Public Law 94-142 had an affect on the psychology of accepting mental disabilities. Federal statues mandate that people with these disabilities must live in the "least restrictive environment." As society realized the needs of other family members, professional service providers were beginning to take time to listen to the normal siblings.<sup>15</sup>

Many siblings and parents of mentally retarded individuals, who had written about their problems, discussed the psychological trauma involved in having a mentally retarded person in the home. For instance, ". . . In my family, we were not allowed to discuss our feelings . . . she was retarded and if we said anything negative, we might hurt her feelings. Well, what about my feelings?"<sup>16</sup>

According to Powell and Ogle (1985), when negative feelings much like the above take place, the family should try to ascertain the origins of such feelings.<sup>17</sup> These negative feelings may be the result of any number of factors which may include:

1. The severity of the handicap.
2. The age of the siblings.
3. The size of the family.
4. The financial status of the family.
5. Internal and external pressures placed on the family.<sup>18</sup>

### Sociological

As the psychology of acceptance of both the mentally disabled and their families appeared to be permeating society, sociological issues regarding this had to be addressed. Because of major changes within our society, the importance of brothers and sisters of the mentally retarded would ultimately increase.<sup>19</sup> According to Bank and Kahn (1982), ". . . children today are growing up in a vastly more complex world than did their grandparents - a world where opportunities for contact, consistency, and permanency are rare. Children are biologically propelled by these vital needs . . . to turn for satisfaction to any accessible person. In a worried, mobile, small family, high stress, fast paced, parent absent America, that person can be a brother or sister."<sup>20</sup>

Some of the sociological changes faced by all siblings included:

1. Smaller families. Couples are having fewer children and these children tend to be closer in age, thus fostering more intense contact with each other.
2. People are living longer and siblings are providing more support to one another through their lifetimes.

3. The mobile society continues to flourish as people are moving more often. Therefore, the difficulties of establishing friends are forcing siblings to rely more on each other.
4. Divorce and remarriage are increasing, also forcing siblings to rely more on each other.
5. Working mothers. Young siblings are spending more time away from the home, either at a sitter's house or at day care centers. As siblings grow older, they find themselves spending much time together in unsupervised situations.<sup>21</sup>

These issues are difficult enough for siblings from normal families. Couple it with the presence of a mentally retarded sibling, and it could become catastrophic without proper and timely support systems. It is essential, therefore, that society become aware of these normal siblings and establish a network of social services. Services not merely for themselves, but to assist the sibling of becoming aware of their problems and that those problems and fears would not go unfounded.

#### Major Issue #2: Public Law 94-142 and the Concept of Mainstreaming

In 1975, the 94th Congress passed a landmark piece of legislation, called the Education for All Handicapped Children Act, by a sweeping vote of 491 to 14.<sup>22</sup> It was signed by President Gerald Ford and mandated that ". . . every child, no matter how severely handicapped, was entitled to a free, and appropriate, public education."<sup>23</sup> From



this act, commonly known as 94-142, every public school district in the United States became responsible for provisions in special education, which before this time, were either optional or unheard of.<sup>24</sup> One of the basic concepts and major issues to derive from 94-142 is the concept of mainstreaming. Mainstreaming can be best defined as "a colloquial term used by educators to refer to the integration of handicapped children into regular classes for part of all of the school day."<sup>25</sup>

What, therefore, has the concept of mainstreaming had on the mentally retarded individual in regard to equal educational opportunity? Also, has mainstreaming had an affect on the siblings of the mentally retarded, especially considering siblings from two separate and different generations.

### Historical

Years ago it was not unnatural to have a handicapped child, especially one who is mentally retarded, attend school away from his or her normal counterparts. Special schools were established and the handicapped student was rarely, if ever, seen in the mainstream of American public education.

In 1975, all tradition was changed because of Public Law 94-142. The well-worn phrase "least restrictive environment" was one of the key concepts of P.L. 94-142.<sup>26</sup> However, the concept of "least restrictive environment" and 94-142 did more than merely place handicapped students within the same building as the other

students. Legally, it tied together two related principles:

1. That handicapped students must be placed in the regular classroom or school setting, or the school must offer an "educationally compelling justification" for any form of separate schooling.<sup>27</sup>
2. That the handicapped student must have the opportunity for student-to-student contact and integration in all areas of student life, not just the classroom.<sup>28</sup>

From a historical viewpoint, there still remained many unanswered questions and issues regarding P.L. 94-142. One, in particular, was the concept of "least restrictive environment" itself. While the lessor disabled child, with the exception of one or two hours a day, was integrated with the norm of school life, the more severely retarded child may be segregated totally within the same building.<sup>29</sup>

Public Law 94-142 and other federal mandates such as deinstitutionalization has instilled within the human and educational services the philosophy of acceptance of the disabled people they serve. Public Law 94-142 had a bearing on society's acceptance of disabled people and had assisted the family in coping and working with its disabled member.

In regard to published accounts and reports pertaining to mainstreaming, the researcher found information through public school personnel and professionals who work with disabled children. Also used by the researcher were newspaper articles discussing

the ramifications of Public Law 94-142 as it celebrated its tenth anniversary, as well as information provided by the State of Wisconsin Developmental Disabilities Office, Department of Public Instruction, and various teacher and parent advocate groups.

The most recent work to deal with mainstreaming and 94-142 was a series of articles by Nancy J. Stohs published in the Milwaukee Journal in November of 1985. In this series, Ms. Stohs discussed how 94-142 had an impact on the Milwaukee area schools and what appeared to be the strong points and shortcomings of the act. She also discussed, in length, various attributes, as well as misconceptions of Public Law 94-142, especially what handicapped students do after their school program has ended.

Other authoritative works regarding mainstreaming and 94-142 include several books which deal specifically with the concept and implementation of the law. These resources include, Complete Special Education Handbook by Katherine Ceren (Parker Publishing Company, 1979), The Handicapped Student in the Regular Classroom by William R. Gearheart and Mel W. Weishahn (The C.U. Mosby Company, 1980), The Mentally Retarded Child by Nancy and Halbert Robinson (McGraw-Hill, 1976) and Educating Exceptional Children by Samuel A. Kirk (Houghton Mifflin Company, 1972). Those books deal with the concept of mainstreaming and special education before and after the inception of Public Law 94-142. In particular, the books discussed various issues brought forth by educators and administrators of programs for handicapped children. Among the issues discussed included the encompassing

philosophical belief of equal educational opportunities for every child and what constitutes "appropriate education" for handicapped students.

Other accounts regarding mainstreaming and 94-142 include a book entitled, Handicapped Students and Special Education, published by Data Research incorporated in 1984. This work described and defined 94-142 and discussed its impact on students, school systems, administrators, private schools, and what services can or cannot be included as a result of the act, as well as procedural safeguards provided by Public Law 94-142. This work also provided an historical perspective of how Public Law 94-142 came to be. In this same vein, the researcher utilized several articles pertaining to mainstreaming in The Journal of Learning Disabilities, which also discussed teacher attitude toward mainstreamed students.

Another reference tool used by the researcher is a publication entitled 94-142 and 504: Numbers that add up to Educational Rights for Handicapped Children. This book was written by Daniel Yohalem and Janet Dinsmore for the Children's Defense Fund. Basically, this publication breaks down 94-142 into various subsections and addresses various issues pertaining to 94-142, to be used by parents and advocates of handicapped students.

By and large, few experts in the field of special education and human services question or doubt the meaning and purpose of 94-142. However, 94-142 does place a great burden on implementing mandated services, especially considering recent federal legislation in the form of the Gramm-Rudman Act.

Mainstreaming and Public Law 94-142 had a far reaching and historical impact on public education in the United States. The following foundations will discuss these ramifications more specifically.

### Philosophical

For the most part, America, historically, has enforced the belief of assisting its disabled population. Even with the current rash of state and federal spending cuts, the disabled population, for the most part, appeared somewhat safe from losing its benefits.

Gearheart and Weishahn (1980) echoed this philosophy especially in regard to the educational opportunities of America's disabled population, and stated that ". . . educational programs should be modified and specialized to meet . . . the needs of disabled individuals."<sup>30</sup> The authors went on to say that ". . . that the handicapped individuals of this nation have a . . . right and that the public, tax supported educational systems of the nation must adjust and adapt . . . educational programs and offerings . . ."<sup>31</sup> This was the basic philosophical thrust behind 94-142, that it was the birthright of every American child to have a "free and appropriate public education."<sup>32</sup>

Public Law 94-142 appeared to be the child of the more encompassing philosophical belief of "least restrictive environment." That concept was the motive for many social reforms involving handicapped individuals. Included in this was

deinstitutionalization, with mainstreaming being a co-equal issue.

Therefore, as one of the basic premises of mainstreaming was the philosophy of equal rights to share in the traditional American dream of equal access to an appropriate education, mainstreaming and the concept behind 94-142 was part of that philosophy. The philosophy of education for handicapped children and youth supported an emphasis of learning strengths and abilities and a deemphasis of labeling of handicapped individuals.<sup>33</sup>

Mainstreaming and 94-142 stress the potential of the student, with supports, not the handicap itself.

### Psychological

Approximately twenty-five years before the passing of 94-142 and other educational legislation, handicapped children and students were treated much in the same way as during the turn of the century and before.<sup>34</sup> However, as stated previously, this was a nation with a tradition of reform. Over the past twenty-five years, there has been a marked attitudinal change which has also had an impact upon the behaviors of the students (both regular and special) and the psychological motivation of teachers and administrators.<sup>35</sup> Some of this attitudinal change can be attributed to the social reforms of the 1960's as brought about by New Frontier and Great Society Legislation. However, a number of other factors contributed to this deluge of positive action. For instance, President John F. Kennedy, along with other major political figures, had an unusual personal interest in the handicapped because of

the presence of handicapped individuals in their immediate families.<sup>36</sup> Therefore, because of their personal involvement and attitude, issues pertaining to handicapped population gained high national visibility. With this push from national political leaders, organizations such as the National Association for Retarded Children and the United Cerebral Palsy Associations became increasingly active along with show business personalities and professional benevolent organizations.<sup>37</sup> Even the United States Congress became involved. After all, few people would criticize efforts to help the handicapped.

However, this psychology of reform, change, and benevolency had to also be impacted upon the public schools. Administrators and regular classroom teachers had to accept the changes that were coming out of Washington, D.C. It was very difficult to legislate attitudinal opinions.

Therefore, the psychology of change and attitude had to be sold to the people who had to administer the concept of special education and mainstreaming. Historically speaking, it was no easy task. Smith and Smith (1985) report that the battle of mainstreaming and special education

" . . . is still waged between regular and special education teachers. The special education teachers do not feel that regular education teachers do enough for special education students in the mainstream. On the other hand, regular education teachers feel that special education teachers 'coddle' students and negotiate for passing grades in order to obtain high school diplomas for students."<sup>38</sup>

The "battle" the Smith's referred to is still waging today. In many cases, handicapped students are mainstreamed on paper only

and not in actuality. This was especially evident in rural areas where resources were often not available. In urban areas, where services and resources are more available, bureaucracy and paperwork interfered with the process of mainstreaming and special education.<sup>39</sup>

In 1985, Pittsburgh researchers undertook four studies to ". . . explore the accommodative power of mainstream secondary schools and the extent to which teacher attitudes and student behaviors . . ." figured into the success or failure of mainstreamed high school students.<sup>40</sup> Four hundred twenty-nine secondary school teachers from twelve Pittsburgh area high schools were sent an open-ended four item questionnaire to assess their attitudes of mainstreamed students. The return rate was thirty-one per cent. Twenty-six percent of the respondents felt that mainstreamed students should not be enrolled in regular classes and 27 percent were unenthusiastic. ". . . though willing to accept the student only if support services were available . . ."41

Although this survey included all mainstreamed students (i.e., Learning Disabled, Emotionally Disturbed, etc.), the figures reflected an alarmingly high percentage of negative teacher attitude. Like all major reforms, mainstreaming has taken a very long time to be totally accepted by all professionals in the field of education.

### Sociological



Public Law 94-142 and mainstreaming had a great bearing on the socialization of the mainstreamed student. Before the advent of 94-142, many disabled students and almost all mentally retarded students were cloistered in separate and segregated schools and classrooms. However, because of the promise of "least restrictive environment" and "appropriate and free public education", handicapped students now had the right to associate with regular students in regular schools, at least in theory. There continued to be some forms of segregation. For instance, there were at least four separate and segregated schools in the Milwaukee area.<sup>42</sup> Also, in most school districts, many special education classrooms may have been in the same buildings as the regular classrooms, but still segregated by locale.

There was also the socio-economic status of the handicapped student and his or her family. Robinson and Robinson (1976) report that, ". . . Social class represents a matrix of interrelated variables, both genetic and acquired. Among the distinguishing features of social classes are parental education and occupation, parental IQ and verbal behavior, family income, health status, childrearing practices, neighborhood and housing conditions, a variety of attitudes toward education, achievement, and the possibility of controlling one's destiny and so on."<sup>43</sup> These issues were important in the etiology of mental retardation due to psychosocial disadvantage. For instance, middle class families may have experienced problems in rearranging their high expectations for their handicapped child. Yet, at the same time, middle-class

families may also have been more financially secure and more able to utilize outside resources besides the public school district.<sup>44</sup>

In other words, upper and middle class families may have been able to fund their child's mainstreaming.

Obviously, the same cannot be said for lower class families. Conversely, families of lower socio-economic status often have limited financial resources and must depend on public school district and other county and state agencies for support.<sup>45</sup>

Some teachers, from both regular and special education programs, have developed handicapped awareness programs for their students. These programs were devised to help regular classroom students to learn and appreciate the handicaps special education students face. For instance, several students from a regular classroom were confined to a wheelchair, blindfolded, or experienced other sensory loss to simulate a handicapping condition. The handicap awareness programs have been very beneficial in assisting the regular classroom teacher and students to understand the disability of their handicapped counterparts.<sup>46</sup>

Another development which was designed to further enhance the concept of mainstreaming was the role of other or third party agencies. In the Shawano-Gresham School District, there was the Interagency School Program (ISP). Essentially, the Interagency School Program involved the local school district and several area social service organizations. The purpose of ISP was to involve as many service providers as possible in developing appropriate curriculum and other services for the handicapped and mainstreamed student.<sup>47</sup>

### Summary

Throughout this chapter, the researcher discussed two issues. One issue concerned the effects of having a mentally retarded sibling. The second issue was the concepts of Public Law 94-142 and mainstreaming in regard to accepting mentally retarded individuals into the mainstream of the American public school system.

The Historical Foundation in the first issue was the historic path of society realizing that siblings of mentally retarded individuals had the need for services not unlike that of their handicapped brothers and sisters. The researcher reviewed literature which dealt specifically with this issue, as well as literature that provided the researcher a broad overview of mental retardation in general.

The Historical Foundation of the second major issue discussed the advent of Public Law 94-142 and the concept of mainstreaming. The literature reviewed for this foundation included several publications dealing specifically with 94-142 and its impact on public school systems. The researcher also interviewed several area professionals concerning the law's impact on the local school district and how that district was dealing with it.

The Philosophical Foundations of both major issues discussed the philosophical beliefs and strategies behind attitudes and actions by both siblings of mentally retarded individuals of those people in the serving professions. Also discussed in both major issues was

America's philosophical concept of reform, which is a traditional value of this nation.

The researcher attempted to correlate the Psychological Foundations with the Philosophical Foundations. The two foundations closely paralleled one another in content and issues, especially considering the psychology and philosophy of change both within the educational structure of the United States (mainstreaming) and the legislation supporting it (94-142).

The Sociological Foundations of major issue number one discussed the changes siblings must face within society in general and correlated with the presence of a mentally retarded sibling. In major issue number two, the researcher discussed how 94-142 and mainstreaming had affected the regular classroom atmosphere, especially considering how and where mentally retarded students were placed before 94-142 and mainstreaming.

From other research and studies conducted to assess the affects of having a mentally retarded sibling, the researcher found most of the studies to have taken place on the east coast of the United States and set almost exclusively in urban areas. The researcher centered this project in Shawano County, Wisconsin, a primarily rural area of east central Wisconsin.

The materials studied by the researcher appeared academically sound, but appeared slanted toward middle class families. The researcher's surveys attempted to cross socio-economic lines.

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## CHAPTER THREE

### Findings, Conclusions, and Recommendations

#### Introduction

##### Purpose of the Project

The purpose of this project was to ascertain what sociological and psychological problems were faced by the siblings of mentally retarded individuals in Shawano County, Wisconsin. Also to determine if the concept of mainstreaming had an effect in the differences of opinion between the surveyed age groups of 7 to 20 year olds and 30 to 45 year olds.

##### Research Methodology

The researcher's hypothesis was that the concept of mainstreaming had a positive effect on the 7 to 20 year old age group because of that age group being more integrated from early life. The researcher also assumed that the older age group would not be as accepting because of the lack of mainstreaming and the lack of services during their childhood. The researcher hypothesized that would have a negative affect on the older age group.

The researcher employed a ten point questionnaire, utilizing multiple choice, yes/no, and Likert Scale questions. For the 30 to 45 year old age group, the researcher included five extra questions



to find out that age group's philosophy toward services for the mentally retarded population.

After surveying and interviewing ten individuals from each age group to check validity of the questionnaire, the researcher sent questionnaires to the remaining thirty siblings. After a return rate of 66 percent was found, the researcher analyzed the data.

The limitations of this study included the relatively small number of actual participants; narrowing the research to one county; not being able to ascertain what specific level of retardation the disabled sibling had; and not specifying the specific ages of the survey participants. The researcher asked for general age groups (7 to 20 and 30 to 45), not specific ages.

### Description of Findings

#### Evaluation Instrument Used

The researcher graphed the percentages of each individual question to determine how each age group felt about certain issues and facts in their life and the differences of opinion between the two age groups. The following are graphs of percentages of answers as found by the researcher for questions one through ten. The graphed answers from questions eleven through thirteen appeared later on in chapter. These questions pertained solely to the older group of siblings.

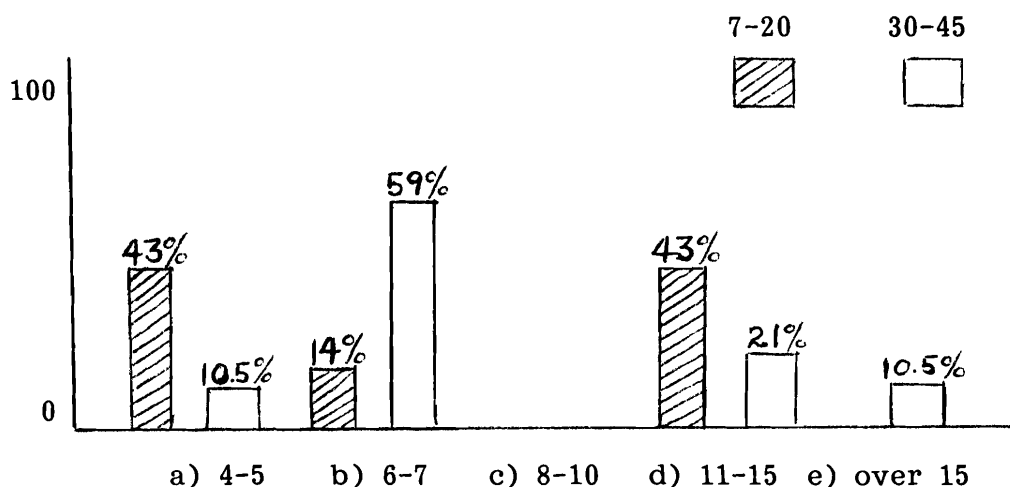
### Statistical Manipulation of Raw Data

#### Question #1

"I first knew there was something wrong with my brother/sister when I was":

Percentage

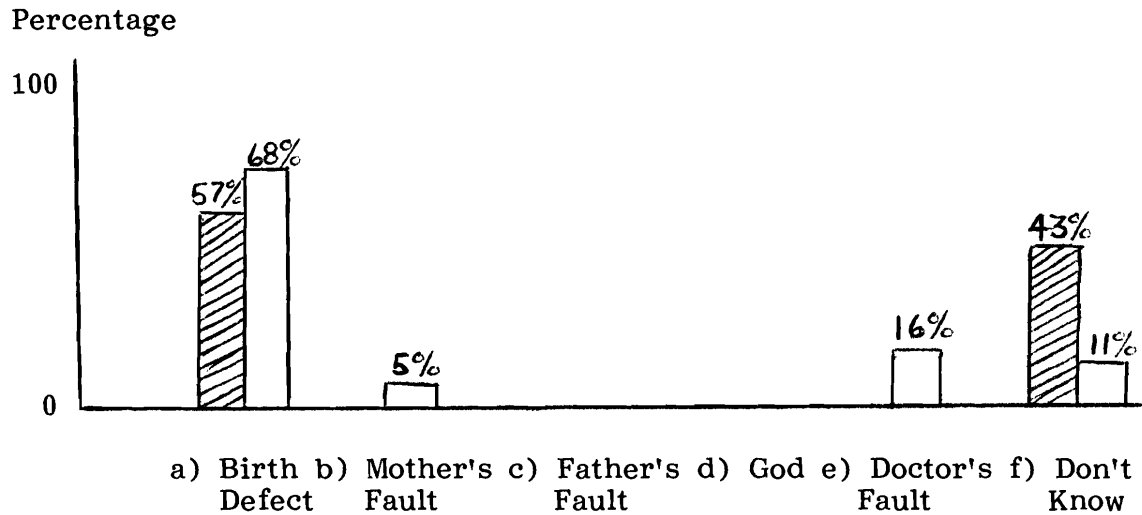
Note:



The researcher asked this question to ascertain whether one group became aware of their sibling's disability earlier in life than the other. From the presented data, the researcher realized that the older group of siblings appeared aware of the disability before the younger group.

## Question #2

"My brother/sister's condition happened because of":

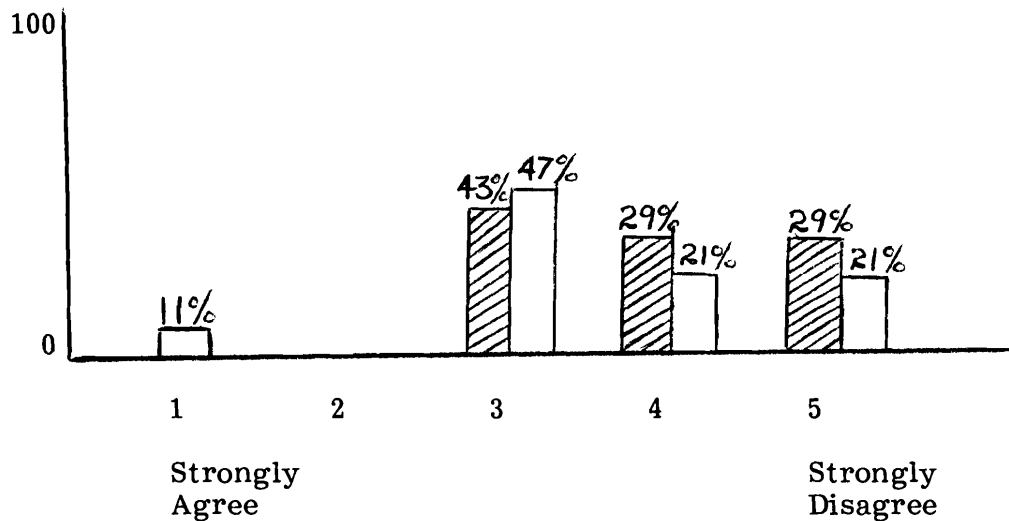


The researcher developed question number two to distinguish what caused the retardation in the minds of the two groups of siblings. According to the answers presented from the survey, both groups overwhelmingly concurred with the belief that the disability was caused by a birth defect. However, the older group of siblings appeared less structured in their answers, as they offered a few more opinions.

## Question #3

"Sometimes I feel that my mother and father pay (paid) more attention to my brother/sister than to me":

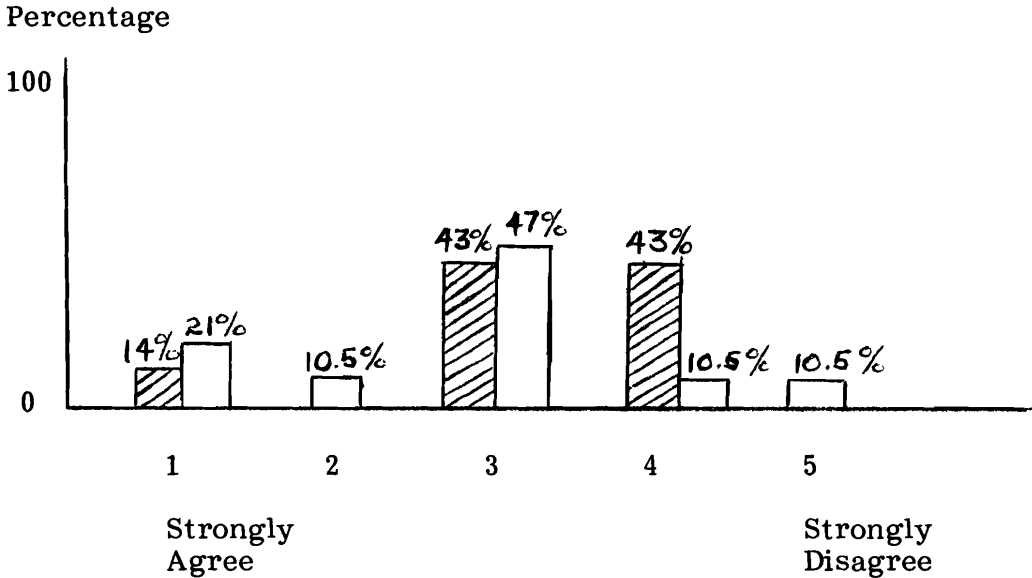
Percentage



Question number three was to establish the feelings of frustration on the part of the normal sibling in regard to family and parental relationships and if there was a difference between the two. The data presented indicated little differences of opinion between the two groups.

Question #4

"I feel (felt) that I must always protect my brother/sister from other people":

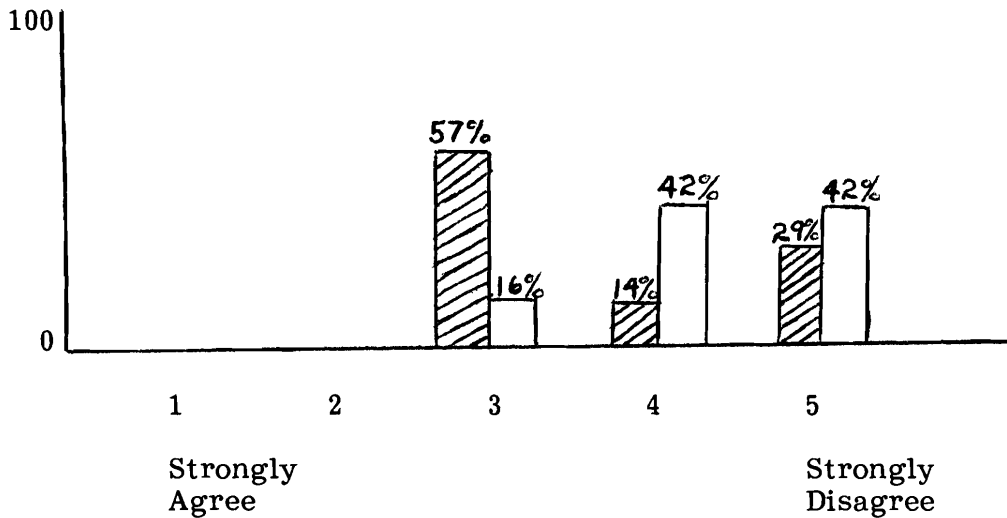


Question number four was developed to ascertain what differences were felt between the age groups in regard to feelings of having to protect their mentally retarded sibling from other people. The data suggests that there was a difference in opinion between the age groups in the form of a 17 percent difference in the "Strongly Agree" area and a 22 percent difference of opinion in the "Strongly Disagree" area.

## Question #5

"At times, I wish my brother/sister would go away forever":

Percentage

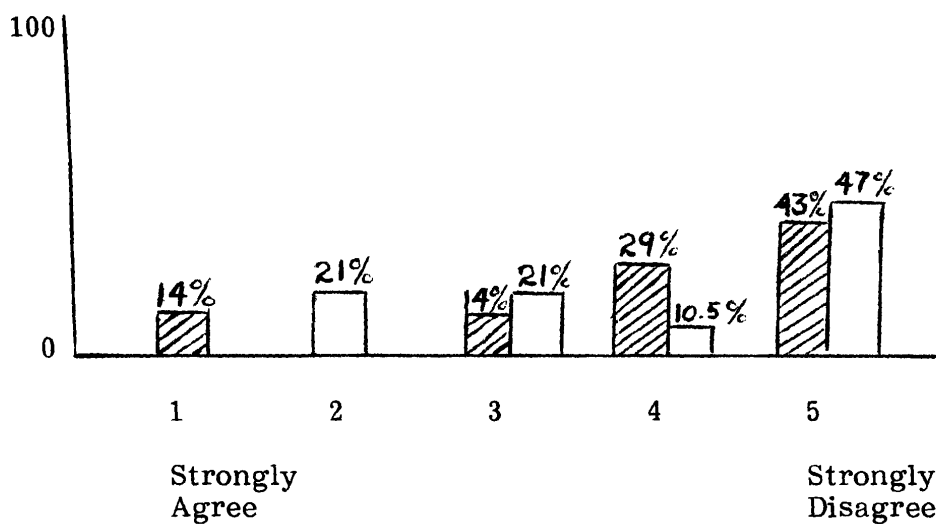


Question number five was to indicate any differences of opinion in regard to the love/hate relationship the age groups may have had for their mentally retarded sibling. The data presented in the middle area suggests that there was a difference of opinion between the two age groups.

## Question #6

"I feel (felt) embarrassed when I have (had) to go out with my brother/sister":

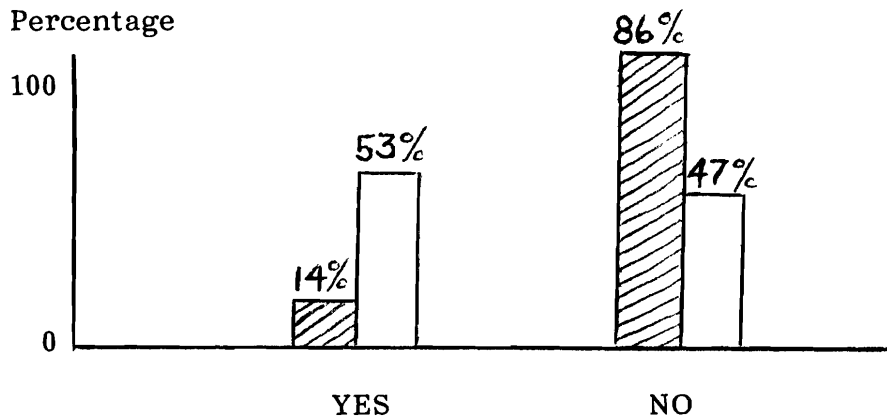
Percentage



The researcher developed question six to indicate how the two ages groups would feel about being seen in public with their mentally retarded sibling and how they might perceive public opinions. The researcher did not find any differences between the two age groups.

## Question #7

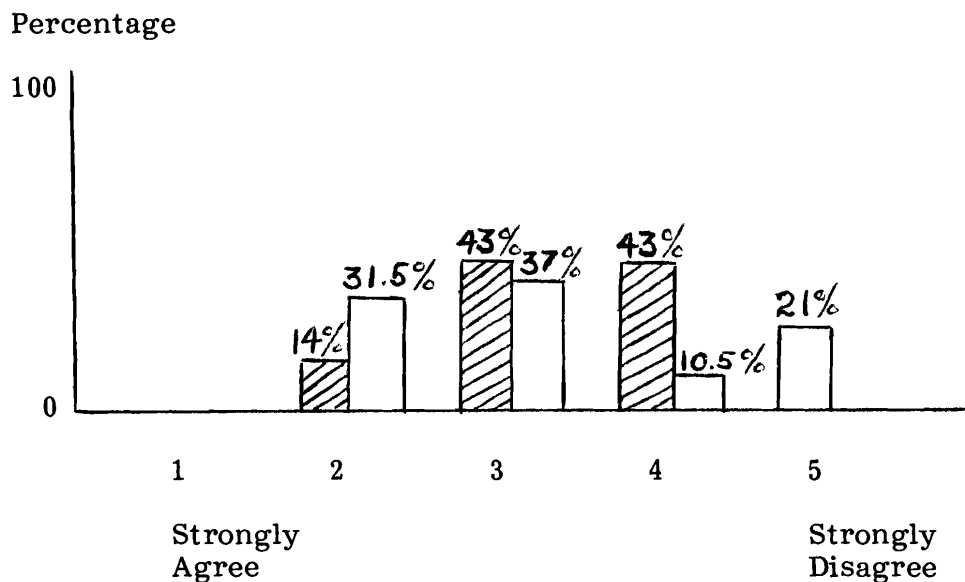
"Sometimes my mother and father would argue because of my brother/sister":



The researcher devised question number seven to learn how the normal sibling felt in regard to parental reaction to the mentally retarded sibling's disability. While it does not appear as though the younger age group recognized any significant problems, the older age group did.

## Question #8

"I think I love my brother/sister more because of his/her condition":



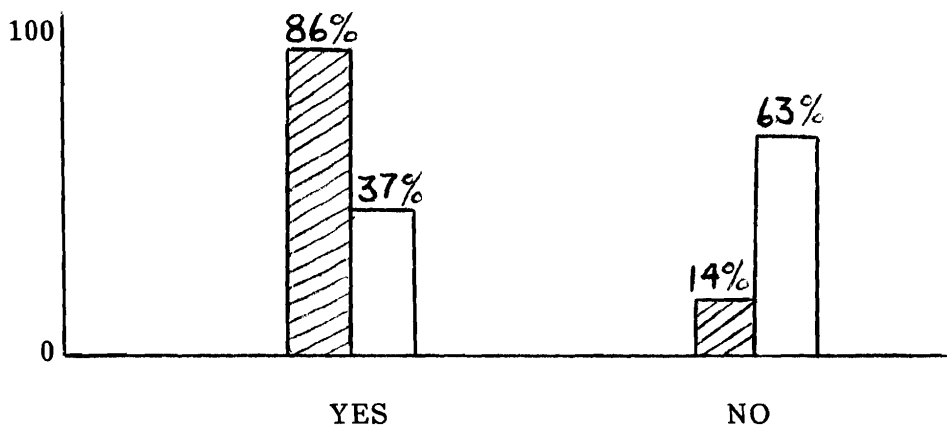


Question number eight was devised to ascertain how the two age groups felt about their sibling's condition and whether their love for their sibling was related to the mental retardation. The data suggested that there were very little differences of opinion between the two age groups.

Question #9

"My brother/sister goes (went) to a "special school" away from normal children":

Percentage

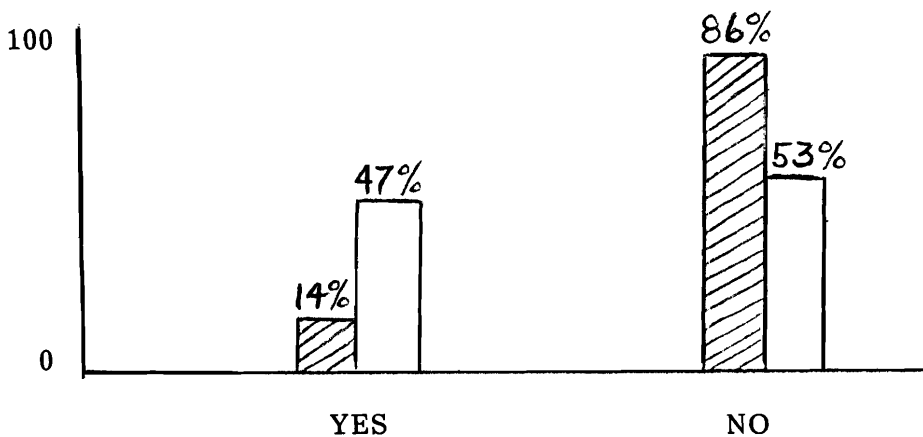


The researcher established this question to determine whether each of the age groups went to the same school as this sibling, thus suggesting the presence of mainstreaming. The researcher found very little agreement between the two age groups. The results also indicated a difference in regard to the researcher's hypothesis. Initially, the researcher assumed the older group of siblings would not have gone to the same school as their mentally retarded brothers and sisters and that the younger siblings would have. However, the results of the questionnaire indicated the opposite.

## Question #10

"I go (went) to the same school as my brother/sister":

Percentage



The researcher devised question number ten to go with question number nine. Essentially, the researcher wanted the respondents to merely "flip flop" the scores and then to find whether the presence of mainstreaming was still an issue. There was a 10 percent swing in the 30 to 45 year old group, which the researcher could not explain. In other words, the answers to question number ten should have been the same as number nine.

#### Findings for Evaluation Objective #1

Evaluation Objective #1 was to ascertain what percentage of the 30 to 45 year old population of siblings of a mentally retarded individual did not understand the concept of mainstreaming, did not philosophically believe in mainstreaming, and continued to harbor ill feelings toward society and the mentally retarded sibling due to feelings of guilt, contempt, or hatred because of the presence of a mentally retarded person in the immediate family. A secondary objective was to distinguish how 30 to 45 year old siblings felt about services and rights of the mentally retarded population on federal, state, and local levels.

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In regard to the concept of mainstreaming, the researcher found that 63 percent of the surveyed 30 to 45 year old age group went to the same school as their mentally retarded sibling, while 37 percent did not. This was contrary to the researcher's hypothesis. Given the generation and time frame of the 30 to 45 year old group, the researcher assumed that most mentally retarded children were sent to special schools, physically segregated from their normal counterparts. According to the survey, that was not the case. The researcher found that the concept of mainstreaming may have had very little affect in regard to the older age group's acceptance or rejection of the mentally retarded sibling.

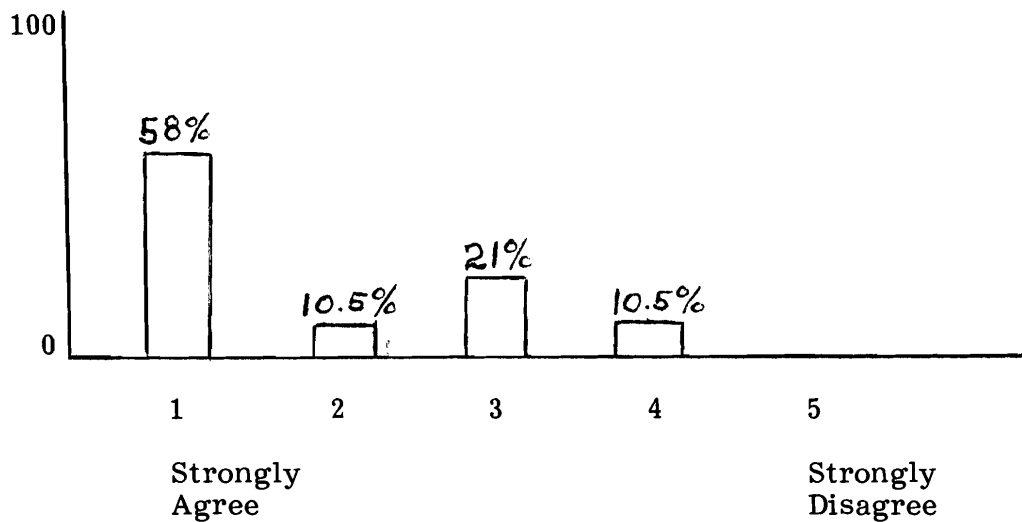
In regard to harboring ill feelings toward society in general and, more specifically, the mentally retarded sibling, the survey results indicated very little correlation with the researcher's hypothesis. The researcher found that 84 percent of the 30 to 45 year old age group surveyed strongly disagreed with question number five, which was designed to elicit such beliefs (please refer to question five on the preceding pages).

As to ascertaining the feelings of the 30 to 45 year old age group in regard to services and rights of the mentally retarded population, the researcher found a great deal of support among that age group. For example, 68.5 percent of those surveyed strongly agreed with the statement from question number twelve. Only 10.5 percent strongly disagreed:

## Question #12

"Mentally retarded individuals should be afforded the same opportunities as other persons":

Percentage

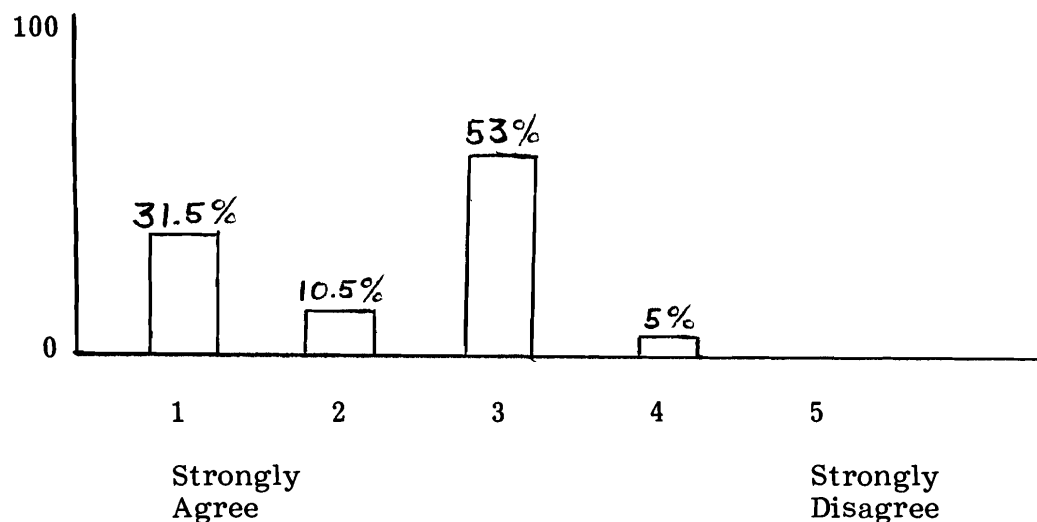


Concerning the issue of support services for the mentally retarded population and how the 30 to 45 year old age group felt about it, the researcher found 42 percent of the surveyed age group strongly agreeing that services should be provided, while only 5 percent strongly disagreed. 53 percent took the middle ground (see below).

## Question #13

"Federal, state, and local governments owe mentally retarded individuals a living":

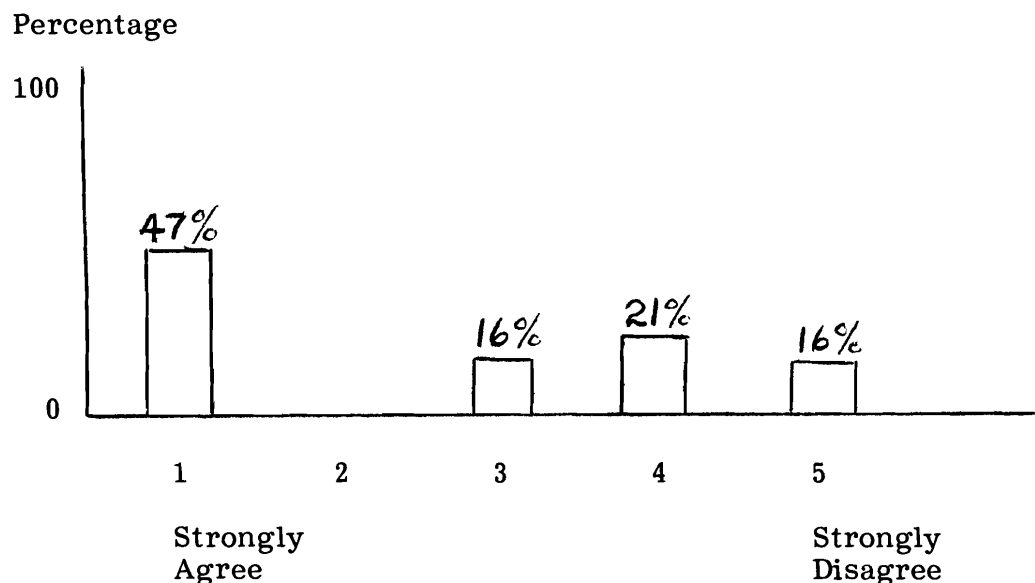
Percentage



On a corresponding issue, the researcher wanted to find what philosophy the 30 to 45 year old age group held in regard to institutionalization versus normalization. With this in mind, the researcher surveyed the age group with question number eleven:

## Question #11

"Profoundly to severely mentally retarded individuals can be better served by being institutionalized, thus surrounded by their own kind":



The researcher hypothesized that this age group would take the more conservative stand on this issue and state that profoundly and severely mentally retarded individuals should be institutionalized and placed with their own kind. The results appear to support that belief, although not as strongly as predicted.

#### Findings for Evaluation Objective #2

Evaluation Objective #2 was to find if the 7 to 20 year old age group appeared more accepting of the mentally retarded sibling because of the inception of mainstreaming. The researcher wanted to compare the results of this group to the older group of siblings.

In regard to the concept of mainstreaming, the researcher found that 86 percent of those persons surveyed in the 7 to 20 year old age group went to a different school from their mentally retarded siblings. This was contrary to the researcher's hypothesis. The researcher assumed that generation of siblings would have been more exposed to the ramifications of mainstreaming than any

other previous generation, thus allowing them more integration with their disabled counterparts. Apparently, however, that was not to be.

The researcher also hypothesized that the younger group would be more accepting of their mentally retarded sibling because of the difference in generations; that their generation was the first to experience mainstreaming and the concept of least restrictive environment from a very early age on. The researcher also hypothesized that youthful naivete would also have a bearing on the assumed attitude. The researcher's hypothesis was unfounded, as no real findings were actualized in any of the questions related to these issues.

#### Analyses of Findings/Conclusions

##### Evaluation Objective #1

Evaluation Objective #1 was to ascertain what percentage of the 30 to 45 year old population of siblings of a mentally retarded individual did not understand the concept of mainstreaming, did not philosophically believe in mainstreaming, and continued to harbor ill feelings toward society and the mentally retarded sibling due to feelings of guilt, contempt, or hatred because of the presence of a mentally retarded person in the immediate family. A secondary objective was to distinguish how 30 to 45 year old siblings felt about services and rights of the mentally retarded population on federal, state, and local levels.

A related objective was to ascertain what percentage continued to harbor ill feelings toward society in general and the mentally retarded sibling in particular, and were those feelings of guilt, contempt, and frustration a result of not being exposed to the concept of mainstreaming as was their younger counterpart.

## Conclusion

Based on the data received from the survey, the researcher realized that the assumed hypothesis did not correlate with the findings. While the hypothesis indicated that the 30 to 45 year old age group would be ignorant or naive about mainstreaming and the ramifications resulting from it, the researcher found an ambivalent philosophy. This ambivalent philosophy was indicated by answers to the survey questions. For example, the researcher found that 63 percent of those surveyed went to the same school as their mentally retarded sibling and an overwhelming 84 percent strongly disagreed with the statement, "At times, I wish my brother/sister would go away forever."

In regard to harboring ill feelings toward society in general and their mentally retarded sibling in particular, the data indicated the 30 to 45 year old age group disagreed with the researcher's hypothesis. Yet, the age group also indicated embarrassment and hurt when, as children, other people would make fun of their disabled sibling. Eighty-one and one-half percent of those responding strongly agreed with the statement, "As a child, I remember being both embarrassed and hurt when people made fun of my brother/sister."

The researcher realized that the initial hypothesis did not correlate with the results of the survey. However, the survey did indicate some harboring of insecurity on the part of the 30 to 45 year old siblings. There appeared to be contradictory beliefs, especially in regard to services. On one hand, the age group



believed that mentally retarded persons should receive services through federal, state, and local governments, yet on the other hand, they believed that certain mentally retarded individuals should be housed in institutions, away from the mainstream of society.

In regard to not experiencing mainstreaming and whether it had an effect on the age group, the researcher found no evidence supporting the original hypothesis.

The results of the survey, however, did indicate to the researcher that persons in this age group should be afforded services from agencies that work with the mentally retarded population. This could be accomplished through initiating a sibling support group or by offering informational seminars to this age group to assist them in realizing the kinds of support services that may be available to them and their mentally retarded siblings.

#### Evaluation Objective #2

Evaluation Objective #2 was to find if the 7 to 20 year old age group appeared more accepting of the mentally retarded sibling because of the inception of mainstreaming. The researcher wanted to compare the results of this group to the older group of siblings.

#### Conclusion

Through the data provided by the questionnaire, it was found that the researcher's hypothesis did not correlate with the results of the survey. The researcher hypothesized that the 7 to 20 year old age group would be more accepting of their disabled brothers

and sisters because of the advent of mainstreaming. The data suggested that this was not the case. 86 percent of those surveyed indicated that they went to a separate school from their mentally retarded sibling. Because of this, the researcher concluded that mainstreaming could not have impacted on this age group because of the segregation of school programs, as indicated in the survey.

In regard to being more accepting of their disabled siblings and disabled people in general because of the attitude of social change and tolerance within the American society over the past twenty-five years, data suggested that there was no real difference between the two age groups. Both groups shared in the love for their siblings, regardless of the disability.

Even though the researcher's hypothesis did not correlate with the collected data, there was evidence that the younger generation of siblings would benefit from services, if for no other reason but to keep them aware of possible future responsibilities. The researcher concluded that the younger generation of siblings appeared to possess a more lackadaisical attitude in regard to some issues brought forth by the survey, as evidenced by oral responses by the target group.

### Summary/Recommendations

#### Policy Recommendations

Through the survey and literature review of this project, the researcher realized that many siblings of mentally retarded

individuals feel they have no alternatives or services available to them. Therefore, it is recommended that support groups be formed for siblings of mentally retarded individuals, especially in rural areas and especially with the younger siblings.

The researcher also recommends a closer look at the concept of mainstreaming and Public Law 94-142. Although the law states that handicapped students must be afforded an education in the least restrictive environment, it appears that mentally retarded students are not being provided with the same rights, as very, very few are actually mainstreamed into classrooms.

#### Future Research Recommendations

The researcher recommends that the survey conducted for this project be expanded to include more specific questions in regard to mainstreaming and its impact on the mentally retarded and normal population. The researcher realized, after the survey was complete, that more questions pertaining to schools and family would have assisted in this project in being more specific in regard to the feelings of siblings of mentally retarded individuals.

Like many research projects, this project raised more questions than it actually answered. For instance, why does the younger generation appear more ambivalent toward their disabled sibling than the other generation? Is it youthful naivete, or perhaps does

the younger generation lack the life experiences of the older, more mature generation?

Should another survey of this kind be performed in the future, this researcher suggests using a broader base and perhaps conducting the survey within regions and not one small rural county. To be sure, more information should be gleaned out of Milwaukee, Dane, or Brown County than from Shawano County.

This researcher also recommends that the next survey of this kind be more specific as to the actual ages of the participants. For instance, if there is a comparison between generations, ask the participants for their specific ages. Then analyze the data by specific ages, not by generations. This researcher's survey found that by grouping a wide range age group together, like the 7 to 20 year olds, the answers to the survey questions did not correlate as first assumed. Even though this researcher interviewed ten members from each age group, it became obvious that some disparities existed within the 7 to 20 year old group, even though the original ten interviewed validated the questionnaire.

Even though this project did not correlate with the researcher's hypothesis, this researcher considers it a success, due to the activity of otherwise inactive members of families of mentally retarded individuals. Some of the questionnaires were returned with comments and suggestions to local agencies about services that could and should be provided to the whole family with a

mentally retarded member. The researcher has taken these comments and suggestions for further study on a professional basis.

Unfortunately, however, we live in a day and age of program cuts and mandated balanced budgets. And even though the current federal and state administrations continue to provide "lip service" to the various disability groups, funding and spending cuts are taking the heart out of human services. Perhaps the day will come when the pendulum will swing back to a more level-headed perspective of human services. Until that time, we, the service providers and the people we serve, whether they are disabled by birth, act of God, human error, or by being a family member, will have to continue to speak out for all disabled people to ensure their rightful place in the American dream.

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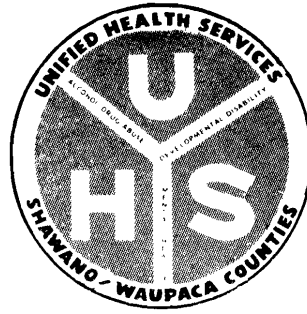
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**APPENDIX**

**Cover Letters and Copy of Survey**

# UNIFIED HEALTH SERVICES



October 31, 1985

Dear Family Member or Guardian:

As part of a Masters Thesis Project, Tom Madsen, D.D. Services Worker from our office has requested names and addresses of siblings of developmentally disabled individuals.

I am writing to ask two things of you: 1) to ask you to participate in this project and, 2) to seek your permission for Tom to mail a questionnaire for you and your child to complete.

Please be advised that neither your name or your child/sibling's name will be used in the Thesis and that all state laws regarding confidentiality will be strictly adhered to.

If you agree to participate in this project, please circle the item marked "yes" and write down your name, address and telephone number next to it and send this letter back in the enclosed self-addressed stamped envelope. Tom will then be contacting you by mail with the questionnaire.

Should you have any questions regarding this project, please feel free to contact either Tom or myself at 526-5547 or 823-6531. Your assistance in this project will be greatly appreciated. Thank you.

Sincerely,

Denise Jansen  
Developmental Disabilities Case Manager

TBM:als  
Enc.

\*\*\*\*\*

Yes, I will participate in the above mentioned project.

Name	Address	Telephone (optional)
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**Administrative Office**  
10 Tenth Street  
P.O. Box 119  
Shawano, WI 54929-0119  
Phone: 715-823-6531  
715-526-5547

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**Richard H. Eggleston, M.S.**  
Executive/Program Director

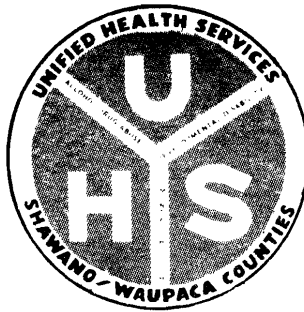
**Charles Hillman, M.S.**  
Executive Program Director

**Thomas Dornfeld, M.S.**  
Administrations Administrator

**Barbara Larson, B.S.**  
Developmental Disabilities  
Coordinator

**Robert Wolf, CPA**  
Financial Manager

UNIFIED  
HEALTH  
SERVICES



November 5, 1985

Administrative Office  
10 Tenth Street  
P.O. Box 119  
Shawano, WI 54929-0119  
Phone: 715-823-6531  
715-526-5547

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Charles H. Eggleston, M.S.  
Executive/Program Director

Charles Hillman, M.S.  
Executive Program Director

Thomas Dornfeld, M.S.  
Operations Administrator

Barbara Larson, B.S.  
Developmental Disabilities  
Coordinator

Robert Wolf, CPA  
Financial Manager

Dear Family Member or Guardian:

As part of a Masters Thesis Project, Tom Madsen, D.D. Services Worker from our office has requested names and addresses of siblings of developmentally disabled individuals.

I am writing to ask two things of you: 1) to ask you to participate in this project and, 2) to seek your permission for Tom to mail a questionnaire for you and your child to complete.

Please be advised that neither your name or your child/sibling's name will be used in the Thesis and that all state laws regarding confidentiality will be strictly adhered to.

If you agree to participate in this project, please circle the item marked "yes" and write down your name, address and telephone number next to it and send this letter back in the enclosed self-addressed stamped envelope. Tom will then be contacting you by mail with the questionnaire.

Should you have any questions regarding this project, please feel free to contact either Tom or myself at 526-5547 or 823-6531. Your assistance in this project will be greatly appreciated. Thank you.

Sincerely,

Trudy Kluba  
Early Intervention Specialist

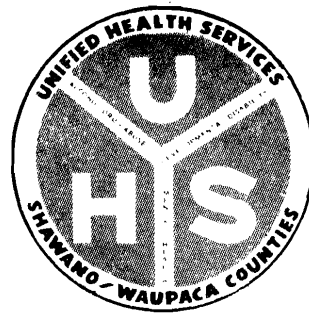
TBM:als  
Enc.

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Yes, I will participate in the above mentioned project.

Name Address Telephone (optional)

# UNIFIED HEALTH SERVICES



November 7, 1985

Dear Family Member or Guardian:

I am a student completing a Master's Degree program in Health Services Administration through Cardinal Stritch College in Milwaukee. One of the requirements for graduation is to submit a research project for approval from the academic staff. I have chosen to assess the effects of having a mentally retarded brother or sister on the siblings of that person.

I am asking for your assistance. At your convenience, could you or your son or daughter please fill out the enclosed questionnaire and return it in the enclosed self addressed stamped envelope. Please be assured that confidentiality will be strictly adhered to.

I am employed at Unified Health Services as the Developmental Disabilities Services Worker and have worked with DD clients for a good number of years. Your assistance and comments are greatly appreciated. If you have any questions, please feel free to call me at 526-5547 or 524-4571. Thank you.

Sincerely,

*Thomas B. Madsen*

Thomas B. Madsen  
Developmental Disabilities Services Worker

TBM:als

Administrative Office  
10 Tenth Street  
P.O. Box 119  
Milwaukee, WI 54929-0119  
Phone: 715-823-6531  
715-526-5547

\*\*\*

Edward H. Eggleston, M.S.  
Executive/Program Director

Charles Hillman, M.S.  
Deputy Program Director

Annis Dornfeld, M.S.  
Communications Administrator

Barbara Larson, B.S.  
Developmental Disabilities  
Coordinator

Robert Wolf, CPA  
Financial Manager

Please fill out the questionnaire and return it in the enclosed self-addressed stamped envelope. Thank-you!

Circle one: 7 - 20 years old

30 - 45 years old

1. I first knew there was something wrong with my brother/sister when I was:

- a) 4 - 5 years old
- b) 6 - 7 years old
- c) 8 - 10 years old
- d) 11 - 15 years old
- e) Over 15 years old

2. My brother/sister's condition happened because of:

- a) A birth defect
- b) My mother's fault
- c) My father's fault
- d) God wanted it
- e) The doctor's fault
- f) I don't know

3. Sometimes I feel that my mother and father pay (paid) more attention to my brother/sister than to me.

Strongly Agree

Strongly Disagree

1            2            3            4            5

4. I feel (felt that) I must always protect my brother/sister from other people.

Strongly Agree

Strongly Disagree

1            2            3            4            5

5. At times, I wish my brother/sister would go away forever.

Strongly Agree

Strongly Disagree

1            2            3            4            5

6. I feel (felt) embarrassed when I have (had) to go out with my brother/sister.

Strongly Agree

Strongly Disagree

1            2            3            4            5

7. Sometimes my mother and father would argue because of my brother/sister.

a) Yes

b) No

8. I think I love my brother/sister more because of his/her condition.

Strongly Agree

Strongly Disagree

1            2            3            4            5

9. My brother/sister goes (went) to a "special school" away from normal children.

a) Yes

b) No

10. I go (went) to the same school as my brother/sister.

a) Yes

b) No

If you are 30 or older, please complete the rest of the questionnaire.

11. Profoundly to severely mentally retarded individuals can be better served by being institutionalized, thus surrounded by their own kind.

Strongly Agree

Strongly Disagree

1            2            3            4            5

12. Mentally retarded individuals should be afforded the same opportunities as other persons.

Strongly Agree

Strongly Disagree

1            2            3            4            5

13. Federal, state and local governments owe mentally retarded individuals a living.

Strongly Agree

Strongly Disagree

1            2            3            4            5

14. Mental Retardation is:

- a) A genetic defect
- b) A social defect
- c) God given
- d) An environmental defect

15. As a child, I remember being both embarrassed and hurt when people made fun of my brother/sister.

Strongly Agree

Strongly Disagree

1            2            3            4            5

If you should have any comments in regard to the contents of this questionnaire or something we failed to ask, please use the space below. If you need more, please use the back of this paper. Again, thank-you very much for your time and effort.