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Attitudes of families of mentally retarded individuals toward deinstitutionalization.

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ATTITUDES OF FAMILIES OF MENTALLY RETARDED INDIVIDUALS TOWARD DEINSTITUTIONALIZATION

by

Mark William Benner

A thesis
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THESIS COMMITTEE

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ABSTRACT

Deinstitutionalization is a concept affecting the lives of many mentally retarded individuals and their families. Although the deinstitutionalization movement has been sanctioned and supported by government ministries and many professionals in the field of mental retardation, there is a growing belief that families of the mentally retarded individuals do not always accept the concept of community living. Few studies were found which specifically attempted to describe or identify family members' attitudes toward the deinstitutionalization of their mentally retarded relatives.

This research project is a quantitative-descriptive study of the attitudes of family members of mentally retarded individuals toward deinstitutionalization.

A total of 67 family members of mentally retarded individuals who have been discharged from the Oxford Regional Centre, Woodstock, Ontario, and placed in a community residence responded to a questionnaire designed to elicit their attitudes toward deinstitutionalization.

Just over half of the family members were initially happy about deinstitutionalization but the majority reported being presently happy about deinstitutionalization.

The family members' attitudes toward several variables concerning the discharge process, the rehabilitative capabilities of their mentally retarded relatives and community living were identified as being associ-

ated with their attitudes toward deinstitutionalization. Most of the family members were satisfied with the manner in which their mentally retarded relatives were discharged and most felt their mentally retarded relatives were capable of increased learning and development in the community residence. Similarly, most family members felt the community placement offered more to their mentally retarded relatives than did the institution. Many family members were concerned about public exploitation and what would happen to their mentally retarded relative when they were no longer alive.

As a result of the review of literature and the research findings of this study, several implications and recommendations for social workers involved with families of the mentally retarded are developed.

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Without the assistance of the sample of the families of the mentally retarded individuals, this study would not have been possible and I wish to thank them for their time and help in completing the questionnaires.

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Chapter I

PROBLEM IDENTIFICATION AND FORMULATION

1.1 PROBLEM IDENTIFICATION

Mental retardation is a social problem which manifests itself in the lives of a number of individuals even though the prevalence of mental retardation is only 1 percent of the general population (See Note 1). The consequences of mental retardation are not however, confined only to the mentally retarded individuals themselves but where the effects proliferate into the lives of the other family members. A chronic question for families of the mentally retarded has been "If my mentally retarded relative cannot live at home, where can s/he live and receive adequate and humane care?" Many families have attempted to resolve this question by placing their relative in an institution for the mentally retarded.

In the past, when a family institutionalized its mentally retarded family member, it was generally expected that the placement represented the best available solution and that it would be a permanent placement (Stedman, 1979). Families generally adopted the notion that they could be assured that their mentally retarded family member would receive adequate care for life in the institution.

During the past ten years, increasing emphasis has been placed on community living for the mentally retarded. From this emphasis grew the deinstitutionalization movement which includes the process of returning or discharging previously institutionalized mentally retarded persons to community settings. Thus families of the mentally retarded are, in increasing numbers, being faced with either the possible or actual discharge of their mentally retarded relative from large institutions to smaller community residences.

This study has developed from the researcher's interest and experience in the field of mental retardation and more specifically, from his work with parents and families of the mentally retarded. Through both direct and indirect involvement and experience in discharging a number of mentally retarded individuals from institutions to community settings, the researcher became interested in how the parents and family members of these deinstitutionalized mentally retarded persons actually felt about the discharge and the fact that their mentally retarded relative was living in a community residence.

Social workers in institutions for the mentally retarded are generally the direct implementers of the deinstitutionalization process where they are active in initial service procurement, pre-discharge preparations and post-discharge follow-up. As well, social workers generally maintain the most direct contact with families of the mentally retarded. Thus it is important for social workers to know and acknowledge the family's attitudes and concerns regarding deinstitutionalization in order to make the transition from institution to community successful for both the mentally retarded individual and his/her family.

Although many professionals actively support the concept of deinstitutionalization of mentally retarded persons, there is a growing belief that parents and families of such persons are questioning the concept of deinstitutionalization and community living. Researchers have acknowledged that parents may be in opposition to deinstitutionalization and have even pointed out that research is needed to assess their attitudes (Meyer, 1980; Roos, 1980). As yet, few studies have attempted to satisfy these suggestions.

1.2 PROBLEM FORMULATION

Macdonald (1960), in speaking of social work research stated:

> the function of social work research is to contribute to the development of a dependable body of knowledge to serve the goals and means of social work in all its ramifications. (p. 1)

By determining the attitudes of family members toward the deinstitutionalization of their mentally retarded family member, social work's body of knowledge can be augmented to better serve this population of families.

Ripple (1960) also spoke of social work research stating that:

> the purpose of all problem-solving efforts is to move from a situation characterized by doubt or ambiguity to a situation in which the uncertainties have been removed. (p. 24)

This study is an attempt to remove the uncertainty, doubt and ambiguity manifested in professionals' views toward families' attitudes toward the deinstitutionaliation of their mentally retarded family member.

In the development of this project, several research questions were developed:

1. Do family members agree with community living for their mentally retarded relative?

2. What are the family's concerns regarding the fact that their mentally retarded relative is living in the community?
3. Are family members satisfied with the actual discharge process from an institution to a community residence?
4. Do family members agree that their mentally retarded relative is capable of living successfully in a community residence?

To accomplish the goals of this research project, the researcher reviewed the relevant literature and identified major concerns of family members regarding community living for their mentally retarded relatives. These concerns will be found in chapter two. Also, in chapter two, the researcher will present the development of the deinstitutionalization movement in Ontario, review the definitions of deinstitutionalization, and examine the effects of deinstitutionalization on families of the mentally retarded. Finally, in this chapter, social work's role in the field of mental retardation and specifically, in the deinstitutionalization process will be reviewed.

In the third chapter of this study, the research design, the rationale for its selection, the development of the data gathering instrument and the method of data collection will be presented. Also, in this chapter, a description of the operational definitions, the sampling procedure and the limitations of the research design will be found.

In chapter four, the results of the data analysis will be presented. The results of the questionnaires will be computer tabulated and analyzed using the Statistical Analysis System. The demographic characteristics of both the responding family members and the discharged mentally retarded individuals will be described statistically as well as the respondents' attitudes toward the questionnaire statements. Finally, the research hypotheses will be discussed.

The findings of the study in relation to the available literature will be discussed in chapter five.

In the final chapter, chapter six, the major findings of the research study will be summarized and its limitations recognized and discussed. Implications of the research will be discussed and recommendations will be made for social workers involved in working with families of those mentally retarded persons who are about to be discharged from institutions to community residences. Finally, recommendations for further research will be suggested.

Chapter II

REVIEW OF LITERATURE

2.1 HISTORICAL PERSPECTIVE

Institutions for the Mentally Retarded

In order to define and understand the concept of deinstitutionalization and its goals, it is necessary to illustrate the very concept which deinstitutionalization attempts to counteract - that is institutionalization.

Historically, the institutionalization of mentally retarded persons has attempted to serve several purposes. Institutions have been used to "cure" the mentally retarded, to protect the mentally retarded from the rest of society and to protect society from the mentally retarded.

During the 1920's, commitment to an institution was seen as appropriate in order to protect the family from the burden and disruptive influence of having a mentally retarded family member. The purposes of institutions during this period were threefold:

> 1. to meet the basic life needs of a mentally retarded person,
> 2. to shelter that person from the demands of a competitive society, and
> 3. to relieve society of the burden of dealing with the mentally retarded individual. (Gollay, Wyngaarden & Kurtz, 1978, p. 10)

During the 1950's and 1960's, it was realized that in many cases, mentally retarded people were capable of learning and doing things of which they were earlier assumed to be incapable.. The mentally retarded were slowly being seen as being capable of rehabilitation and community care was increasingly being viewed as a desireable alternative to permanent institutionalization.

The deinstitutionalization movement has its roots during this period, where the features of institutional life for the mentally retarded became the conditions which the community care movement attempted to overcome. The features of institutional living have been described as deindividualized and regimented where a large number of people are segregated from the rest of society with little autonomy (Wolfensberger, 1971, p.14).

Ontario Developments

In 1971, Walter B. Williston presented a landmark document reporting the arrangements for care and supervision of mentally retarded persons in Ontario to the Ontario Ministry of Health. He described many of Ontario's institutions for the mentally retarded as large, overcrowded, and isolated. These institutions emphasized custody and life-long commitment rather than training, rehabilitation or environment enrichment (Williston, 1971, p. 65).

Williston recommended that the large hospital institutions for the mentally retarded be phased down as quickly as was feasible and pointed out the following advantages of the smaller residential community facilities:

> 1. they are more humane,
> 2. the mentally retarded can much more easily be integrated into society,
> 3. they are very inexpensive as compared with an institution. (Williston, 1971, p. 76)

In 1974, parliament enacted the <u>Developmental Services Act</u> which provided a legislative base for initiating a program toward community living for the mentally retarded in Ontario. The new Ministry of Community and Social Services became the co-ordinating ministry for services to the mentally retarded which provided for a change in emphasis from institutional to community living for them. The objective of the Ministry of Community and Social Services became the implementation of many of the recommendations and suggestions of the "Williston Report" (1971) and the Government's Green Paper, "Community Living for the Mentally Retarded in Ontario: A New Policy Focus" (1973). These two reports emphasized the importance of:

> 1. developing a new community orientation whereby comprehensive services for the handicapped would be available close to home rather than in a remote situation.
> 2. rehabilitating, whenever possible, residents of facilities for the retarded into new or expanded community services. (Ministry of Community and Social Services, 1974, p. 1)

The ministry developed a "reorientation mission", the targets or goals of which included the implementation of a new community orientation and a plan to de-emphasize long-term institutionalization. A long term goal became the planning and establishment of delivery systems providing local services that would enable the return of all persons capable of rehabilitation to their own communities. The Ministry estimated that they could reduce the institutional population by 50% within 5 years (Ministry of Community and Social Servies, 1974, p. 4).

The Ministry recognized the need to complement this community thrust with an expansion, promotion and improvement of community-based resources and services that would service those returning to the community from the mental retardation institutional facilities.

Thus by 1974, the Ontario government had committed itself to the deinstitutionalization movement through its adoption of policies to phase down large and remote institutions while simultaneously developing a wide range of community based services. This commitment can be illustrated by a reduction of 1,150 residents of provincial facilities for the mentally retarded between the years of 1974 to 1980 (Ministry of Community and Social Services, 49th Annual Report, 1980).

The Ministry's commitment to normalization and deinstitutionalization was adopted by each of Ontario's Schedule I facilities. The setting for this study, the Oxford Regional Centre, is one of 17 Ontario Schedule I facilities. The goals and philosophy of the Oxford Regional Centre reflect this commitment through its aim to:

> assist every client/resident as far as he can along the continuum from dependency to independent living and re-entry into community life. (Oxford Regional Centre, Standards for Care, Treatment and Training Manual, 1978)

2.2 DEINSTITUTIONALIZATION

In reviewing the literature, many definitions of deinstitutionalization were found. The term deinstitutionalization has come to mean anything from the negative concept of "dumping" vast numbers of unprepared, formerly institutionalized mentally retarded persons into unprepared community neighbourhoods to the positive concept of integrating prepared, formerly institutionalized mentally retarded persons into communities which will foster social and emotional growth and fulfillment.

Scheerenberger (1974) has stated that deinstitutionalization involves three interrelated processes:

> 1. the prevention of admission by finding and developing alternative community methods of care and training,
> 2. the return to the community of all residents who have been prepared through programs of habilitation and training to function adequately in appropriate local settings, and
> 3. the establishment and maintenance of a responsive residential environment which protects human and civil rights and which contributes to the expeditious return of the individuals to normal community living, whenever possible. (p. 8)

For the purposes of this research, the researcher accepts the concept of deinstitutionalization as expounded by Scheerenberger in numbers 2 and 3 above. Specifically, deinstitutionalization has been viewed as the process of returning or discharging rehabilitated, formerly institutionalized mentally retarded persons to community settings which emphasize their individuality and basic human rights.

There are three philosophical concepts which are implicit in the policy of deinstitutionalization. Bruininks (1980) describes these concepts as: 1) normalization, 2) the least restrictive alternative, and 3) the developmental model of programming.

Normalization

The principle of normalization implies that all developmentally disabled persons should be treated and have access to ways and experiences that are as normal as possible. This includes living in a community setting. Speaking of deinstitutionalization and normalization, Ferrara (1979) has stated that:

> implicit in the success of deinstitutionalization efforts is the assumption that retarded individuals will, after training, acquire behaviour patterns that will ensure their full or partial integration into the 'normal' life setting and will be able to meet some or all of the expectations of society. (p. 145)

Sproger (1980) has suggested that there are positive changes in mentally retarded persons after they have been discharged to community settings. Sproger (1980) contends that "normal environments" enhance personal growth and competence where, "persons in these environments seem more spontaneous, energetic and happier than their institutionalized counterparts" (p. 200).

However, there are opposing views concerning the normalization principle. The researcher contends that to lead as much of a "normal" life as possible is recognized as an inherent human right. It is a right to live in a community and it is a recognized right to have access to community services. In opposition, the researcher points out that some discharged mentally retarded persons can be given this right to normalized living only to lead lonely, unproductive lives with little community support or orientation. Menolascino (1978) has challenged those in mental retardation not to "dump" mentally retarded persons onto communities as was done by some professsionals in the mental health field (p. 599).

The term normalization does not attempt to testify that mentally retarded persons are "normal". They will always require special needs and services, perhaps even more when placed in the community. The researcher contends that normalization, and specifically community living, as a human right is imperative and essential, but is dependent upon the capabilities of the individual, his/her subsequent training and the support services available to him/her in the community.

Least Restrictive Alternative

The second concept which Bruininks describes as being implicit in the policy of deinstitutionalization is the concept of the least restrictive alternative. This concept suggests that of the possible services and living arrangements, the one selected should be the least limiting or confining (Bruininks, 1980, p. 57).

Again, the researcher points out that the mentally retarded require specialized services, and that although the services and living arrangements should not unnecessarily confine, restrict or limit, they should, as is with the normalization principle, be dependent upon the capabilities of the individual and support services available to the mentally retarded individual.

Developmental Programming

The concept of developmental programming is based on the belief that all developmentally disabled individuals have the potential for increased growth, learning and development (Bruininks, 1980). This concept contradicts the belief that the conditions of mental retardation are permanent and challenges the approach that the mentally retarded need to be protected from an abundance of roles and situations (Downey, 1963).

This concept is perhaps the most pivotal aspect when considering deinstitutionalization. This potential for increased growth, learning and development may suggest that a mentally retarded person can reach a maximum potential in the institution, but still be capable of growing, learning and developing to meet a higher potential in the community. This "developmental potential" is an essential component of the principles of normalization and the least restrictive environment, but again is dependent upon the capabilities of the individual and the available support services.

In order to focus the review of the available literature, the researcher has made the assumption that deinstitutionalization can be an acceptable, if not an advantageous alternative to life-long institutionalization of mentally retarded persons. This assumption is based on two fundamental suppositions. One assumption is that those discharged have been adequately trained and prepared for life in the community. Another assumption is that the community and the residences themselves will adequately support and promote the orientation and integration of the discharged individual into the community. It is assumed by the researcher that after placement, there will be sufficient follow-up services, supervision and continued training and rehabilitation.

A concensus of opinion is found in the literature where the authors agree that deinstitutionalization represents more than a simple physical removal of a mentally retarded person from an institution. It has been long recognized that deinstitutionalization requires a personal transition for the mentally retarded person; a transition between institutional life and the community. Researchers have begun to consider the community's attitudes, including their resistances to having mentally retarded persons placed in their neighbourhoods (Kastner, Repucci & Pezzoli, 1979). Researchers are just beginning to appreciate that the families of the mentally retarded must also be considered when proposing deinstitutionalization (Meyer, 1980; Stedman, 1979; Menolascino, 1979; Bradley, 1978; Willer, Intagliata & Atkinson, 1978; Payne, 1976). Stedman (1979) states that a bonding process between person, family and community is required to assure successful deinstitutionalization. Professionals and researchers in the field of mental retardation are now beginning to acknowledge and consider this necessary "bonding".

2.3 DEINSTITUTIONALIZATION AND THE FAMILY

Scheerenberger (1976) has stated that present parents of the mentally retarded can be divided into two groups:

> 1. those whose retarded children have been born within recent years and who are receptive to the idea of maintaining their child in the local community, and
> 2. those whose retarded children were born a number of years ago and are now confronted with the prospect of deinstitutionalization. (p. 167)

The focus of this review of literature and subsequent study has been focused on parents and families of the second group or more specifically, those families who institutionalized their mentally retarded family member in the past and are now confronted with the fact that their family member has been returned to the community via the process of deinstitutionalization.

Stedman (1977) has considered the factor of "family undoing" when completing the process of deinstitutionalization. He believes that "family undoing" refers to the fact that deinstitutionalization generally involves "a painful reversal and revisitation of earlier decisions to separate the child from the family" (p. 8). Therefore, to understand fully the impact of deinstitutionalization on the family, it is necessary to consider the impact of the initial diagnosis of mental retardation and the subsequent institutionalization.

Diagnosis represents perhaps the most difficult crisis event for families of the mentally retarded. From the diagnosis, many parents may consider their child as abnormal, permanently handicapped and even inhuman. Typical reactions include guilt, grief, denial, repression, and overprotectiveness (Willer, Intagliata and Atkinson, 1978, p. 2).

Parents are frequently told to institutionalize their child as soon as possible and to forget that they ever had the child (Gollay et. al, 1978). The child is seen as a burden to the family and institutionalization is seen as a solution to the problem of raising and caring for the child.

There have been many studies which have focused on the parental and familial reactions and attitudes toward the institutionalization of a mentally retarded family member (Fotheringham, Skelton & Hoddinott, 1972; Caldwell & Guze, 1960). Family homeostasis can be threatened and parents have been shown to encounter feelings of guilt and failure when a member is institutionalized (Willer et al., 1978, p. 12).

As with the study by Willer et al. (1978), Klaber (1969) describes the self-images of the parents of institutionalized mentally retarded individuals as a poor one, where parents see themselves as overprotective, neglectful, guilt-ridden and ineffectual (p. 178).

In the past, when a family institutionalized its mentally retarded member, the institution generally represented the only available alternative to family care. Community residences and community support services were not as abundant as they now are. Thus, the family made the decision to institutionalize the mentally retarded relative, convincing themselves that it was a legitimate decision. Then they continued with their lives, satisfied that the mentally retarded member would be cared for for life in the institution. Now an institutional employee, which is generally a social worker, initiates the notion that their family member can indeed function in the community and the family may feel guilty that they perhaps had made a mistake in institutionalizing the individual. Few people appreciate being shown or proven wrong, which can in effect, be what parents or families perceive.

Willer, Intagliata and Atkinson (1980) describe deinstitutionalization as a crisis event for families and feel that this crisis event is predictable on the basis of how the family dealt with past crisis periods including diagnosis and institutionalization.

Although the deinstitutionalization movement has been sanctioned and supported by government ministries and professionals in the field of mental retardation, there is a growing belief that parents of mentally retarded individuals do not always accept the concept of community living. As Williston (1971) had predicted over 10 years ago:

> many parents who have become accustomed to having their problems stowed a long way away would now be shocked at the prospect of the return of their child. (p. 69)

Over the past 10 years, this prediction has become a reality to many parents.

This parental or familial opposition to the trend toward deinstitutionalization has been described as the "parent veto" (Turnbull & Turnbull, 1975), "a barrier to deinstitutionalization" (Menolascino, 1977) and "the deinstitutional backlash" (Payne, 1976). In speaking of "Canadian Developments", Roeher (1980) has stated that

> parents inherently do not want to move their offspring from the setting in which they are settled, even when the situation is less than reasonable or ideal. (p. 178)

Several authors have attempted to determine parents' and families' attitudes toward the possible deinstitutionalization of their mentally retarded family member. Several researchers have studied the parents of institutionalized mentally retarded individuals and their attitudes toward deinstitutionalization (Meyer, 1980; Halpin, 1973; Payne, 1972). The concensus of these researchers and their subsequent writings has been that families and parents of mentally retarded individuals do not always agree that normalized community living is an acceptable alternative to a life-time in an institutional setting.

As Ferrara (1979) pointed out, there is a discrepancy between what parents think and what professionals think parents think. In the case of deinstitutionalization, the discrepancy lies in the fact that, although professionals and their agencies may support the concept, and believe that parents and families do likewise, in reality parents are not always in agreement with community living for their mentally retarded family members.

For example, in Halpin's "Family Survey" in 1973 of families of mentally retarded individuals living at the Rideau Regional Centre, Smith Falls, Ontario, well over one-half indicated that they did not wish to discuss any type of relocation. In fact, only 19.2% of the families surveyed were interested in the relocation of the family member to their community in suitable accommodation (1973, p. 22).

Meyer's study of attitudes of parents of institutionalized mentally retarded individuals seven years later duplicated the findings of Halpin (1973). Meyer's survey of parents found 83% believing that the larger institution was the best presently available placement for their mentally retarded children (1980, p. 186).

In reviewing the literature, a mulititude of authors suggested that parents and families of mentally retarded persons are not passively accepting the movement of their family members from institutional to community settings. With this thought in mind, it is notable that no studies can be found which specifically attempt to determine and assess the attitudes of these parents and family members towards the movement of their mentally retarded family members after the discharge has taken place. There have been many assumptions with very little concrete research testing.

Researchers have identified few consistent variables which appear to influence parents' or families' attitudes toward either normalization or deinstitutionalization. Ferrara (1979) found that age, sex and level of retardation of the child have no significant effect on parents' attitudes toward normalization activities. In his use of variables which included relationship to resident, age of respondent, sex, age, functioning level of the resident and length of institutional care, Meyer (1980) found the only significant variable to be the age of the respondent, where younger respondents were more likely to prefer community placement.

2.4 FAMILY REACTIONS TO THE RELEASE

Numerous authors have discussed the reactions of family members to the release of a mentally retarded relative from an institution. Schodek, Liffiton-Chrostowski, Adams, Minihan and Yamguchi (1980) have stated that deinstitutionalization challenges the family's adaption and stability to the mentally retarded individual which was gained through institutionalization. Bergman (1975) echoed this belief when he described deinstitutionalization as a potential threat to family balance that had been gained while the mentally retarded person was removed from the family through institutionalization. These thoughts are in contradiction to the research by Fotheringham (1970) who found that families who institutionalized their child showed no changes in family functioning over the year since the child had been admitted.

In their studies of families of deinstitutionalized mentally retarded persons, Willer et al. (1978) found the primary emotion was guilt and the feeling of inadequacy in institutionalizing the individual in the first place. Many families feared that after placement in a community residence, the next step might be placement back in the family's home.

Turnbull and Turnbull (1975) explained the family's emotion of guilt in terms of the family's perception that discharge to a community placement could mean that other persons are capable of caring for their mentally retarded family member in the community while they themselves are not. Thus, deinstitutionalization could confirm their feelings that they are failures as parents or failures as supportive family members.

Parents frequently are concerned that community residences do not offer the protection and security of the large, government-operated institutions. Bradley (1978) has reported that parents protest that private or community agencies make no long-term commitment to their children and that parents seriously desire assurance that the state will continue to advocate for their children. Parents view the institutional setting as a stable, secure, permanent and progressive provider of care (Schodek et al., 1980; Bergman, 1975). Parents also strongly agree that a large institution is better for retarded persons simply because it is the "tried and tested way" of caring for them (Payne, 1976).

Meyer (1980) described parents' satisfaction with the care provided by institutions serving the mentally retarded. Literature has described parents' concerns regarding the supervision, protection, security, and safety on a 24-hour basis which they feel the institution provides to a greater extent than does a community placement (Baker & Seltzer, 1977; Bergman, 1975). Parents may resist community placement because of an overconcern for the safety of the mentally retarded person. Institutional settings are also seen as a means of protecting the mentally retarded person from the stresses of community life (Payne, 1976).

The concentration of mental retardation experts and the availability of medical and behavioural specialists are other reasons cited by parents as reasons why their mentally retarded children should remain in an institutional setting (Meyer, 1980; Payne, 1976). Klaber (1969) has noted that parents perceive institutional "attendents" in unrealistically favourable and even "quasi-religious" terms which he describes as a reality distortion.

Many families regard their mentally retarded family member as happy and well-adjusted in the institution, not wishing to have him/hér adjust to a new life in the community (Meyer, 1980). In arguments favouring the institution, parents have stated that mentally retarded individuals are happier among other mentally retarded persons, feeling that it would be upsetting for them to have to interact with other members of the community (Payne, 1976; Klaber, 1969).

Many families strongly feel that their mentally retarded family member has reached his/her potential in the institution and is incapable of functioning in the community (Meyer, 1980). Families often resist community placement while underestimating the mentally retarded person's abilities and learning potential. These two thoughts challenge the "developmental model" which suggests that the mentally retarded have the potential for increased growth, learning and development.

Ferrara (1979), when studying parents' attitudes toward normalization activities, found that parents are more positive toward normalization activities when the reference is to the mentally retarded in general, rather than when the reference is specific to their child. Parents therefore, may accept a general concept but they may not accept its implication to their specific child.

It is essential to note these parental or familial reactions to the release of a mentally retarded family member from an institution. Intrinsic to these reactions are the realistic and practical implications of discharging a previously institutionalized person to a community setting. These reactions must be acknowledged and considered when considering the movement of a mentally retarded person from an institutional to community setting.

2.5 FAMILY CONCERNS REGARDING COMMUNITY CARE

The literature has pointed out that when faced with the possibility or actual reality of the deinstitutionalization of a mentally retarded relative, many families have expressed their thoughts and concerns about the future care of their family members in the community.

Stedman (1977) has suggested that most families, when institutionalizing their mentally retarded relatives, assume that the institution will be a permanent placement. Their concerns for the future of their relative are dulcified by the guarantee that the stable, protective and perpetual nature of the institution will care for the relative for life. After placement in the community, many parents see these guarantees being forfeited.

A study conducted by Gollay et al. (1978) revealed that families often perceive institutional training to use community resources as inadequate. Families question the stability and availability of community resources and services. Many families fear that their mentally retarded family member may be exploited in the community and that the community may not even accept the relative (Bradley, 1978).

When considering the future care of their mentally retarded child in the community, an alarming concern of parents is what will happen to their child when they are no longer alive, especially if the present community placement proves unsuccessful or inadequate. This fear or concern does not limit itself to the parents of the mentally retarded, but also manifests itself in the concerns of siblings. Schodek et al.(1980) have stated:

> upon the deaths of both parents, a sibling is often expected to take a more active role which, for someone who has never done so, can be very anxiety-provoking. (p. 70)

Like the family reactions to the release of their mentally retarded family member from the institution, it is imperative to note family concerns regarding the future care of the relative in the community. Like the family's reactions, these fears, concerns and hesitations are realistic and concrete and suggest some of the objective issues related to the movement of mentally retarded persons from institutional to community settings.

2.6 FAMILY INVOLVEMENT IN DEINSTITUTIONALIZATION

According to Downey (1963), professional evaluation of the family's role in the rehabilitative process has produced contradictory therapeutic directives:

1. the family is a disruptive force and a permanent separation of the patient and family is advised, or

> 2. the family is a positive, therapeutic agent and intimate relations should be maintained. (p. 186)

To understand fully the family's involvement in deinstitutionalization, it is necessary to review the family's involvement in the institutionalization of its mentally retarded family member. In many instances, family involvement in institutionalization appears to be representative of Downey's first directive where parents are advised to institutionalize their mentally retarded child as soon as possible and then told to forget they ever had the child (Gollay et. al., 1978). Thus, family involvement with the mentally retarded family member after institutionalization may not be supported, either by the family members themselves, or the institution. Families therefore, can be totally unaware of their relative's activities, and the prospect of community living may pose a complete surprise or even shock to them.

Family involvement in the deinstitutionalization process, according to Schodek et. al. (1980):.

> ranges from the families' passive receipt of the information that deinstitutionalization is about to take place to their active support of or oppposition to the individual's anticipated move into the community. (p. 67)

The family is being seen, more and more, as a positive and therapeutic agent in the rehabilitative process. The importance of parental attitudes in the habilitation and treatment of the mentally retarded is increasingly being recognized, although a study of families of discharged mentally retarded persons by Willer et. al. (1978) concludes that the families "felt little control and received little or no information or preparation" (p. 17).

Turnbull and Turnbull (1975) have discussed the institution's role in preparing parents for deinstitutionalization in terms of an emerging legal problem. Bradley (1978) has stated that involvement of the client and guardian in the selection of service and residential setting contributes to the success of predischarge planning.

The family of the mentally retarded should be consulted, counselled and informed regarding the standards and accountability of community residential programs. The advantages as well as the fears about community life should be addressed. Ferrara (1970) has cited studies which indicate that:

> parental attitudes can not only influence children's behaviour, but can, in fact, undermine the acquisition of behaviour skills identified by legislators and professionals as being desirable. (p. 147)

In his study of parents of institutionalized mentally retarded individuals, Payne (1976) found strong agreement from parents that if both institutional and community facilities were available, the parents should have the right to decide where their mentally retarded child should live. Payne found even a stronger assertion that:

> parents should always be consulted, but that professional staff who work with the retarded person daily should make the final decision of what is the best residential facility for that person. (p. 44)

In order to successfully monitor, evaluate, diagnose and plan service, the client and his/her family should be involved in the deinstitutionalization process. Schodek et. al. (1980) have stated that the family can represent a constant source of support for the mentally retarded individual, especially at a time when ties are being changed from institution to community. If the individual looks to his/her family for support, their involvement in the deinstitutionalization process should be maximized. There should always be a family-resident relationship assessment to determine the degree of family involvement where levels of family involvement should be determined on a case-by-case basis.

The concensus of various authors is that families of mentally retarded persons who have been discharged to community residences should be actively involved in the selection of service and residential settings before the discharge takes place (Meyer, 1980; Schodek et al., 1980; Stedman, 1979; Bradley, 1978; Payne, 1976). If the family contact since institutional admission has been minimal or non-existent, an attempt may be made to re-acquaint the family with the mentally retarded family member. Research has shown that families generally do desire involvement and several authors have suggested that this involvement can represent a source of support to the discharged mentally retarded individual (Schodek et al., 1980; Payne, 1976; Stedman, 1976). It is important that the family's fears and concerns about becoming involved be realized and counselling should be provided to assure the family that the community placement is or was done in the mentally retarded person's best interest.

2.7 SOCIAL WORK INVOLVEMENT IN DEINSTITUTIONALIZATION

Proctor (1976) feels that the traditional emphasis of social work in working with parents and families of the mentally retarded has been limited to intervention at the time of diagnosis. She has stated that:

> social work practice and theory, then, may not have moved far beyond issues related to diagnosis, and may reflect a view of retardation as an irreversible, relatively static condition to

> which acceptance at times, and resignation, seems the only possible responses. (p. 260)

Beck (1969) has also remarked on mental retardation and the profession of social work, suggesting that a "seeming lack of promise of returns from work in the field of mental retardation has hampered professional involvements" (p. 101).

Social work practice, despite its numerous opportunities, has not concerned itself to any great depth with the issues of mental retardation. Nonetheless, social workers in institutions for the mentally retarded are seen as the mandated implementers of the deinstitutionalization process. Social work's preoccupation with individuals and their families and social environments appears to depict the very core of the deinstitutionalization movement. Social workers therefore, must begin to acknowledge the vast opportunities for practice in the field of mental retardation, and more specifically, in regard to the issue of deinstitutionalization and community living for the mentally retarded.

In a study conducted by Lippman (1977), respondents which included both parents and social workers perceived a need for social workers to provide counselling and other helping services to mentally retarded persons and their families. In his study which included families of discharged psychiatric patients, Goldstein (1979) pointed out that "parental expectations were more realistic in those parents who had high-intensity social work involvement" (p. 357). Parents can be used as collaborators in the helping process and as a potential support system. Schodek et al. (1980) felt that deinstitutionalization challenged family stability and represented a reversal of family policy. They felt that this had several implications for the social worker's role with families. They stated that:

> the social worker must acknowledge the reversal, explain the reasons behind the change, and elicit its impact on families whose resident members are being considered for community placement. (p. 70)

The role of social work is best described as the "liason" between the family and the institution. The family should be kept involved in the planning with the mentally retarded family member and social workers should be responsible for communicating and negotiating with the family, the decisions and plans that concern the mentally retarded individual.

Social work involvement in deinstitutionalization thus represents the "untapped potential". The role of social work is unlimited in not only helping to prepare the actual individual who is about to be discharged, but also in preparing the family members whose support is recognized as being so very important. Social work involvement in deinstitutionalization can elicit the concerns and attitudes of families when confronted with the issue of community living, helping the family to accept the movement as an acceptable and advantageous alternative to continued institutionalization.

2.8 SUMMARY

The researcher has endeavoured to provide the reader with a brief history of the development of Ontario's deinstitutionalization movement. The concept of deinstitutionalization was defined as well as the major philosophical concepts implicit in the policy of deinstitutionalization. Through the review of literature, the major concerns of family members regarding community living for their mentally retarded relatives and the effects of deinstitutionalization on the families of the mentally retarded were presented. The role of social work in the field of mental retardation and its specific role in deinstitutionalization was reviewed.

The subsequent chapter will detail the research design and methodology involved in this study of family members' attitudes toward deinstitutionalization.

Chapter III

METHODOLOGY

This chapter discusses and explains the research design and methodology that were used in this study. Specific topics to be discussed are: classification of the research, research questions and hypotheses, operational definitions, the population, the sample, the development of the instrument and its administration and the limitations of the study.

3.1 CLASSIFICATION OF THE RESEARCH

In the development of the methodology of this study, the researcher used a.quantitative-descriptive design of the population description and hypotheses testing subtypes.

Tripodi, Fellin and Meyer state that a general purpose of the quantitative-descriptive study is that of describing quantitative relations among specified variables, where there are two objectives:

> 1. to measure a series of specific variables in order to answer specific questions posed by the research study,
> 2. to search for relationships among disignated variables in order to articulate more precise hypotheses for subsequent investigation. (Tripodi et al., 1969, p. 24-35)

This research study includes two methods to accomplish its objectives and can be classifiable into two subtypes of research. The research study is amenable to the subtypes of population description and hypotheses testing research. Tropodi et al. have defined population description studies as

> those quantitative-descriptive studies which have as their primary function the accurate description of quantitative characteristics of selected populations, organizations, or other collectivities. . .some of these studies are descriptive of characteristics of designated populations such as roles, functions, needs, attitudes, and opinions. (Tripodi et al, 1969, p. 42)

Tripodi et al. have defined hypothesis testing studies as

> those quantitative-descriptive studies which contain in their design of research explicit hypotheses to be tested. The hypotheses . . . may be . . . statements of association between two or more variables without reference to a causal relationship. (1969, p. 39)

3.2 RESEARCH QUESTIONS

There were six specific research questions which were developed from the literature reviewed in Chapter II:

1. What are the demographic characteristics of the mentally retarded persons who have been discharged from the Oxford Regional Centre to a community residence?
2. What are the demographic characteristics of the family members of these mentally retarded persons?
3. What changes, if any was there in the family members' first reactions and present feelings concerning deinstitutionalization?
4. What are the family members' attitudes toward the discharge process?
5. What are the family members' attitudes toward the capabilities of the discharged mentally retarded individual?

6. What are the family members' attitudes toward community living for their mentally retarded relatives?

3.3 RESEARCH HYPOTHESES

In an attempt to describe the family members' attitudes toward deinstitutionalization, the following hypotheses were developed from the underlying concepts of the review of literature:

1. The family members' attitudes toward the following variables concerning the discharge process are associated with both their first reactions and present feelings concerning deinstitutionalization:
   a) the preparation and information they received regarding the discharge.
   b) the mentally retarded relative's readiness to be discharged when the discharge took place.
   c) the information and advice they received regarding the discharge.
   d) the training their mentally retarded relative received before being discharged.
   e) the say or control they felt concerning the discharge.
2. The family members' attitudes toward the following variables concerning the capabilities of the mentally retarded relative are associated with both their first reactions and present feelings concerning deinstitutionalization:
   a) the relative's potential to learn more in the community setting.

b) the relative's progress since discharge.

c) the relative's capabilities of learning more despite his/her level of retardation.

d) the relative's capabilities of living successfully in the community.

3. The family members' attitudes toward the following variables concerning community living are associated with both their first reactions and present feelings concerning deinstitutionalization:

a) normalized community living.

b) the effects of the discharge on their family.

c) the mentally retarded relative's quality of life in the community setting.

d) the personal attention their mentally retarded relative receives in the community setting.

e) the mentally retarded relative's opportunities for growth and learning in the community setting.

f) the care and supervision their mentally retarded relative receives in the community setting.

g) the services and professionals available in the community setting.

h) the strength of their relationship with their mentally retarded relative since discharge.

i) the number of friends their mentally retarded relative has in the community setting.

j) the adequacy of trained staff of community residences.

k) the protection offered by the community setting.

l) the care and programs available to the mentally retarded in the community setting.

m) their concerns regarding public exploitation.

n) their concerns regarding public acceptance.

o) their concerns about what will happen to the mentally retarded relative when they die.

p) their mentally retarded relative's happiness with other mentally retarded persons.

3.4 OPERATIONAL DEFINITIONS

An operational definition consists of "steps, actions, 'operations' one performs in order to relate the concept to events in the real world" (Polansky, 1975, p. 23). The following definitions will make explicit the meaning of the terms used within the context of this study.

Family members include one of the following: a mother, father, brother, sister, aunt, uncle, grandmother or grandfather.

The Oxford Regional Centre is a 554 bed institution for the mentally retarded which is operated by the Ontario Ministry of Community and Social Services. The centre is located near Woodstock, Ontario, and serves seven counties. The Centre ministers to the mentally retarded of all levels of retardation who are eighteen years of age or older. The aim of the Centre is to "assist every resident/client as far as he can along the continuum from dependency to independent living and re-entry into community life" (Oxford Regional Centre Standards for Care, Treatment and Training Manual, 1978, p. 1).

Deinstitutionalization involves "the return to the community of residents of institutions who have been prepared through programs of habilitation and training to function adequately in appropriate local settings". (Scheerenberger, 1978, p. 2)

The term community implies "the involvement of the mentally retarded with other members of society in programs that emphasize their needs as individuals". (Welch, 1973, p. 2) Community residences are generally small in size and number of residents and are located in community neighbourhoods. (Gollay et al., 1978)

Webster's Third International Dictionary (1976) defines an attitude as "behaviour representative of feeling or conviction: a disposition that is primarily grounded in affect and emotion and is expressive of opinions rather than belief". Shaw and Wright (1967) define an attitude as:

> a relatively enduring system of affective, evaluative reactions based upon and reflecting the evaluative concepts or beliefs which have been learned about the characteristics of a social object or class of social objects. (p. 16)

3.5 POPULATION

The population of this study is derived from family members of all the mentally retarded adults who were discharged from the Ontario Schedule I facilities. There are 17 Schedule I facilities in the province of Ontario. Schedule I facilities are operated by the Ontario Ministry of Community and Social Services and are legislated by the Developmental Services Act. These facilities are generally large in size, highly structured, often isolated and provide most of their care and programs within the grounds of the facility.

To be considered eligible for this population, the family member had to have a mentally retarded relative who met the following criteria:

1. The mentally retarded relative had to have been discharged to a community residence offering treatment programs, therefore excluding nursing home, parental, and "Homes for Special Care" placements.
2. The mentally retarded relative had to have been discharged during the period May 1, 1974 to March 31, 1981 and not been re-admitted to an institutional facility.
3. The mentally retarded relative had to have been diagnosed as mentally retarded, therefore excluding psychiatric diagnoses.
4. The mentally retarded relative had to have been institutionalized for a minimum of one year.

These criteria were formulated under several assumptions. It was assumed that the mentally retarded person required a minimum of one year of institutionalization in order to benefit from any type of discharge planning and also in order for family members to become acquainted with institutional services and programmes.

It is recognized that a reduction in the number of individuals residing in institutions does not necessarily mean that the individual is no longer residing in an institutional setting. Many mentally retarded individuals are discharged or merely transferred to settings which are as large, restrictive, segregated, highly structured or sheltered as the institution from which they were discharged. Examples of these settings include nursing homes, chronic care hospitals, "Homes for Special Care", and Ontario Schedule II facilities for the mentally retarded. Thus, in order for the family members to compare the institutional residence and the community residence, only placements to community residences which offered treatment programmes were included. The assumption was made that without treatment programmes, community placements offer little community orientation or rehabilitative training. Psychiatric diagnoses were omitted as it was realized that these diagnoses could pose a realm of unique and distinct manifestations of their own.

3.6 SAMPLE

The sample consisted of 118 singular family members of mentally retarded persons who were discharged from the Oxford Regional Centre and who met the above criteria. The family members' names and addresses were obtained from the closed files of the Oxford Regional Centre. These family members were selected on their basis of being the mentally retarded individual's closest next-of-kin.

A purposive sampling procedure was utilized in this study. Concerning the purposive sampling type, Selltiz et al have stated:

> The basic assumption behind purposive sampling is that with good judgment and an appropriate strategy, one can handpick the cases to be included in the sample and thus develop samples that are satisfactory in relation to one's need. (Selltiz et al., 1976, p. 521)

The selection of a purposive sample permitted the researcher to choose cases which meet the above criteria as established by the researcher.

3.7 DEVELOPMENT OF THE INSTRUMENTS

The Case Review Schedule

The case review schedule was developed to gather information available from the Oxford Regional Centre. The information gathered included the age, sex, and level of retardation of the discharged mentally retarded person. The information also included the total number of years of institutionalization, date of discharge, and name and location of the community residence where the mentally retarded individual was discharged.

The Questionnaire

The questionnaire, as a data collection instrument was selected for several reasons:

1. it is relatively inexpensive,
2. it gathers required information quickly,
3. because of anonymity, respondents feel freer to express views, and
4. it places little pressure on the respondents for immediate response (Selltiz et al., 1976).

The questionnaire included demographic data regarding the responding family member such as relationship to the discharged individual, address by city, age, and frequency of visitation to both the former institution and present community residence.

The researcher developed a Likert-type questionnaire which included 2 statements adapted from Willer's *Family Questionnaire* (B), (1978). Several social workers with direct experience in the field of mental retardation were consulted in the development of the questionnaire.

Selltiz et al. have suggested several advantages to the likert-type scale:

> It permits the use of items that are not manifestly related to the attitude being studied...it is simple to construct...it is generally reliable... it permits the expression of several degrees of agreement/disagreement and it provides precise information...(Selltiz et al., 1976, p. 419)

The questionnaire statements were grouped into three categories as follows:

1. statements directed at family members' involvement, reactions and attitudes toward the actual dicharge process of the mentally retarded relative from the Oxford Regional Centre to the community residence.
2. statements directed at family members' attitudes toward the rehabilitative capacities of their mentally retarded relative, and
3. statements directed at family members' attitudes concerning the fact that their mentally retarded relative is now living in a community residence after living in an institution.

The questionnaire was standardized with a series of structured questions where respondents answered the same questions in the same order. The questions permitted only fixed alternative responses. Selltiz et al. state that

> a 'fixed alternative' (or 'closed') question is one in which the responses of the subject are limited to stated alternatives. These alternatives may be simply yes or no, or they may provide for indicating various degrees of approval or agreement. (1979, p. 310)

The alternatives which the family members could select were strongly agree, agree, undecided, disagree, strongly disagree and don't know. The "don't know" alternative was included as it was assumed by the researcher that there might be a significant number of family members who might not have sufficient information concerning the mentally retarded family member and his/her living arrangements in order to express any level of agreement or disagreement.

A section was included in the questionnaire which allowed the family members an opportunity to comment on areas which they might not have felt were included in the questionnaire.

When completed, the preliminary questonnaire was presented to five social workers with experience in working with the mentally retarded and their families. The questionnaire was also presented to the Oxford Regional Centre Research Committee. A total of 10 professionals with experience in working with the mentally retarded were asked to comment on the questionnaire's clarity, simplicity, and relevance. Appropriate changes, additions, and deletions were then made.

Because many of the names and addresses of the family members obtained from the Oxford Regional Centre were over 5 years old, it was expected that many of the family members might have died or moved leaving no forwarding address. Due to the age of these records, a low response rate was anticipated and the researcher chose not to reduce the available sample by using the family memebers in a pretest. Selltiz et al. have suggested that the pretest should ideally be in the form of personal interviews (1976). Due to time limitations and the fact that the family members were scattered throughout Ontario, the researcher felt that it would be difficult to contact and interview them.

One hundred and eighteen questionnaires were sent out. In an attempt to induce as great a response rate as was possible, the questionnaire included a stamped return envelope. Also, in an attempt to prompt the sample to complete the questionnaire, a covering letter with a hand-written signature, an explanation of the social utility of the research, and an appeal to help the researcher conduct and complete the study was included.

Two weeks after the questionnaires had been mailed, a second covering letter and questionnaire was mailed to those family members who had not yet returned their completed questionnaires.

3.8 INSTRUMENTATION

The questionnaire was designed so that statements could be scored on a five point scale. The five possible responses weighed 1-2-3-4-5 or 5-4-3-2-1. A score of five consistently represented a favourable attitude towards community living, the discharge process, and the rehabilitative capacities of the discharged mentally retarded individual. The continuum was reversed in approximately half the statements. That is, approximately half the statements were worded so that a strongly agree response indicated a favourable or positive attitude towards the three categories, while the other half of the statements were worded so that a strongly agree response indicated an unfavourable or negative attitude.

3.9 ANALYSIS OF THE DATA

The data obtained by the questionnaires were computer analyzed using the Statistical Analysis System. In the following chapter, the demographic characteristics of the discharged mentally retarded individuals and the responding family members will be described using frequency distributions.

The responding family members' attitudes toward the questionnaire's 25 statements will also be described with the use of frequency distributions.

The hypotheses were tested using the Spearman Correlation Test (Rs). The Spearman Rs was used because of its easiness to compute and because of its appropriateness in measuring the association between ordinal level variables (Siegel, 1956). Levels of significance of .05 and .01 were used in testing the various hypotheses.

3.10 LIMITATIONS OF THE RESEARCH DESIGN

There are limitations inherent in any research study. Several limitations of this particular research design have been recognized. Because the sampling method was purposive, the representativeness of the selected sample is determinant only to the extent that the Oxford Regional Centre sample approximates individuals discharged from other Ontario Schedule I facilities. Since all mental retardation facilities are sanctioned and regulated under one Government Ministry and one act of legislation, it is assumed that discharge practices and available community services are similar. Therefore, the external validity or the extent to which the results can be generalized beyond the specific sample is also relative to these assumptions. A larger sample, involving more institutional facilities, would have allowed freer generalizations of the findings.

Since the questionnaire was constructed of fixed-alternatives, respondents were not able to explain their answers or to introduce new ideas. With the use of this type of data- gathering instrument, the respondents may have been forced to choose a response that may not conform to their actual opinion.

Another recognized limitation originated from factors which might influence families' attitudes toward deinstitutionalization and which were beyond the control of the researcher. Issues such as past experiences with institutional or community personnel and personality factors of the discharged individual or the responding relative could have affected the respondents' attitudes toward deinstitutionalization.

Finally, because the questionnaire included a covering letter written on Oxford Regional Centre stationary and because it included an authorization statement from the Chief Social Worker of the Centre, the respondents' answers may have been positively influenced.

3.11 SUMMARY

This chapter examined the components of the research design and methodology used in the study.

The following chapter presents an analysis of the data.

Chapter IV

ANALYSIS OF DATA

4.1 INTRODUCTION

In this chapter, the data are presented in four major sections. In the first section, the characteristics of the discharged mentally retarded persons are described. In the second section, the characteristics of the sample population of responding family members are presented. In section three, the respondents' attitudes toward the questionnaire's statements regarding the discharge process, the capabilities of the discharged mentally retarded relative, and deinstitutionalization or community living are presented and described. In the fourth section, the associations between the respondents' attitudes toward the questionnaires' statements and their first reactions and present feelings concerning deinstitutionalization are described.

4.2 DESCRIPTION OF THE DISCHARGED INDIVIDUAL

Age

Mentally retarded individuals who were 30-39 years of age represented 44.78 percent of those who were discharged from the Oxford Regional Centre to a community residence. Figure 1 shows that 50 or 74.63 percent of the individuals were 20-39 years of age.

```
 AGE                                                 FREQ  CUM.  PERCENT   CUM.
                                                           FREQ            PERCENT
              |
 20-29        |********************                   20    20    29.85     29.85
              |
 30-39        |******************************         30    50    44.78     74.63
              |
 40-49        |*********                               9    59    13.43     88.06
              |
 50-59        |******                                  6    65     8.96     97.01
              |
 60-69        |*                                       1    66     1.49     98.51
              |
 70+          |*                                       1    67     1.49    100.00
              |
              -----+----+----+----+----+----+
                   5   10   15   20   25   30

                        FREQUENCY
```

Figure 1: Age of discharged individuals

mode = 30-39

Sex

Of the total discharged individuals, 55.22 percent were male and 44.78 percent were female. Figure 2 shows the sex distribution of the individuals.

```
SEX                                                          FREQ  CUM.   PERCENT   CUM.
                                                                   FREQ             PERCENT
       |
FEM    |******************************                        30    30     44.78     44.78
       |
MALE   |*************************************                 37    67     55.22    100.00
       |
       ----+----+----+----+----+----+----+--
           5   10   15   20   25   30   35

                     FREQUENCY
```

Figure 2: Sex of discharged individuals

mode = male

Level of Retardation

Figure 3 illustrates the frequency distribution of the five levels of retardation. It can be seen that there were 31 (46.27%) individuals that were diagnosed as moderately retarded. Mildly retarded individuals were represented by 23.88 percent of the individuals and severely retarded individuals constituted 13.43 percent of the individuals. The extreme high and low levels of mental retardation of borderline and profound retardation were represented by 11.94 percent and 4.48 percent respectively.

```
LEVEL                                                FREQ  CUM.   PERCENT    CUM.
                                                           FREQ             PERCENT
           |
PROFOUND   |***                                         3     3     4.48      4.48
           |
SEVERE     |*********                                   9    12    13.43     17.91
           |
MODERATE   |*******************************            31    43    46.27     64.18
           |
MILD       |****************                           16    59    23.88     88.06
           |
BORDERLINE |********                                    8    67    11.94    100.00
           |
           ----+----+----+----+----+----+
               5   10   15   20   25   30

                     FREQUENCY
```

Figure 3: Level of retardation of discharged individuals

mode = moderate

Length of Institutionalization

Of the total discharged individuals, 15 or 22.39 percent had been institutionalized for 15-19 years. Length of institutionalization ranged from 1 year to 35 years or more. Figure 4 shows that 71.64 percent of the individuals were institutionalized for 1-19 years.

```
YEARS                                          FREQ  CUM.   PERCENT   CUM.
                                                     FREQ           PERCENT
        |
 0-4    |**********************                 11    11    16.42     16.42
        |
 5-9    |************************               12    23    17.91     34.33
        |
10-14   |********************                   10    33    14.93     49.25
        |
15-19   |******************************         15    48    22.39     71.64
        |
20-24   |**********************                 11    59    16.42     88.06
        |
25-29   |******                                  3    62     4.48     92.54
        |
30-34   |**                                      1    63     1.49     94.03
        |
35+     |********                                4    67     5.97    100.00
        |
        ----+---+---+---+---+---+---+--
            2   4   6   8  10  12  14

                  FREQUENCY
```

Figure 4: Number of years in institution

mode = 15-19

Time in Community Residence

Figure 5 shows the frequency distribution of length of time since the individual was placed in the community residence. Of the total individuals, 62.69 percent have been living in the community residence less than 3 years.

```
YEARS                                                  FREQ  CUM.  PERCENT    CUM.
                                                             FREQ           PERCENT
       |
 <.1   |*******                                           7     7   10.45     10.45
       |
 2-3   |***********************************              35    42   52.24     62.69
       |
 4-5   |************                                     12    54   17.91     80.60
       |
 6-7   |*************                                    13    67   19.40    100.00
       |
       ----+----+----+----+----+----+----+
           5   10   15   20   25   30   35

                    FREQUENCY
```

Figure 5: Number of years since discharge

mode = 2-3

4.3 CHARACTERISTICS OF THE RESPONDENTS

Response Rate

Questionnaires were mailed to 118 family members of mentally retarded persons who were discharged from the Oxford Regional Centre to a community residence. Of the 118 questionnaires, several were unanswered or returned and were therefore unable to be used in the study. One questionnaire was unanswered because the mentally retarded person had been readmitted to the Oxford Regional Centre and therefore did not meet the sample requirements. One mentally retarded person was deceased and one mentally retarded individual had no living famiy members. One family declined to answer the questionnaire because of illness and 22 questionnaires were returned because the family had moved leaving no forwarding address. Therefore, a total of 93 family members were contactable. Of the contactable individuals, 67 questionnaires were returned, representing a response rate of 72.1 percent.

Age of Respondents

Of the total sample, 14 or 21.54 percent of the responding family members were within the 50-59 year age range, 25 or 38.46 percent were within the 60-69 year age range and 12 or 18.46 percent were within the 70-79 year age range. Thus the respondents were of an older age where 51 or 78.45 percent were 50 years of age or older. Figure 6 illustrates the age distribution of the respondents' ages.

```
YEARS                                               FREQ  CUM.   PERCENT     CUM.
                                                          FREQ              PERCENT
                |
30-39           |***                                   3     3     4.62       4.62
                |
40-49           |***********                          11    14    16.92      21.54
                |
50-59           |**************                       14    28    21.54      43.08
                |
60-69           |*************************            25    53    38.46      81.54
                |
70-79           |************                         12    65    18.46     100.00
                |
                -----+----+----+----+----+
                     5   10   15   20   25

                         FREQUENCY
```

Figure 6: Age of respondent

mode = 60-69

Relationship of Respondents

The respondents' relationships to the discharged mentally retarded person are illustrated by Figure 7. Figure 7 shows that 41 or 61.19 percent of the involved family members were mothers. Of the total respondents, fathers represented 13 or 19.40 percent. It can therefore be suggested that parents (80.59%) represented the majority of the responding relatives in the study.

```
RESPONDENT                                FREQ  CUM.   PERCENT     CUM.
                                                FREQ             PERCENT
            |
 BROTHER    |***                              5     5     7.46      7.46
            |
 FATHER     |*******                         13    18    19.40     26.87
            |
 MOTHER     |*********************           41    59    61.19     88.06
            |
 SISTER     |****                             7    66    10.45     98.51
            |
 UNCLE      |*                                1    67     1.49    100.00
            |
            ----+----+----+----+-
               10   20   30   40

                  FREQUENCY
```

Figure 7: Relationship of respondent

mode = mother

Visitation to Institution

The frequency of the respondents' visitation with the mentally retarded relative while living in the institution is illustrated by Figure 8. It is pertinent to note that 31 or 50.00 percent of the respondents visited 0-4 times per year where 3 respondents never visited at all.

```
VISITS/YEAR                                        FREQ  CUM.   PERCENT    CUM.
                                                         FREQ              PERCENT
            |
0-4         |*******************************        31    31     50.00      50.00
            |
5-9         |*********                               9    40     14.52      64.52
            |
10-14       |*************                          13    53     20.97      85.48
            |
15-19       |***                                     3    56      4.84      90.32
            |
20-24       |**                                      2    58      3.23      93.55
            |
25-29       |**                                      2    60      3.23      96.77
            |
30-34       |*                                       1    61      1.61      98.39
            |
35+         |*                                       1    62      1.61     100.00
            |
            -----+----+----+----+----+----+-
                 5   10   15   20   25   30

                     FREQUENCY
```

Figure 8: Frequency of visitation to institution

mode = 0-4

Visitation to Community Residence

The frequency of the respondents' visitation with the mentally retarded family member after discharge to the community residence is illustrated by Figure 9. After discharge, 29 or 50.88 percent of the respondents visited 0-9 times per year where 4 respondents had not yet visited the mentally retarded relative.

```
VISITS/YEAR
                                              FREQ   CUM.   PERCENT   CUM.
                                                     FREQ             PERCENT
               |
   0-4         |********************           20     20     35.09     35.09
               |
   5-9         |*********                       9     29     15.79     50.88
               |
   10-14       |*****************              17     46     29.82     80.70
               |
   15-19       |*                               1     47      1.75     82.46
               |
   20-24       |*                               1     48      1.75     84.21
               |
   25-29       |*                               1     49      1.75     85.96
               |
   30-34       |*                               1     50      1.75     87.72
               |
   35-39       |                                0     50      0.00     87.72
               |
   40 +        |*******                         7     57     12.28    100.00
               |
               -----+----+----+----+
                    5   10   15   20

                      FREQUENCY
```

Figure 9: Frequency of visitation to community residence

mode = 0-4

Distance From Residence

The distribution of distance between the home of the respondents and the community residence to where the mentally retarded relative was living is illustrated by Figure 10. The Figure shows that 18 or 27.27 percent of the respondents lived in the same city as their discharged mentally retarded relative and that 49 or 74.24 percent lived within 99 kilometers of the community residence.

```
DISTANCE (km)                              FREQ   CUM.   PERCENT    CUM.
                                                  FREQ              PERCENT
                |
   SAME CITY    |******************         18     18     27.27     27.27
                |
   < 49         |************               12     30     18.18     45.45
                |
   50-99        |*******************        19     49     28.79     74.24
                |
   100-149      |*********                   9     58     13.64     87.88
                |
   150-199      |****                        4     62      6.06     93.94
                |
   200-249      |                            0     62      0.00     93.94
                |
   250-299      |**                          2     64      3.03     96.97
                |
   300 +        |**                          2     66      3.03    100.00
                |
                -----+----+----+----
                     5   10   15

                      FREQUENCY
```

Figure 10: Distance from responding relative to community residence

mode = 50-99

Idea of Discharge

Of the total respondents, 38 or 56.72 percent indicated that the idea of discharging their mentally retarded family member came from an institutional social worker. Figure 11 illustrates that 15 or 22.39 percent of the respondents felt that the mentally retarded relative him/herself initiated the idea of being discharged. The Figure also shows that only 5 or 7.46 percent of the respondents felt that they themselves had the first idea. It is interesting to note that 6 or 8.96 percent of the respondents did not know who initiated the idea of deinstitutionalization.

```
-------------------------------------------------------------------------------

PERSON                                FREQ  CUM.   PERCENT    CUM.
                                            FREQ             PERCENT
               |
NO RESPONSE    |*                        1     1      1.49      1.49
               |
DON'T KNOW     |***                      6     7      8.96     10.45
               |
OTHER          |*                        2     9      2.99     13.43
               |
M.R. PERSON    |********                15    24     22.39     35.82
               |
RESPONDENT     |***                      5    29      7.46     43.28
               |
SOCIAL WORKER|*******************       38    67     56.72    100.00
               |
               -----+----+----+----
                   10   20   30

                    FREQUENCY
```

Figure 11: Who initiated deinstitutionalization

```
-------------------------------------------------------------------------------
                         mode = social worker
```

Reactions/Feelings to Deinstitutionalization

The first reactions of the respondents when they learned that their mentally retarded relative was to be discharged to a community residence are shown by Figure 12. It is interesting to note that 36 or 54.55 percent of the respondents were "happy" about the idea and that 30 or

45.45 percent of the respondents were either "not happy" (6.06%) or had "mixed feelings" (39.39%).

```
REACTION                                FREQ  CUM.   PERCENT   CUM.
                                              FREQ            PERCENT
                  |
NOT HAPPY         |**                      4     4      6.06     6.06
                  |
MIXED FEELING     |*************          26    30     39.39    45.45
                  |
HAPPY             |****************** 36    66     54.55   100.00
                  |
                  ------+----+----+---
                       10   20   30

                       FREQUENCY
```

Figure 12: First reaction to deinstitutionalization

mode = happy

The respondents' present feelings toward the fact that their mentally retarded family member was living in a community residence are shown by Figure 13. The Figure shows that 42 or 71.19 percent of the respondents were presently "happy" about the idea and that 17 or 28.81 percent of the respondents were either "not happy" (5.08%) or had "mixed feelings" (23.73%).

It is important to note the changes in the respondents' first reaction and their present feelings about community living for their mentally retarded relative. Of the 57 respondents who completed both

```
FEELING                                   FREQ  CUM.   PERCENT   CUM.
                                                FREQ             PERCENT
                |
NOT HAPPY       |**                          3     3     5.08      5.08
                |
MIXED FEELING   |*******                    14    17    23.73     28.81
                |
HAPPY           |*********************      42    59    71.19    100.00
                |
                ----+----+----+----+-
                   10   20   30   40

                     FREQUENCY
```

Figure 13: Present feeling concerning deinstitutionalization

mode = happy

questions about first reaction and present feeling about community living, 29 or 50.88 percent indicated that their first reaction was "happy" and that their present feeling was "happy". Table 1 illustrates that 11 or 19.30 percent of the respondents had a "mixed reaction" when community living was proposed but their present feeling changed to "happy". The Table also shows that 11 or 19.30 percent of the respondents remained to have a "mixed feeling" after the discharge. There were 2 respondents (3.51%) whose reaction of "happy" changed to a "mixed feeling" regarding community living. There was only 1 respondent (1.75%) whose reaction of "not happy" did not change. The Table also shows that there were 2 (3.51%) respondents whose first reaction of "not happy" changed to a present feeling of "happy" and only 1 (1.75%) respondent had a first reaction of "happy" which changed to a feeling of "not happy".

TABLE 1

First reaction versus present feeling

	PRESENT FEELING		
FIRST REACTION	NOT HAPPY	MIXED FEELINGS	HAPPY
NOT HAPPY	1 1.75%	0	2 3.51%
MIXED FEELINGS	0	11 19.30%	11 19.30%
HAPPY	1 1.75%	2 3.51%	29 50.88%

4.4 ATTITUDES TOWARD DISCHARGE PROCESS

The questionnaire included 5 statements aimed at determining the family members' attitudes toward the discharge process.

Preparation and Information

Figure 14 shows that regarding the discharge, of the 59 family members who responded to this statement, 37 or 62.71 percent of the respondents either disagreed (40.68%) or strongly disagreed (22.03%) that they were not given enough preparation and information regarding the discharge of their mentally retarded relative. Only 11 or 18.64 percent of the respondents either agreed (15.25%) or strongly agreed (3.39%) that they were not adequately prepared and informed concerning the discharge and 9 or 15.25 percent of the respondents felt they didn't know.

```
ATTITUDE                                   FREQ  CUM.   PERCENT    CUM.
                                                 FREQ            PERCENT
         |
     DK  |*********                           9     9     15.25     15.25
         |
     SA  |**                                  2    11      3.39     18.64
         |
      A  |*********                           9    20     15.25     33.90
         |
     UN  |**                                  2    22      3.39     37.29
         |
      D  |************************           24    46     40.68     77.97
         |
     SD  |*************                      13    59     22.03    100.00
         |
         -----+----+----+----+----
              5   10   15   20

                 FREQUENCY
```

Figure 14: Not given enough information and preparation

---

mode = disagree

Readiness to be Discharged

Figure 15 shows that of the 62 family members who responded to this statement 39 or 62.90 percent either agreed (46.77%) or strongly agreed (16.13%) that their mentally retarded relative was ready to be discharged when the discharge took place. Only 5 or 8.07 percent of the respondents either disagreed (3.23%) or strongly disagreed (4.84%) that their relative was ready to be discharged and 16.13 percent were undecided. A total of 8 or 12.90 percent of the respondents felt that they didn't know.

```
ATTITUDE                                              FREQ  CUM.   PERCENT   CUM.
                                                            FREQ             PERCENT
               |
       DK      |********                                 8     8    12.90     12.90
               |
       SD      |***                                      3    11     4.84     17.74
               |
        D      |**                                       2    13     3.23     20.97
               |
       UN      |**********                              10    23    16.13     37.10
               |
        A      |*****************************           29    52    46.77     83.87
               |
       SA      |**********                              10    62    16.13    100.00
               |
               -----+----+----+----+----+---
                    5   10   15   20   25

                        FREQUENCY
```

Figure 15: Relative was ready to be discharged

mode = agree

Information and Advice

Figure 16 shows that of the 61 family members who responded to this statement, 42 or 68.86 percent either agreed (57.38%) or strongly agreed (11.48%) that the institution had adequately informed and advised them regarding the discharge of their mentally retarded relative. A total of 14 respondents (11.48%) disagreed and an equal number strongly disagreed that they were adequately informed and advised regarding the discharge and 1 respondent felt that s/he didn't know.

```
ATTITUDE                        FREQ  CUM.   PERCENT    CUM.
                                      FREQ             PERCENT
              |
      DK      |*                   1     1     1.64      1.64
              |
      SD      |****                7     8    11.48     13.11
              |
       D      |****                7    15    11.48     24.59
              |
      UN      |**                  4    19     6.56     31.15
              |
       A      |******************  35    54    57.38     88.52
              |
      SA      |****                7    61    11.48    100.00
              |
              -----+----+----+---
                  10   20   30

                  FREQUENCY
```

Figure 16: Institution adequately informed and advised

---

mode = agree

Pre-discharge Training

Figure 17 shows that of the 55 family members who responded to this statement, 26 or 47.27 percent either disagreed (38.18%) or strongly disagreed (9.09%) that their mentally retarded relative did not receive enough training at the institution before being discharged to the community residence. Of the respondents, 10 or 18.18 percent either agreed (10.91%) or strongly agreed (7.27%) with the statement and 18.18 percent of the respondents were undecided. There were 9 or 16.36 percent of the respondents who felt they didn't know.

```
ATTITUDE                                  FREQ  CUM.   PERCENT    CUM.
                                                FREQ              PERCENT
                  |
         DK       |*********                 9     9     16.36     16.36
                  |
         SA       |****                      4    13      7.27     23.64
                  |
          A       |******                    6    19     10.91     34.55
                  |
         UN       |**********               10    29     18.18     52.73
                  |
          D       |*********************    21    50     38.18     90.91
                  |
         SD       |*****                     5    55      9.09    100.00
                  |
                  -----+----+----+----+-
                       5   10   15   20

                      FREQUENCY
```

Figure 17: Relative did not receive enough predischarge training

---

mode = disagree

Say and Control

There were 61 family members who responded to this statement. Figure 18 shows that only 31 or 50.82 percent either agreed (40.98%) or strongly agreed (9.84%) that they had enough say or control concerning the discharge of their mentally retarded relative. A total of 18 or 29.51 percent either disagreed (18.03%) or strongly disagreed (11.48%) that they felt enough say or control. Of the responding family members, 8 or 13.11 percent were undecided and 4 or 6.56 percent of the respondents felt they didn't know.

```
   ATTITUDE                                   FREQ  CUM.   PERCENT    CUM.
                                                    FREQ            PERCENT
              |
        DK    |****                             4      4     6.56      6.56
              |
        SD    |*******                          7     11    11.48     18.03
              |
         D    |***********                     11     22    18.03     36.07
              |
        UN    |********                         8     30    13.11     49.18
              |
         A    |*************************       25     55    40.98     90.16
              |
        SA    |******                           6     61     9.84    100.00
              |
              -----+----+----+----+----+
                   5   10   15   20   25

                      FREQUENCY
```

Figure 18: Enough say or control

---

mode = agree

4.5 ATTITUDES TOWARD DISCHARGED PERSON

There were 4 statements in the questionnaire which were aimed at determining the family members' attitudes toward the rehabilitative capabilities of the discharged mentally retarded person.

Potential to Learn

Figure 19 shows that of the 56 family members who responded to this statement 43 or 76.78 percent either disagreed (48.21%) or strongly disagreed (28.57%) that their mentally retarded relative had reached his/her potential while living at the institution and was incapable of learning much more in the community setting. Only 3 or 5.36 percent either agreed (3.57%) or strongly agreed (1.79%) with this statement and 5 or 8.93 percent of the family members felt they didn't know.

```
ATTITUDE                                          FREQ  CUM.   PERCENT    CUM.
                                                        FREQ             PERCENT
               |
          DK   |*****                                5     5     8.93      8.93
               |
          SA   |*                                    1     6     1.79     10.71
               |
           A   |**                                   2     8     3.57     14.29
               |
          UN   |*****                                5    13     8.93     23.21
               |
           D   |***************************         27    40    48.21     71.43
               |
          SD   |****************                    16    56    28.57    100.00
               |
              -----+----+----+----+----+--
                   5   10   15   20   25

                       FREQUENCY
```

Figure 19: Relative has reached potential

mode = disagree

Progress Since Discharge

The respondents were asked to agree or disagree with the statement that their relative had made significant progress since being discharged from the institution. Figure 20 shows that of the 62 family members who responded to this statement, 45 or 72.58 percent either agreed (46.77%) or strongly agreed (25.81%) that their relative had made significant progress. Only 4 or 6.45 percent either disagreed (4.84%) or strongly disagreed (1.61%) with this statement and 7 or 11.29 percent of the respondents felt they didn't know.

```
ATTITUDE
                                                          FREQ  CUM.   PERCENT    CUM.
                                                                FREQ            PERCENT
           |
        DK |*******                                          7     7     11.29     11.29
           |
        SD |*                                                1     8      1.61     12.90
           |
         D |***                                              3    11      4.84     17.74
           |
        UN |******                                           6    17      9.68     27.42
           |
         A |*****************************                   29    46     46.77     74.19
           |
        SA |****************                                16    62     25.81    100.00
           |
           -----+----+----+----+----+----
                5   10   15   20   25

                    FREQUENCY
```

Figure 20: Relative has made progress since discharge.

mode = agree

Capable of Learning More

Figure 21 shows that of the 64 family members who responded to this statement, 46 or 71.88 percent either agreed (50.00%) or strongly agreed (21.88%) that their mentally retarded relative despite his/her level of retardation, could still learn more. Only 4 or 6.25 percent either disagreed (1.56%) or strongly disagreed (4.69%) with this statement and 7 or 10.94 percent were undecided. There were 7 or 10.94 percent of the family members who felt they didn't know.

```
ATTITUDE                                       FREQ  CUM.   PERCENT    CUM.
                                                     FREQ             PERCENT
          |
    DK    |*******                                7     7     10.94     10.94
          |
    SD    |***                                    3    10      4.69     15.63
          |
     D    |*                                      1    11      1.56     17.19
          |
    UN    |*******                                7    18     10.94     28.13
          |
     A    |********************************      32    50     50.00     78.13
          |
    SA    |**************                        14    64     21.88    100.00
          |
          -----+----+----+----+----+----+--
               5   10   15   20   25   30

                      FREQUENCY
```

Figure 21: Relative can still learn more

mode = agree

Capable of Community Living

The respondents were asked to what degree they felt their mentally retarded relative was capable of living successfully in the community. Figure 22 shows that of the 63 family members who responded to this statement, 38 or 60.32 percent either agreed (46.03%) or strongly agreed (14.29%). Of the respondents, 11 or 17.46 percent either disagreed (9.52%) or strongly disagreed (7.94%) that their relative was capable of living successfully in the community and 8 or 12.70 percent were undecided. There were 6 or 9.52 percent of the respondents who reported they didn't know.

```
ATTITUDE                                        FREQ  CUM.   PERCENT    CUM.
                                                      FREQ              PERCENT
           |
      DK   |******                                 6     6      9.52      9.52
           |
      SD   |*****                                  5    11      7.94     17.46
           |
       D   |******                                 6    17      9.52     26.98
           |
      UN   |********                               8    25     12.70     39.68
           |
       A   |*****************************         29    54     46.03     85.71
           |
      SA   |*********                              9    63     14.29    100.00
           |
           -----+----+----+----+----+-----
                5   10   15   20   25

                   FREQUENCY
```

Figure 22: Relative capable of living successfully in community

mode = agree

4.6 ATTITUDES TOWARD COMMUNITY LIVING

The questionnaire included 16 statements which were aimed at determining the family members' attitudes toward deinstitutionalization or community living.

Normalization

Figure 23 shows that of the 60 family members who responded to this statement, 51 or 85.00 percent either agreed (55.00%) or strongly agreed (30.00%) that community residences were better because they allow mentally retarded persons like their relative to live more like normal people do. No respondents disagreed and only 4 or 6.67 percent strongly disagreed with this statement. There were 3 or 5.00 percent of the family members who felt they didn't know.

```
ATTITUDE                                               FREQ  CUM.  PERCENT   CUM.
                                                             FREQ          PERCENT
            |
      DK    |***                                          3     3     5.00     5.00
            |
      SD    |****                                         4     7     6.67    11.67
            |
      UN    |**                                           2     9     3.33    15.00
            |
       A    |*********************************           33    42    55.00    70.00
            |
      SA    |******************                          18    60    30.00   100.00
            |
            ----+----+----+----+----+----+---
                5   10   15   20   25   30

                     FREQUENCY
```

Figure 23: Community allows for normalized living

mode = agree

Effect on Family

The questionnaire included the statement that "it would have been better for my family if my relative had stayed in the institution". Figure 24 shows that of the 59 respondents who responded to this statement, 43 or 72.88 percent either disagreed (44.07%) or strongly disagreed (28.81%). Only 4 or 6.78 percent of the respondents either agreed (3.39%) or strongly agreed (3.39%) with the statement and 7 or 11.86 percent of the family members felt they didn't know.

```
ATTITUDE                                           FREQ  CUM.   PERCENT    CUM.
                                                         FREQ            PERCENT
            |
       DK   |*******                                  7     7    11.86     11.86
            |
       SA   |**                                       2     9     3.39     15.25
            |
        A   |**                                       2    11     3.39     18.64
            |
       UN   |*****                                    5    16     8.47     27.12
            |
        D   |**************************              26    42    44.07     71.19
            |
       SD   |*****************                       17    59    28.81    100.00
            |
            ----+----+----+----+----+
                5   10   15   20   25

                     FREQUENCY
```

Figure 24: Better if relative had stayed in institution

mode = disagree

Quality of Life

Figure 25 shows that of the 55 family members who responded to this statement, 39 or 70.91 percent either disagreed (43.64%) or strongly disagreed (27.27%) that their mentally retarded relative lived a better life when s/he was living in the institution. Only 3 or 5.46 percent either agreed (3.64%) or strongly agreed (1.82%) with this statement and 7 or 12.73 percent were undecided. There were 6 or 10.91 percent of the respondents who felt they didn't know.

```
ATTITUDE                                    FREQ  CUM.   PERCENT    CUM.
                                                  FREQ             PERCENT
               |
         DK    |******                        6      6    10.91     10.91
               |
         SA    |*                             1      7     1.82     12.73
               |
          A    |**                            2      9     3.64     16.36
               |
         UN    |*******                       7     16    12.73     29.09
               |
          D    |************************     24     40    43.64     72.73
               |
         SD    |***************              15     55    27.27    100.00
               |
               -----+----+----+----+----
                    5   10   15   20

                      FREQUENCY
```

Figure 25: Relative lived better quality of life in institution

mode = disagree

Personal Attention

Figure 26 shows that strong agreement was found with a statement concerning personal attention from the community residence. Of the 60 family members who responded to this statement, 40 or 66.67 percent either agreed (45.00%) or strongly agreed (21.67%) that community residences give more personal attention to the mentally retarded than do institutions. There were no respondents who disagreed with this statement, 3 or 5.00 percent of the respondents strongly disagreed and 8 or 13.33 percent of the respondents were undecided. There were 9 or 15.00 percent of the family members who reported that they didn't know.

```
ATTITUDE                                       FREQ  CUM.  PERCENT    CUM.
                                                     FREQ           PERCENT
          |
       DK |*********                              9     9    15.00    15.00
          |
       SD |***                                    3    12     5.00    20.00
          |
       UN |********                               8    20    13.33    33.33
          |
        A |***************************           27    47    45.00    78.33
          |
       SA |*************                         13    60    21.67   100.00
          |
          ----+----+----+----+----+--
              5   10   15   20   25

                 FREQUENCY
```

Figure 26: Community residence gives more personal attention

mode = agree

Growth and Learning

Figure 27 shows that of the 61 family members who responded to this statement, 43 or 70.49 percent either agreed (44.26%) or strongly agreed (26.23%) that the community residence provided more opportunities for growth and learning than the institution did. Only 4 or 6.56 percent either disagreed (3.28%) or strongly disagreed (3.28%) with this statement and 8 or 13.11 percent were undecided. There were 6 or 9.84 percent of the respondents who felt they didn't know.

```
ATTITUDE                                              FREQ  CUM.  PERCENT   CUM.
                                                            FREQ           PERCENT
             |
        DK   |******                                     6     6     9.84     9.84
             |
        SD   |**                                         2     8     3.28    13.11
             |
        D    |**                                         2    10     3.28    16.39
             |
        UN   |********                                   8    18    13.11    29.51
             |
        A    |***************************               27    45    44.26    73.77
             |
        SA   |****************                          16    61    26.23   100.00
             |
             -----+----+----+----+----+--
                  5   10   15   20   25

                      FREQUENCY
```

Figure 27: Community provides more opportunities for growth

mode = agree

Care and Supervision

The questionnaire included the statement that, "my relative received better care and supervision in the institution than s/he now receives in the community residence". Figure 28 shows that of the 59 family members who responded to this statement, 38 or 64.40 percent either disagreed (49.15%) or strongly disagreed (15.25%). Of the total respondents, 7 or 11.86 percent either agreed (6.78%) or strongly agreed (5.08%), 8 or 13.56 percent were undecided and 6 or 10.17 percent felt they didn't know.

```
ATTITUDE                                          FREQ  CUM.   PERCENT    CUM.
                                                        FREQ             PERCENT
                |
       DK       |******                              6     6     10.17     10.17
                |
       SA       |***                                 3     9      5.08     15.25
                |
        A       |****                                4    13      6.78     22.03
                |
       UN       |********                            8    21     13.56     35.59
                |
        D       |*****************************      29    50     49.15     84.75
                |
       SD       |*********                           9    59     15.25    100.00
                |
                ----+----+----+----+----+---
                    5   10   15   20   25

                          FREQUENCY
```

Figure 28: Received better care and supervision in institution

mode = disagree

Services and Professionals

Figure 29 shows that of the 62 family members who responded to this statement, 35 or 56.46 percent either agreed (41.94%) or strongly agreed (14.52%) that there were more services and professionals available to the mentally retarded relative since placement in the community residence. Of the total respondents, 7 or 11.29 percent were undecided and 7 or 11.29 percent either disagreed (8.06%) or strongly disagreed (3.23%) with this statement. There were 13 or 20.97 percent of the respondents who felt they didn't know.

```
ATTITUDE                                          FREQ  CUM.   PERCENT   CUM.
                                                        FREQ             PERCENT
             |
      DK     |*************                         13    13    20.97     20.97
             |
      SD     |**                                     2    15     3.23     24.19
             |
       D     |*****                                  5    20     8.06     32.26
             |
      UN     |*******                                7    27    11.29     43.55
             |
       A     |**************************            26    53    41.94     85.48
             |
      SA     |*********                              9    62    14.52    100.00
             |
             ----+----+----+----+----+-
                 5   10   15   20   25

                      FREQUENCY
```

Figure 29: More services and professionals in community

mode = agree

<u>Family Relationship</u>

Figure 30 shows that there were 59 family members who responded to this statement. Of the total respondents, 39 or 66.10 percent either agreed (45.76%) or strongly agreed (20.34%) that they had a stronger relationship with the relative since placement in the community residence. Of those who completed this statement, 8 or 13.56 percent were undecided and 9 or 15.25 percent either disagreed (6.78%) or strongly disagreed (8.47%) with the statement. There were 3 or 5.08 percent of the family members who felt they didn't know.

```
ATTITUDE                                         FREQ  CUM.   PERCENT    CUM.
                                                       FREQ             PERCENT
              |
        DK    |***                                  3     3      5.08      5.08
              |
        SD    |*****                                5     8      8.47     13.56
              |
         D    |****                                 4    12      6.78     20.34
              |
        UN    |********                             8    20     13.56     33.90
              |
         A    |***************************         27    47     45.76     79.66
              |
        SA    |************                        12    59     20.34    100.00
              |
              ----+----+----+----+----+--
                  5   10   15   20   25

                      FREQUENCY
```

Figure 30: Have stronger relationship since discharge

mode = agree

Number of Friends

The questionnaire included the statement "my relative had more friends when s/he lived in the institution". Figure 31 shows that of the 58 family members who responded to this statement, 28 or 48.27 percent either disagreed (37.93%) or strongly disagreed (10.34%). The Figure also shows that 18.97 percent of the respondents were undecided and 6 or 10.35 percent either agreed (6.90%) or strongly agreed (3.45%) with this statement. There were 13 or 22.41 percent of the respondents who reported that they didn't know.

```
ATTITUDE                              FREQ  CUM.   PERCENT   CUM.
                                            FREQ           PERCENT
              |
      DK      |*************           13    13     22.41     22.41
              |
      SA      |**                       2    15      3.45     25.86
              |
       A      |****                     4    19      6.90     32.76
              |
      UN      |***********             11    30     18.97     51.72
              |
       D      |**********************  22    52     37.93     89.66
              |
      SD      |******                   6    58     10.34    100.00
              |
              ----+----+----+----+--
                  5   10   15   20

                   FREQUENCY
```

Figure 31: Relative had more friends in institution

mode = disagree

Trained Staff

Figure 32 shows that a total of 58 family members responded to the statement that "institutional staff are better trained than staff of community residences". The Figure also shows that 15.52 percent were undecided and 23 or 39.65 percent either disagreed (31.03%) or strongly disagreed (8.62%). Of the total respondents, 5 or 8.62 percent either agreed (5.17%) or strongly agreed (3.45%) that institutional staff were better trained than staff of community residences. There were 21 or 36.21 percent of the respondents who felt they didn't know.

```
ATTITUDE                          FREQ  CUM.   PERCENT    CUM.
                                        FREQ             PERCENT
        |
     DK |*********************     21    21     36.21     36.21
        |
     SA |**                         2    23      3.45     39.66
        |
      A |***                        3    26      5.17     44.83
        |
     UN |*********                  9    35     15.52     60.34
        |
      D |******************        18    53     31.03     91.38
        |
     SD |*****                      5    58      8.62    100.00
        |
        ----+----+----+----+-
            5   10   15   20

              FREQUENCY
```

Figure 32: Staff of institutions are better trained

mode = don't know

Protection

Figure 33 shows that of the 57 family members who responded to this statement, 32 or 56.14 percent either disagreed (40.35%) or strongly disagreed (15.79%) that institutions were better than community residences because they protect the mentally retarded. Of the respondents, 11 or 19.30 percent were undecided, 10 or 17.55 percent either agreed (14.04%) or strongly agreed (3.51%) with the statement and 4 or 7.02 percent of the respondents felt they didn't know.

```
ATTITUDE                                 FREQ  CUM.   PERCENT    CUM.
                                               FREQ             PERCENT
              |
      DK      |****                         4     4     7.02      7.02
              |
      SA      |**                           2     6     3.51     10.53
              |
       A      |********                     8    14    14.04     24.56
              |
      UN      |***********                 11    25    19.30     43.86
              |
       D      |*********************** 23    48    40.35     84.21
              |
      SD      |*********                    9    57    15.79    100.00
              |
             -----+----+----+----+---
                  5   10   15   20

                  FREQUENCY
```

Figure 33: Institutions are better because they protect

mode = disagree

Care and Programs

The questionnaire included the statement, "institutions for the mentally retarded are outdated and do not provide as good care or programs as do community residences". Figure 34 shows that there were 56 family members who responded to this statement and 29 or 51.79 percent either agreed (33.93%) or strongly agreed (17.86%). The Figure also shows that 23.21 percent were undecided and 9 or 16.07 percent either disagreed (12.50%) or strongly disagreed (3.57%) with the statement. There were 5 or 8.93 percent of the family members who reported that they didn't know.

```
ATTITUDE                          FREQ  CUM.   PERCENT    CUM.
                                        FREQ             PERCENT
            |
      DK    |*****                   5     5      8.93      8.93
            |
      SD    |**                      2     7      3.57     12.50
            |
       D    |*******                 7    14     12.50     25.00
            |
      UN    |*************          13    27     23.21     48.21
            |
       A    |******************* 19    46     33.93     82.14
            |
      SA    |**********             10    56     17.86    100.00
            |
           -----+----+----+----
                5   10   15

                FREQUENCY
```

Figure 34: Institutions do not provide as good care or programs

mode = agree

<u>Public</u> <u>Exploitation</u>

Figure 35 shows that of the 61 family members who responded to this statement, 26 or 42.62 percent either disagreed (29.51%) or strongly disagreed (13.11%) that they were concerned that the public may take advantage of their mentally retarded relative now that s/he lives in the community residence. Of the total respondents, 7 or 11.48 percent were undecided and 16 or 26.32 percent either agreed (16.39%) or strongly agreed (9.84%) with this statement. There were 12 or 19.67 percent of the respondents who felt that they didn't know.

```
ATTITUDE                                 FREQ   CUM.   PERCENT    CUM.
                                                FREQ              PERCENT
                |
        DK      |************             12     12     19.67     19.67
                |
        SA      |******                    6     18      9.84     29.51
                |
         A      |**********               10     28     16.39     45.90
                |
        UN      |*******                   7     35     11.48     57.38
                |
         D      |******************       18     53     29.51     86.89
                |
        SD      |********                  8     61     13.11    100.00
                |
                ------+-----+-----+---
                      5    10    15

                      FREQUENCY
```

Figure 35: Public will exploit relative

mode = disagree

Public Acceptance

The questionnaire included the statement, "I am concerned that the public will never accept my mentally retarded relative". Figure 36 shows that of the 56 family members who responded to this statement, 15 or 26.79 percent either disagreed (25.00%) or strongly disagreed (1.79%). The Figure also shows that 21.43 percent were undecided and that 20 or 35.72 percent either agreed (26.79%) or strongly agreed (8.93%) with the statement. There were 9 or 16.07 percent of the respondents who reported not knowing.

```
ATTITUDE                                              FREQ  CUM.   PERCENT   CUM.
                                                            FREQ             PERCENT
        |
    DK  |******************                              9      9    16.07     16.07
        |
    SA  |**********                                      5     14     8.93     25.00
        |
     A  |******************************                 15     29    26.79     51.79
        |
    UN  |************************                       12     41    21.43     73.21
        |
     D  |****************************                   14     55    25.00     98.21
        |
    SD  |**                                              1     56     1.79    100.00
        |
        ----+---+---+---+---+---+---+--
            2   4   6   8  10  12  14

                  FREQUENCY
```

Figure 36: Concerned that public will never accept relative

mode = agree

Death of Respondent

Figure 37 shows that of the 60 family members who responded to this statement, only 14 or 23.34 percent either disagreed (16.67%) or strongly disagreed (6.67%) that they were concerned about what would happen to the discharged relative when they were no longer alive. Of the respondents, 16.67 percent were undecided and 28 or, 46.67 percent either agreed (30.00%) or stongly agreed (16.67%) with the statement. There were 8 or 13.33 percent of the family members who felt they didn't know.

```
ATTITUDE                            FREQ  CUM.   PERCENT    CUM.
                                          FREQ            PERCENT
            |
       DK   |********                 8     8     13.33     13.33
            |
       SA   |**********              10    18     16.67     30.00
            |
       A    |******************      18    36     30.00     60.00
            |
       UN   |**********              10    46     16.67     76.67
            |
       D    |**********              10    56     16.67     93.33
            |
       SD   |****                     4    60      6.67    100.00
            |
            ----+----+----+---
                5   10   15

              FREQUENCY
```

Figure 37: Concerned of what will happen when they die

mode = agree

Happiness With Other Mentally Retarded

The questionnaire included the statement, "my relative is happier when s/he is with other mentally retarded persons." Figure 38 shows that of the 56 family members who responded to this statement, 12 or 21.43 percent disagreed and no respondents strongly disagreed. Of the respondents, 32 or 57.14 percent either agreed (44.64%) or strongly agreed (12.50%) with this statement and 6 or 10.71 percent of the respondents felt they didn't know.

```
ATTITUDE                                      FREQ  CUM.   PERCENT    CUM.
                                                    FREQ             PERCENT
           |
    DK     |******                               6     6    10.71     10.71
           |
    SA     |*******                              7    13    12.50     23.21
           |
     A     |*************************           25    38    44.64     67.86
           |
    UN     |******                               6    44    10.71     78.57
           |
    D.     |************                        12    56    21.43    100.00
           |
           ----+----+----+----+----+
               5   10   15   20   25

                   FREQUENCY
```

Figure 38: Relative is happier with other mentally retarded

mode = agree

4.7 HYPOTHESES

The researcher was interested in assessing the association between several variables and the respondents' first reactions and present feelings concerning deinstitutionalization. Twenty-five hypotheses were developed from 3 major hypotheses in order to test for significant associations between the respondents' attitudes toward the discharge process, the mentally retarded relative's capabilities and community living and both their first reactions and present feelings concerning deinstitutionalization. The Spearman Correlation Test (Rs) was used to determine whether there was a significant association between the repondents' agreement or disagreement with the 25 statements included in the questionnaire and their first reactions and present feelings concerning deinstitutionalization.

Hypotheses Concerning the Discharge Process

The family members' attitudes toward the following variables concerning the discharge process are associated with both their first reactions and present feelings concerning deinstitutionalization:

1. the preparation and information they received regarding the discharge.
2. the mentally retarded relative's readiness to be discharged when the discharge took place.
3. the information and advice they received regarding the discharge.
4. the training their mentally retarded relative received before being discharged.
5. the say or control they felt concerning the discharge.

Table 2 illustrates that of the 5 statements concerning the disharge process, only the respondents' attitudes toward their say or control, preparation and information, and their perception of the relatives' readiness to be discharged were found to be associated with their first reactions to the deinstitutionalization of their mentally retarded relatives.

Table 3 illustrates that of the 5 statements concerning the discharge process, the respondents' attitudes toward their say or control, preparation and information, advice and perception of the relatives' readiness to be discharged were found to be associated with their present feelings concerning deinstitutionalization.

TABLE 2

First reaction and attitudes toward discharge process

	Rs	t
Readiness to be discharged	.456	3.66**
Say or control	.318	2.46**
Preparation and information	.298	2.14*
Information and advice	.104	.789
Pre-discharge training	-.037	-.243

* $p < .05$.
** $p < .01$.

TABLE 3

Present feeling and attitudes toward discharge process

	Rs	t
Readiness to be discharged	.598	5.12**
Say or control	.460	3.66**
Preparation and information	.459	3.43**
Information and advice	.405	3.16**
Predischarge training	.115	.732

The hypothesis which stated that the family members' attitudes toward the preparation and information they received regarding the discharge are significantly associated with both their first reactions and present feelings concerning deinstitutionalization was accepted. The associations were significantly positive.

The hypothesis concerning the family members' attitudes toward their mentally retarded relative's readiness to be discharged was also accepted. The family members' attitudes toward their relative's readiness to be discharged were found to be associated with both their first reactions and present feelings concerning deinstitutionalization. The associations were significantly positive.

The hypothesis which stated that the family members' attitudes toward the say or control they felt concerning the discharge are associated with both their first reactions and present feelings concerning deinstitutionalization was also accepted. The associations were significantly positive.

The hypothesis which stated that the family members' attitudes toward the information and advice they received regarding the discharge are associated with both their first reactions and present feelings concerning deinstitutionalization was not accepted. The null hypothesis that the family members' attitudes toward the information and advice they received are not associated with both their first reactions and present feelings concerning deinstitutionalization was therefore accepted.

The hypothesis concerning the training the mentally retarded person received before being discharged was not accepted. The null hypothesis that the family members' attitudes toward the training their mentally retarded relative received before being discharged are not associated with both their first reactions and present feelings concerning deinstitutionalization was therefore accepted.

Hypotheses Concerning Capabilities of Relative

The family members' attitudes toward the following variables concerning the capabilities of the mentally retarded relative are associated with both their first reactions and present feelings concerning deinstitutionalization:

1. the relative's potential to learn more in the community setting.
2. the relative's progress since discharge.
3. the relative's capabilities of learning more despite his/her level of retardation.
4. the relative's capabilities of living successfully in the community.

Table 4 illustrates that of the four statements concerning the capabilities of the discharged mentally retarded individuals, only the respondents' attitudes toward the relative's potential to learn and their progress since discharge were found to be associated with the respondents' first reactions to deinstitutionalization.

TABLE 4

First reaction and attitudes toward capabilities of relative

	Rs	t
Potential to learn	.442	3.41**
Progress since discharge	.263	1.97*
Capable to learn more	.158	1.18
Capable of community living	.151	1.12

* $p < .05$.
** $p < .01$.

Table 5 illustrates that of the 4 statements concerning the capabilitites of the mentally retarded individual, only the respondents' attitudes toward the relatives' potential to learn, progress since discharge and capability of community living were found to be associated with the respondents' present feelings concerning deinstitutionalization.

TABLE 5

Present feeling and attitude toward capabilities of relative

	Rs	t
Progress since discharge	.574	4.70**
Potential to learn	.377	2.70**
Capable of community living	.286	2.05*
Capable to learn more	.228	1.16

* p < .05.
** p < .01.

The hypothesis which stated that the family members' attitudes toward their mentally retarded relative's potential to learn more in the community are associated with both their first reactions and present feelings concerning deinstitutionalization was accepted. The associations were significantly positive.

Significant positive associations were found between the family members' attitudes toward their mentally retarded relative's progress since discharge and both their first reactions and present feelings concerning deinstitutionalization. The hypothesis that the family members' attitudes toward their relative's progress since discharge are associated with both their first reactions and present feelings concerning deinstitutionalization was therefore accepted.

The hypothesis concerning the family members' attitudes toward their mentally retarded relative's capabilities to learn more despite his/her level of retardation was not accepted. The null hypothesis that the family members' attitudes toward their relative's capabilities to learn more despite his/her level of retardation are not associated with both their first reactions and present feelings concerning deinstitutionalization was therefore accepted.

The hypothesis which stated that the family members' attitudes toward their mentally retarded relative's capabilities of living successfully in the community are associated with both their first reactions and present feelings concerning deinstitutionalization was not accepted. The null hypothesis that there is no association was therefore accepted.

Hypotheses Concerning Community Living.

The family members' attitudes toward the following variables concerning community living are associated with both their first reactions and present feelings concerning deinstitutionalization:

1. normalized community living.
2. the effects of the discharge on their family.
3. the mentally retarded relative's quality of life in the community setting.

4. the personal attention their mentally retarded relative receives in the community setting.
5. the mentally retarded relative's opportunities for growth and learning in the community setting.
6. the care and supervision their mentally retarded relative receives in the community setting.
7. the services and professionals available in the community setting.
8. the strength of their relationship with their mentally retarded relative since discharge.
9. the number of friends their mentally retarded relative has in the community setting.
10. the adequacy of trained staff of community residences.
11. the protection offered by the community setting.
12. the care and programs available to the mentally retarded in the community setting.
13. their concerns regarding public exploitation.
14. their concerns regarding public acceptance.
15. their concerns about what will happen to the mentally retarded relative when they die.
16. their mentally retarded relative's happiness with other mentally retarded persons.

Table 6 illustrates that of the 16 statements concerning deinstitutionalization or community living, only the respondents' attitudes toward quality of life, protection, family relationship, staffing, care and supervision, death of respondent, normalization, growth and learning and public exploitation were found to be associated with the respondents' first reactions to deinstitutionalization.

TABLE 6

First reaction and attitudes toward community living

	Rs	t
Quality of life	.491	3.74**
Family	.433	3.40**
Protection	.355	2.69**
Family relationship	.319	2.47**
Staff	.382	2.41*
Care and supervision	.293	2.17*
Death of respondent	.294	2.15*
Normalization	.260	1.98*
Growth and learning	.233	1.73*
Public exploitation	.247	1.73*
Personal attention	.231	1.64
Happier with other mr	.220	1.55
Services and professionals	.221	1.54
Public acceptance	.291	1.51
Friends	.215	1.43
Care and programs	.172	1.21

---

* $p < .05$.
** $p < .01$.

Table 7 illustrates that of the 16 statements concerning deinstitutionalization or community living, only the responding family members' attitudes toward public acceptance and the relatives' happiness with other mentally retarded persons were not found to be associated with the respondents' present feelings concerning deinstitutionalization.

TABLE 7

Present feeling and attitudes toward community living

	Rs	t
Family	.590	5.12**
Care and supervision	.544	4.63**
Protection	.523	4.16**
Services and professionals	.546	4.07**
Care and programs	.517	4.05**
Growth and learning	.467	3.73**
Quality of life	.477	3.56**
Staff	.515	3.55**
Death of respondent	.469	3.48**
Family relationship	.435	3.31**
Normalization	.411	3.12**
Personal attention	.403	3.08**
Friends	.377	2.51**
Public exploitation	.292	2.00*
Public acceptance	.187	1.22
Happiness with other mr	.097	.639

* $p < .05$.
** $p < .01$.

Significant positive associations were found between the family members' attitudes toward normalized community living and both their first reactions and present feelings concerning deinstitutionalization. The hypothesis that the family members' attitudes toward normalized community living are associated with both their first reactions and present feelings concerning deinstitutionalization was therefore accepted.

The hypothesis which stated that the family members' attitudes toward the effects of the discharge on their family are associated with their first reactions and present feelings concerning deinstitutionalization was accepted. The associations were significantly positive.

The hypothesis concerning the family members' attitudes toward the mentally retarded relative's quality of life in the community was also accepted. Significant positive associations allowed the researcher to accept the hypothesis that the family members' first reactions and present feelings concerning deinstitutionalization are associated with their attitudes toward their mentally retarded relative's quality of life.

Significant positive associations were found between the family members' attitudes toward their mentally retarded relative's opportunities for growth and learning in the community setting and both their first reactions and present feelings concerning deinstitutionalization. The hypothesis that the family members' attitudes toward their relative's opportunities for growth and learning are associated with both their first reactions and present feelings concerning deinstitutionalization was therefore accepted.

The hypothesis which stated that the family members' first reactions and present feelings concerning deinstitutionalization are associated with their attitudes toward the care and supervision their mentally retarded relative receives in the community setting was also accepted. The associations were significantly positive.

The hypothesis concerning the family members' attitudes toward the strength of their relationship with their mentally retarded relative since discharge was accepted. Significant positive associations allowed the researcher to accept the hypothesis that the family members' attitudes toward the strength of their relationship with their mentally retarded relative since discharge are associated with both their first reactions and present feelings concerning deinstitutionalization.

Significant positive associations were also found between the family members' first reactions and present feelings concerning deinstitutionalization and their attitudes toward the adequacy of trained staff in the community residence. The hypothesis that the family members' attitudes toward the adequacy of trained staff in community residences are associated with both their first reactions and present feelings concerning deinstitutionalization was therefore accepted.

The hypothesis which stated that the family members' attitudes toward the protection offered by community residences are associated with both their first reactions and present feelings concerning deinstitutionalization was accepted. The associations were significantly positive.

The hypothesis concerning the family members' attitudes toward their concerns about public exploitation was accepted. Significant positive associations allowed the researcher to accept the hypothesis that the family members' first reactions and present feelings concerning deinstitutionalization are associated with their attitudes toward their concerns about public exploitation.

Significant positive associations were found between the family members' attitudes towards their concerns about when they die and both their first reactions and present feelings concerning deinstitutionalization. The hypothesis that the family members' attitudes toward their concerns about what will happen to their relative when they die are associated with both their first reactions and present feelings concerning deinstitutionalization was therefore accepted.

The hypothesis concerning the family members' attitudes toward the personal attention their mentally retarded relative receives in the community residence was not accepted. The null hypothesis that the family members' first reactions and present feelings concerning deinstitutionalization are not associated with their attitudes toward the personal attention their relative receives in the community residence was therefore accepted.

The hypothesis which stated that the family members' attitudes toward the services and professionals available in the community are associated with both their first reactions and present feelings concerning deinstitutionalization was not accepted. The null hypothesis that there is no association was therefore accepted.

The lack of significant associations caused the researcher to accept the null hypothesis that there is no association between the family members' attitudes toward the number of friends their mentally retarded relative has in the community and both their first reactions and present feelings concerning deinstitutionalization.

The hypothesis concerning the family members' attitudes toward community care and programs was not accepted. The null hypothesis that the family members' first reactions and present feelings concerning deinstitutionalization are not associated with their attitudes toward community care and programs was therefore accepted.

The hypothesis which stated that the family members' attitudes toward their concerns regarding public acceptance are associated with both their first reactions and present feelings concerning deinstitutionalization was not accepted. The null hypothesis that there is no association was therefore accepted.

The hypothesis which stated that there is an association between the family members' first reactions and present feelings concerning deinstitutionalization and their attitudes toward the mentally retarded relative's happiness with other mentally retarded persons was not accepted. The null hypothesis that there is no association was therefore accepted.

4.8 SUMMARY

This chapter presented the analysis of the data. The discharged mentally retarded individuals and their responding family members were demographically described. The responding family members' attitudes toward the questionnaire's statements were presented. The associations between the respondents' attitudes toward the questionnaire's statements and their attitudes toward deinstitutionalization were described.

The subsequent chapter will discuss and interpret the research findings.

Chapter V

DISCUSSION OF FINDINGS

5.1 INTRODUCTION

The purpose of this chapter is to discuss and interpret the research findings based on the data presented and analyzed in the previous chapter and the available literature. The purpose of this research has been to describe family members' attitudes toward the deinstitutionalization of their mentally retarded family members. The researcher was interested in attempting to answer the following research questions:

1. What are the demographic characteristics of the mentally retarded persons who have been discharged from the Oxford Regional Centre to a community residence?
2. What are the demographic characteristics of the family members of these mentally retarded persons?
3. What changes, if any, were there in the family members' first reactions and present feelings concerning deinstitutionalization?
4. What are the family members' attitudes toward the discharge process?
5. What are the family members' attitudes toward the capabilities of the discharged mentally retarded individual?
6. What are the family members' attitudes toward community living for their mentally retarded relatives?

The researcher was also interested in testing the following hypotheses:

1. The family members' attitudes toward the discharge process are significantly associated with both their first reactions and present feelings concerning deinstitutionalization.
2. The family members' attitudes toward the capabilities of their mentally retarded relative are significantly associated with both their first reactions and present feelings concerning deinstitutionalization.
3. The family members' attitudes toward community living for their mentally retarded relative are significantly associated with both their first reactions and present feelings concerning deinstitutionalization.

5.2 DEMOGRAPHIC CHARACTERISTICS OF THE DISCHARGED PERSON

The discharged mentally retarded individuals were generally young adults and were generally of the moderate level of mental retardation. The frequency of males and females were almost equal with a small predominance of males. Most of the discharged individuals had been institutionalized less than 19 years where the mode was 15-19 years. Most of the individuals had been living in the community residence less than 3 years.

5.3 DEMOGRAPHIC CHARACTERISTICS OF THE FAMILY MEMBERS

The response rate (72.1%) for a mailed questionnaire of this nature was high. Selltiz et al. (1976) have stated that returns of questionnaires are "notoriously low - from 10 to 40 percent . . ." (p. 80). The family members may have been motivated by this perhaps being their first opportunity to make known their attitudes toward the deinstitutionalization of their mentally retarded relative.

The modal age range of the family members was 60-69 years of age which suggests an older sample population. The literature points out that the values of today's society are very different than they were 30 or 40 years ago which may make the process of deinstitutionalization particularly difficult for the older parent or family member (DeHaan, 1981). Thirty or forty years ago, institutionalization was considered an acceptable, if not advantageous solution for families of the mentally retarded (Gollay et al., 1978). Community living for the mentally retarded represents a new philosophy which may be difficult for the older family member to accept. Deinstitutionalization may challenge the adaptation of older family members when they may be less able to integrate change (Schodek et al., 1980). A past study has indicated that younger family members are more likely to prefer community placement (Meyer, 1980). It may therefore be suggested that this sample population because of their age, may have found it difficult to accept community living for their mentally retarded family members.

The relationship of the respondents to the discharged mentally retarded person was generally that of parent, and in most cases, mothers were the respondents. The questionnaire asked that the family member most involved with the mentally retarded person complete the questionnaire. In many cases where the questionnaire was addressed to the parents of the mentally retarded person, it was the mother who completed the questionnaire. It would appear then that mothers were the family members most involved with the mentally retarded individual.

Approximately 20 percent of the respondents were family members other than the mentally retarded inidividual's parents. Perhaps in such cases the parents were deceased and another family member had assumed the role of next-of-kin. It is suggested that if the responding family member was a brother, sister or uncle, that s/he, because the role of next-of-kin had been handed down, may not have been as familiar with the mentally retarded individual and his/her various living arrangements as was the parent.

One-half of the family members reported visiting the relative while s/he was institutionalized less than 5 times per year. This may have been due to the possibility that visits were limited to birthdays, Christmas or other special occasions. Few family members (14.52%) visited more than 14 times per year which may be explained by the possibility that visits were carried out on a monthly basis.

Approximately one-half of the responding family members visited the mentally retarded relative after discharge to the community residence less than 10 times per year. There were a few family members (12.28%) who visited the community residence 40 or more times per year, perhaps an indication of week-end visits throughout the year.

Visitation to the community residence may not have increased due to the fact that most of the responding family members were of an older age. These family members, because of their age may have suffered from health and mobility problems and found it difficult to travel even short distances.

Although it is the Ministry of Community and Social Services' aim to move mentally retarded persons from distant institutional settings to their local communities, only 27.27 perecnt of the individuals were placed in the same city or community as their family members. Most mentally retarded individuals (74.24%) were placed within a 99 kilometer distance or about a one-hour automobile drive from the responding family member. It is interesting to note that even though many of the mentally retarded individuals probably lived closer to their families, that contact or visitation to the relative did not increase to any great extent.

Most of the responding family members felt someone other than themselves initiated the first idea of placing the institutionalized mentally retarded individual in a community residence. Perhaps most important is the fact that over half of the family members felt that it was a social worker who initiated the idea. It may be suggested that many families as well as professionals saw social workers as the primary implementers of the deinstitutionalization process. Approximately 20 percent of the respondents felt the mentally retarded relative initiated the first idea of community living. The literature suggests that many families underestimate the abilities of their mentally retarded family members (Menolascino, 1977). It is proposed then, that if it was the mentally retarded individual who initiated the idea of community living, that his/her family may have underestimated his/her ability to make such a decision and ultimately underestimated his subsequent ability to live successfully in the community residence.

5.4 CHANGES IN ATTITUDES TOWARD DEINSTITUTIONALIZATION

Near the beginning of the questionnaire, the responding family members were asked if their first reaction when they learned that their relative was to be discharged to a community setting was happy, not happy or mixed. The last question of the questionnaire asked the respondents to indicate if their present feeling concerning the fact that their mentally retarded relative is living in the community residence was happy, not happy or mixed.

These two questions were aimed at determining whether or not the respondents' attitudes toward deinstitutionalization had changed over time. The researcher was also interested in what direction the respondents' attitudes toward deinstitutionalization had changed.

Approximately 70 percent of the respondents' attitudes toward deinstitutionalization did not change. These respondents, therefore, either had a happy first reaction and a happy present feeling, a mixed first reaction and a mixed present feeling or an unhappy first reaction and an unhappy present feeling.

Over 20 percent of the respondents' attitudes changed in a positive direction. Their attitudes thus changed from an unhappy first reaction to a mixed or happy present feeling or from a mixed first reaction to a happy present feeling concerning deinstitutionalization.

Only approximately 5% of the respondents' attitudes changed in a negative direction. Their attitudes thus changed from a happy first reaction to a mixed or unhappy present feeling or from a mixed first reaction to an unhappy present feeling concerning deinstitutionalization.

There are elements which may distinguish the respondents' first reactions from their present feelings concerning deinstitutionalization. Perhaps the respondents' first reactions may have been made quickly and may have been based on a limited number of experiences. The respondents' present feelings, on the other hand, may have been based on more of a reflective nature where the responding family members had more time to assess both their own and their mentally retarded relative's experiences since discharge to the community residence.

The respondents whose attitudes changed in a negative direction may have had unrealistic expectations regarding community living for their mentally retarded relative. The community residence may not have met their expectations, the relative may not have done as well as had been hoped or the relative may have had difficulties in the community residence.

The respondents whose attitudes concerning deinstitutionalization remained the same may not have had sufficient time to distinguish between their first reactions and present feelings. The relative may have been just recently discharged or the family member may not have had sufficient contact with the mentally retarded relative to cause a change in his/her attitude.

Those respondents whose attitudes changed in a positive direction may, for example, have had reservations about deinstitutionalization in the beginning, but found through time and experience that these reservations may not have been valid. The reservations may also have been alleviated through follow-up counselling from Oxford Regional Centre social workers.

5.5 ATTITUDES TOWARD THE DISCHARGE PROCESS

There were 5 statements included in the questionnaire which were concerned with attitudes of the respondents toward the discharge of their mentally retarded relative from the Oxford Regional Centre to a community residence. The statements attempted to determine the respondents' perceptions as to whether or not they felt the institution adequately involved and prepared them in the discharge process.

Over 60 percent of the responding family members agreed that their mentally retarded relative was ready to be discharged when the discharge took place and that the institution had adequately informed and advised them regarding the discharge. Approximately one-half of the responding family members agreed that they had enough say or control concerning the discharge of their mentally retarded relative. Approximately one-half of the respondents disagreed that their mentally retarded relative did not receive enough training at the institution before being discharged to the community residence. Over 60 percent of the respondents disagreed that they were not given enough preparation and information regarding the discharge of their mentally retarded relative.

A number of respondents indicated that they didn't know if they received enough preparation and information (15.25%), if the relative received enough pre-discharge training (16.36%), or if the relative was ready to be discharged when the discharge took place (12.90%).

The fact that a number of respondents felt they didn't know if the mentally retarded relative received enough pre-discharge training or if s/he was ready to be discharged is important to note. This may be due to the possibility that because of limited visitation, the family member may not have known the mentally retarded individual enough to determine the adequacy of his/her training or subsequent readiness to move to the community residence.

A number of responding family members were undecided as to whether or not the relative was ready to be discharged when the discharge took place (16.13%) or whether or not the relative received enough pre-discharge training (18.18%).

The fact that a number of respondents indicated that they were undecided as to whether the relative was ready to be discharged when the discharge took place and whether the relative received enough pre-discharge training is also important to note. Again, this could have been due to their lack of visitation or involvement with the mentally retarded person. The respondents may also have felt undecided at that point in time, waiting until both themselves and the mentally retarded relative had had time to experience the discharge before making judgements or opinions concerning the discharge process.

Significant positive associations were found between the family members' attitudes toward their mentally retarded relative's readiness to be discharged and their attitudes toward deinstitutionalization. The association suggests that the more they agreed that their relative was ready to be discharged when s/he was discharged, the more positive were their attitudes toward deinstitutionalization.

The finding that many respondents (62.90%) agreed that the mentally retarded relative was ready to be discharged when the discharge took place may suggest that the respondents may have felt the institution had helped the mentally retarded individual reach a potential and that the relative was ready to move on, perhaps to a community residence. This finding is not consistent with a study by Gollay et al. (1978) which found that families perceived inadequate training in advanced areas including crucial skills in using community resources. Huey (1978) reported that parents felt preparation of the mentally retarded individual is a necessary component of successful deinstitutionalization.

The significant positive associations found between the family members' attitudes toward deinstitutionalization and their attitudes toward the say or control they felt concerning the discharge suggests that the more they agreed that they had enough say or control, the more positive were their attitudes toward deinstitutionalization.

The finding that approximately only one-half of the responding family members agreed that they had enough say or control in the discharge process is supported by a past study where families were found to feel little control in the discharge process (Willer et al., 1978). This finding is also consistent with a study which has shown that parents may feel the institution should make the final decision of what is the best residential facility for their mentally retarded child (Payne, 1976).

The significant positive associations found between the family members' attitudes toward the preparation and information they received regarding the discharge and their attitudes toward deinstitutionalization suggests that the more the family members believed that they received enough preparation and information, the more positive were their attitudes toward deinstitutionalization.

The finding that many responding family members (62.71%) believed that they were given enough preparation and information regarding the discharge is contrary to past studies. The literature has suggested that parents may be dissatisfied with not being kept informed by the institution and that many families feel they receive little or no information or preparation concerning the discharge (Meyer, 1980; Willer et al., 1978).

5.6 ATTITUDES TOWARD THE DISCHARGED INDIVIDUAL

There were 4 statements included in the questionnaire which were concerned with the responding family members' attitudes toward the discharged mentally retarded relative and his/her rehabilitative capabilites.

Over 70 percent of the responding family members agreed that their mentally retarded relative, despite his/her level of retardation, could still learn more and that their relative had made significant progress since discharge from the institution.

Over 70 percent of the respondents disagreed that their mentally retarded relative had reached his/her potential while living at the institution and was incapable of learning much more in the community setting.

Approximately 60 percent of the responding family members agreed that their mentally retarded relative was capable of living successfully in the community.

A number of respondents indicated that they didn't know if the mentally retarded relative had made significant progress since discharge (11.29%), if the relative was capable of living successfully in the community (9.52%) or if s/he was capable of learning more (10.94%). The respondents who indicated that they didn't know to these statements may not have known the mentally retarded relative well enough to assess their capabilities. Also, depending on the amount of time since discharge, the respondents may not have had adequate time to assess the relative's capabilities. The respondents may also not have visited the discharged mentally retarded relative to any extent since discharge, therefore perhaps not being able to assess adequately any changes since placement in the community residence.

A number of respondents indicated that they were undecided as to whether the mentally retarded reative was capable of learning more (10.94%) or whether s/he was capable of living successfully in the community (12.70%). These respondents may have felt that at that time, they could not adequately determine these capabilities. The respondents may have been allowing the mentally retarded relative time to experience the community residence before voicing opinion regarding the relative's capabilities.

Significant positive associations were found between the family members' attitudes toward their mentally retarded relative's potential to learn more in the community setting and their attitudes toward deinstitutionalization. The association suggests that the more the family members disagreed that their mentally retarded relative had reached his/her potential in the institution and was incapable of learning much more in the community setting, the more positive were their attitudes toward deinstitutionalization.

The finding that most responding family members (76.78%) disagreed that their mentally retarded relative had reached his/her potential while living at the institution and was incapable of learning much more in the community setting may indicate the respondents' belief in the concept of developmental programming. This concept, as stated in Chapter II, is based on the belief that all developmentally disabled persons have the potential for increased growth, learning and development. The evidence of the respondents' belief in their mentally retarded relative's potential to learn more in the commmunity setting may suggest that most family members believed the community setting provided an opportunity for increased learning and development. The finding may also suggest that the respondents may have felt the institution hindered or stagnated their mentally retarded relative's development. This finding is not supported by the literature which indicates that parents of institutionalized mentally retarded persons maintain an unrealistically low appraisal of the mentally retarded individual's abilities and learning potentials (Menolascino, 1977). Meyer (1980) found similar results when he suggested that parents may feel the mentally retarded individual reached his/her potential and has nothing to gain from the community setting.

The significant positive associations found between the family members' attitudes toward the progress their relative had made since the discharge and their attitudes toward deinstitutionalization suggests that the more they agreed that progress had been made, the more positive were their attitudes toward deinstitutionalization.

? The finding that most responding family members (72.58%) agreed that their mentally retarded relative had made significant progress since being discharged from the institution may be due to two factors. The respondents may have felt ~~that~~ their mentally retarded relative had progressed because of their belief in the individual's potential or ability to learn more as suggested by the preceding finding. Another factor which may account for the respondents' attitudes may be their belief that the community residence, including its services or programmes, may have been the reason for the mentally retarded individual's progress since discharge.

5.7 ATTITUDES TOWARD COMMUNITY LIVING

There were 16 statements included in the questionnaire which were concerned with the responding family members' attitudes toward community living for their mentally retarded relatives.

Over 80 percent of the responding family members agreed that community residences were better because they allow mentally retarded persons like their relative to live more like "normal" people do.

Approximately 70 percent of the responding family members disagreed that it would have been better for their family if their mentally retarded relative had stayed in the institution and that the relative lived a better life when s/he was living in the institution.

Over 60 percent of the respondents agreed that community residences give more personal attention to the mentally retarded than do institutions, that they had a stronger relationship with the relative since placement in the community residence and that the community residence provided more opportunities for growth and learning than the institution did.

Over 60 percent of the responding family members disagreed that their mentally retarded relative received better care and supervision in the institution than s/he received in the community residence.

Approximately one-half of the respondents agreed that there were more services and professionals available to their mentally retarded relative since placement in the community residence, that institutions were outdated and did not provide as good care or programs as did community residences and that their mentally retarded relative was happier when s/he was with other mentally retarded persons. Less than one-half of the respondents agreed that they were concerned about what would happen to the discharged relat~~ive when~~ they were no longer alive.

Over one-half of the responding family members disagreed that institutions were better than communinty residences because they protected the mentally retarded. Less than one-half of the respondents disagreed that their relative had more friends when s/he lived in the institution and that they were concerned that the public may take advantage of their mentally retarded relative now that s/he lives in the community residence.

Well over one-half of the responding family members agreed that they were concerned that the public will never accept their mentally retarded relative.

Approximately 40 percent of the respondents disagreed that institutional staff were better trained than staff of community residences.

Over 10 percent of the responding family members felt they didn't know if it would have been better for their family if the relative had stayed in the institution. Similarly, over 10 percent of the respondents felt they didn't know if their relative received better care and supervision in the institution, if their relative was happier with other mentally retarded persons or if they were concerned about public acceptance or what would happen to the relative when they were no longer alive. Over 20 percent of the respondents felt they didn't know if there were more services and professionals available in the community residence, if the relative had more friends in the institution or if they were concerned that the public may take advantage of their mentally retarded relative now that s/he is living in the community residence.

The finding that a number of respondents felt they didn't know how they felt about these various statements concerning community living may suggest that the respondents didn't know or were unfamiliar with the relative himself, the Oxford Regional Centre and its programs or staff, or the present community residence and its programs and staff. This finding may have been due to a lack of contact with the mentally retarded relative because of limited visitation. Also, the respondents may not have had adequate time to become familiar with the community residence and issues such as public exploitation or acceptance.

Over 10 percent of the responding family members indicated that they were undecided concerning their mentally retarded relative's quality of life and the personal attention, care and supervision that s/he received. Similarly, over 10 percent of the respondents felt they were undecided as to which setting provided or stimulated more growth, learning, services or professionals. Over 10 percent of the respondents were undecided as to the adequacy of trained staff, if the public would exploit the relative, if the relative was happier with other mentally retarded persons or if they had a stronger relationship with the relative since the discharge took place. Approximately 20 percent of the respondents indicated that they were undecided concerning the number of friends their mentally retarded relative had, whether institutions were better because they protected or provided better care and supervision or whether they were concerned about public acceptance or what would happen to their relative when they were no longer alive.

The finding that a number of respondents were undecided concerning various statements concerning community living may suggest that the family members, at that time, felt they could not commit themselves to a negative or positive attitude or opinion. The respondents may have felt that at that time, they did not have enough information or they may have felt the mentally retarded inidividual had not experienced the community setting to a degree that they could make judgements concerning community living for their relative. Time and experience for both the respondents and their mentally retarded relatives may move them from an undecided position to one which is negative or positive concerning community living.

The fact that the questionnaire included a covering letter which was written on an Oxford Regional Centre letterhead and which included a statement from the Chief Social Worker of the Centre may have caused the respondents to be reluctant to express their attitudes concerning areas such as staffing, care, services or programs provided by the institution. Because the completed questionnaires were asked to be returned to the Oxford Regional Centre and despite guarantees of confidentiality and anonymity, the respondents may have been hesitant to express negative attitudes regarding the institution or their mentally retarded relative's care at the Centre. The literature has indicated that parents may express a loyalty to the institution, not wishing to condemn their services or practices (Payne, 1976).

The significant positive associations found between the family members' attitudes toward the effects of the discharge on their family and their attitudes toward deinstitutionalization suggests that the more the family members disagreed that it ~~would~~ have been better for their family if their relative had stayed in the institution, the more positive were their attitudes toward deinstitutionalization.

The finding that most responding family members (72.88%) disagreed that it would have been better for their family if the mentally retarded relative had stayed in the institution may suggest that these respondents felt deinstitutionalization did not pose many problems for their families. The literature has stated that institutionalization may serve a family function in maintaining family homeostasis or balance and that deinstitutionalization may be a potential threat to family balance (Bergman, 1975). It appears that the responding family members may not have felt this threat to their family functioning.

Significant positive associations were found between the family members' attitudes toward deinstitutionalization and their attitudes toward care and supervision. The associations suggest that the more positive the attitudes were toward deinstitutionalization, the more the family members disagreed that their mentally retarded relative received better care and supervision in the institution than s/he received in the community residence.

The finding that many responding family members (64.40%) disagreed that their relative received better care and supervision in the institution than s/he received in the community residence may suggest that these respondents felt the community residence provided adequate, if not better care and supervision. A past study has suggested that a major concern of parents of mentally retarded individuals is the quality and availability of care and supervision from the community residence (Meyer, 1980).

The significant positive associations found between the family members' attitudes toward deinstitutionalization and their attitudes toward protection suggests that the more they disagreed that institutions were better than community residences because they protected the mentally retarded, the more positive were their attitudes toward deinstitutionalization.

The finding that approximately only one-half of the responding family members disagreed that institutions were better than community residences because they protected the mentally retarded may suggest that the respondents may have felt their relatives, to some extent, still needed the security and protection of the institutional setting. This finding is consistent with the literature which has suggested that parents argue that community residences cannot offer the protection and security of institutional programs (Baker & Seltzer, 1977).

The family members' attitudes toward their mentally retarded relative's opportunities for growth and learning were found to be significantly positively associated with their attitudes toward deinstitutionalization. The association suggests that the more the family members agreed that the community residence provided more opportunities for growth and learning than the institution did, the more positive were their attitudes toward deinstitutionalization.

The evidence that most responding family members (70.49%) agreed that the community residence provided more opportunities for growth and learning than the institution did may be based on their perceptions that the community residence promoted a wider range of opportunities from which the mentally retarded relative could learn, grow or develop.

The significant positive associations found between the family members' attitudes toward deinstitutionalization and their attitudes toward their mentally retarded relative's quality of life suggests that the more the family members disagreed that their relative lived a better life when s/he was living in the institution, the more positive were their attitudes toward deinstitutionalization.

The finding that most of the responding family members (70.91%) disagreed that their mentally retarded relative lived a better life when s/he was living in the institution may suggest that the respondents felt the community residence allowed the relative to enjoy an adequate, if not enriched, life. The respondents may have witnessed the mentally retarded relative progress, learn and develop and feel his/her quality of live had been enhanced.

The family members' attitudes toward deinstitutionalization were found to be significantly positively associated with their attitudes toward the adequacy of trained staff. The association suggests that the more the family members disagreed that institutional staff were better trained than staff of community residences, the more positive were their attitudes toward deinstitutionalization.

Less than 40 percent of the responding family members disagreed that institutional staff were better trained than staff of community residences. This finding is somewhat consistent with a perhaps dated study which found that parents of non-institutionalized mentally retarded persons were not impressed by the staff of the institution where they frequently referred to their lack of training (Klaber, 1970). Very few respondents (8.62%) agreed that institutional staff were better trained but over one-half of the responding family members either felt they didn't know or were undecided. This finding may suggest that many respondents either didn't know the staff or didn't know the adequacy of their training. It is important also, to note that only 58 of the total 67 family members responded to this statement. The finding that many family members chose not to respond to this statement, or indicated that they didn't know or were undecided may indicate that the respondents were perhaps not comfortable in assessing the training of the staff, knowing that the questionnaires were being returned to the Oxford Regional Centre. Payne (1976) found parents of institutionalized mentally retarded persons to be satisfied with the staff of institutions, and at times describing them in unrealistic terms.

The family members' attitudes toward deinstitutionalization were found to be significantly and positively associated with their concerns about when they die. The association suggests that the more the family members disagreed that they were concerned about what would happen to their mentally retarded relative when they were no longer alive, the more positive were their attitudes toward deinstitutionalization.

Apptoximately one-half of the responding family members agreed that they were concerned about what would happen to the discharged relative when they were no longer alive. This finding may indicate that many of the respondents were concerned about who would assume the responsibility of advocating for the mentally retarded relative when they die. The respondents may have viewed the community residence as unstable, not making any long-term commitment to caring for the mentally retarded individual. The finding is supported by the literature which has indicated that parents may feel the institution is a permanent home and a place where the mentally retarded individual can live after the parents die (Huey, 1976; Payne 1976).

The significant positive associations found between the family members' attitudes toward the strength of their relationship with their mentally retarded relative and their attitudes toward deinstitutionalization suggests that the more they agreed that they had a stronger relationship with their relative, the more positive were their attitudes toward deinstitutionalization.

The finding that many responding family members (66.10%) agreed that they had a stronger relationship with their mentally retarded relative since placement in a community residence may suggest that deinstitutionalization may have been successful in re-uniting the mentally retarded person and his/her family. This finding is supported by the literature which has suggested that families can sometimes accept and be closer to the mentally retarded relative after discharge to the community residence (Bergman, 1975). It is interesting to note that although most of the mentally retarded individuals were living closer in physical proximity to their family members and that most family members felt they had a stronger relationship with their mentally retarded relative, that visitation of the responding family members to the community residence did not increase as much as might be expected. The respondents may have assumed that because the mentally retarded relative lived closer to them, that this itself created a closer relationship.

Significant positive associations were found between the family members' attitudes toward deinstitutionalization and their attitudes toward normalized community living. The association suggests that the more the family members agreed that community residences were better because they allow mentally retarded persons like their relative to live more like normal people do, the more positive were their attitudes toward deinstitutionalization.

Almost all of the responding family members (85.00%) agreed that community residences were better beacuse they allow mentally retarded persons like their relative to live more like normal people do. This finding is supported by the literature although a past study of parents of institutionalized mentally retarded individuals found only marginal agreement that group homes enable the mentally retarded to be more a part of normal life in society (Ferrara, 1979; Payne, 1976). The respondents' high agreement with this statement may have been due to at least partial agreement with the normalization principle. The idea of their mentally retarded relative living in a home-like setting enjoyed by the rest of society may have appealed to the respondents rather than the qualities of traditional institutional life.

Significant positive associations were found between the family members' concerns about public exploitation and their attitudes toward deinstitutionalization. The association suggests that the more the family members agreed that the public may take advantage of their mentally retarded relative, the less positive were their attitudes toward deinstitutionalization.

The finding that less than one-half of the responding family members disagreed that they were concerned that the public may take advantage of their mentally retarded relative now that s/he is living in the community residence may suggest that this was, or will become an area of concern for the respondents. This finding is supported by the literature where it has been suggested that families may fear that their mentally retarded family members may be prime targets for exploitation (Bradley, 1978). The responding family members may have felt that once the mentally retarded individual had left the shelter of the institution, that the individual may have been unprepared for a society which may take advantage of him/her.

5.8 COMMENTS FROM RESPONDENTS

A section at the end of the questionnaire allowed the responding family members to comment on areas which they may have felt were not included in the questionnaire.

Many of the family members used this section to inform the researcher of the many activities in which their mentally retarded relative was presently involved. Some of these comments were:

> My relative seems to be happier now. Every Sunday he goes for supper either at my brother's place or mine. (Sister, 65 years old, happy present feeling concerning deinstitutionalization)

> Since living in a community residence our daughter has learned how to do all types of housework, cooking, meal planning and grocery shopping. We are extremely proud of the progress she has made. (Mother, 59 years old, happy present feeling concerning deinstitutionalization)

> She travels on the bus by herself. She seems very happy and is encouraged to be self-sufficient. (Mother, 61 years old, happy present feeling concerning deinstitutionalization)

Many of the family members, while indicating their happiness or satisfaction that the mentally retarded relative had been discharged, made a point of pointing out that they were also happy with the care received from the institution. Comments such as these were made:

> I feel he received good care in the institution but may receive more personal care in (the) residence as they have fewer to cope with. (Mother, 67 years old, happy present feeling concerning deinstitutionalization)

> While my brother had excellent care in the institution, he is enjoying a happier more full life. (Brother, 71 years old, happy present feeling concerning deinstitutionalization)

> I feel that my . . . son is progressing wonderfully. The staff . . . are very good. I have nothing to say but the very best of your (Oxford Regional Centre) staff. My son also received good care in Woodstock (Oxford Regional Centre). (Father, 76 years old, happy present feeling concerning deinstitutionalization)

There were a number of family members who made remarks such as these on the progress made by their mentally retarded relative:

> She talks now so we can understand her. (Mother, 46 years old, happy present feeling concerning deinstitutionalization)
>
> Since the transfer to (the) community, my child has reached far beyond her expected potential. I am amazed at what she is capable of doing. (Mother, 63 years old, happy present feeling concerning deinstitutionalization)
>
> I feel that the community residence provides a more homey atmosphere and the retarded get more attention and are trained to their full capacity to be as self-sufficient as possible. (Sister, 49 years old, happy present feeling concerning deinstitutionalization)
>
> My brother has done so well this past year that no one would believe it without seeing it for themselves. (Sister, 34 years old, happy present feeling concerning deinstitutionalization)

A few of the family members commented on the discharge process:

> My child was transferred several times - received the notice after (the) transfer. Woodstock (Oxford Regional Centre) was the first to consult me about change . . . . I must admit some of the workers are very tactless in their approach to parents' feelings regarding their child . . . (in speaking of a boyfriend - girlfriend relationship which had developed) . . . I feel strongly that parents should be advised and prepared that a situation like this could develop if a child is transferred to community life. (Mother, 63 years old, happy present feeling concerning deinstitutionalization)
>
> When the social worker informed me as to releasing my brother from Woodstock Regional Centre, I don't think we were informed enough as it appeared that a decision had already been made to that effect. (Brother, 47 years old, mixed feeling concerning deinstitutionalization)

Many family members indicated their present and future concerns regarding community living for their mentally retarded relative:

> I think that she has a little too much freedom now. I don't think she should be out alone on streets at night. (Mother, 72 years old, mixed present feeling concerning deinstitutionalization)
>
> Now that she has been moved . . . there is less care, indifference towards her, little effort made to care for her particular needs . . . I feel the staff are not interested in

> her, simply doing a job. There is little or no communication between (the residence) and me but nonetheless, she is closer to home, has her own room, and I can keep in touch more often. (Mother, 53 years old, happy present feeling concerning deinstitutionalization)

> Will these residences be maintained at the standard they are now or will they be allowed to slip? Will these children or young adults be able to live out there (sic) life time here or be placed back in (the) institution as they reach old age? (Mother, 56 years old, mixed present feeling concerning deinstitutionalization)

> I do think they should go out on streets in two's and three's, not alone this day and age. (Mother, 79 years old, mixed present feeling concerning deinstitutionalization)

> We are concerned about the next step along the road to our son's independence - an apartment. He talks of it constantly and that is the goal he is working toward. We fear that if the social workers at the group home deem him ready for such a move, we will be put in the awkward position of dashing his hopes. He has had enough freedom during the past 18 months that he would be destroyed if he were sent back to an institution. (Mother, 61 years old, mixed present feeling concerning deinstitutionalization)

One family member described well the impact that deinstitutionalization has had on her family:

> It is easier on the family when the relative lives in an institution. Now he is close to home which is nice but our son gets upset quite easy and he calls home at least 3 times a week and tells of his problems. Also, he comes home most Sundays which sometimes causes tension. But we are happy for him and don't wish him back in the institution. When a relative is in an institution you bring them home once a month, for the rest you kind of forget about them. It sounds cruel, but it is a fact. (Mother, 44 years old, mixed present feeling concerning deinstitutionalization)

5.9 SUMMARY

This chapter discussed and interpreted the research findings in relation to the available literature.

The last chapter will summarize the research findings. The limitations of the research findings will be presented and several recommendations will be suggested.

Chapter VI

SUMMARY, CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

This chapter is divided into three sections. In the first section the major findings of the study will be summarized in relation to the research questions which were presented in Chapter III. Several conclusions will be drawn in describing the family members' attitudes toward deinstitutionalization.

In the second section, the limitations of the findings of this study will be presented.

In the third section of this chapter, the researcher will present several recommendations based on the review of literature and the findings of this study. The recommendations include specific suggestions for social workers involved with families of mentally retarded individuals about to be discharged to community placements.

6.1 SUMMARY AND CONCLUSIONS

The purpose of this study was to describe the attitudes of family members of mentally retarded individuals toward deinstitutionalization.

The Respondents

A total of 67 family members completed the questionnaire which represented a response rate of 72%. The respondents in this study were generally parents of mentally retarded individuals who had been discharged from an institution and placed in a community residence. Mothers constituted 60 percent of the responding family members. Most of the family members were of an older age, where 78 percent of the respondents were over 50 years of age.

There was very little increase in the frequency of the family members' visitation with their mentally retarded relative after community placement. Most of the family members lived within 99 kilometers of their discharged mentally retarded relative.

Over 90 percent of the family members felt someone other than themselves initiated the first idea of having their mentally retarded relative discharged from the institution and placed in the community residence. Social workers were indentified by over half of the family members as being the initiators of the idea idea of deinstitutionalization.

Attitudes Toward Deinstitutionalization

The questionnaire included 25 statements regarding deinstitutionalization or community living. Of these 25 statements, 5 were aimed at determining the family members' attitudes toward the discharge process, 4 were aimed at determining their attitudes toward their mentally retarded relative's rehabilitative capabilities and 16 statements were aimed at determining their attitudes toward community living for their mentally retarded relative.

A comparison of the family members' first reactions and present feelings concerning deinstitutionalization yielded a number of notable findings. Of the 57 family members who indicated both their first reactions and present feelings concerning deinstitutionalization, 56 percent felt their first reaction was happy, 39 percent felt their first reaction was mixed and 5 percent felt their first reaction was unhappy. In comparison, 74 percent of the family members felt their present feeling concerning deinstitutionalization was happy, 23 percent felt their present feeling was mixed and 4 percent felt their present feeling was unhappy. When the family members' first reactions and present feelings concerning deinstitutionalization were cross-tabulated, it was noted that 72 percent of the family members' attitudes did not change, 23 percent of the family members' attitudes changed to a more positive attitude and 5 percent changed to a less positive attitude toward deinstitutionalization.

The findings suggested that the family members' present feelings concerning deinstitutionalization were generally more favourable than were their first reactions. It appeared that most of those family members who had a mixed first reaction moved to a happy present feeling concerning deinstitutionalization. The researcher has concluded that very few family members were unhappy about deinstitutionalization. Although most family members indicated that they were happy, a considerable number indicated that they still had a mixed feeling concerning deinstitutionalization.

The findings of this study implied that the family members' attitudes toward deinstitutionalization were subject to change. Therefore, a family with initial mixed or unhappy feelings may eventually come to accept deinstitutionalization or community placement.

The findings of this study suggested that a family member's positive attitude toward deinstitutionalization did not imply that s/he was without concern or fear for his/her mentally retarded relative living in the community setting. Many family members in this study indicated a happy feeling concerning deinstitutionalization but expressed areas of deep concern regarding community placement.

The family members' attitudes toward the preparation and information they received and the say or control they felt concerning the discharge of their mentally retarded relative as well as their attitudes toward their relative's readiness to be discharged were found to be significantly associated with their attitudes toward deinstitutionalization.

The moderate disagreement expressed by the family members to the statement that they were not given enough preparation and information regarding the discharge caused the researcher to conclude that many family members felt they received adequate information and preparation concerning the discharge of their mentally retarded relative from the institution to the community residence.

There was moderate agreement from the family members that their mentally retarded relative was ready to be discharged when the discharge took place. The researcher therefore concluded that many family members felt the institution discharged their relative at an appropriate time or when the relative was ready for community placement.

Only approximately half (51%) of the family members agreed that they had enough say or control concerning the discharge of their mentally retarded relative. The researcher concluded that many family members may have desired more input, say or control in the discharge of their mentally retarded relative to the community setting.

The family members' attitudes toward their mentally retarded relative's potential to learn more in the community setting and their attitudes toward their mentally retarded relative's progress since being discharged from the institution were found to be significantly associated with their attitudes toward deinstitutionalization.

There was strong disagreement from the family members that their mentally retarded relative had reached his/her potential while living at the institution and that s/he was incapable of learning much more in the community setting. The researcher therefore concluded that most family members felt strongly that their mentally retarded relative was capable of learning more in the community residence.

The strong agreement from the family members that their mentally retarded relative had made significant progress since being discharged from the institution caused the researcher to conclude that most family members felt strongly that the community placement stimulated their relative's growth, learning and development.

The family members' attitudes toward normalized community living, the effects of the discharge on their family, their relative's growth, learning, quality of life, care, supervision, protection, their relationship with their mentally retarded relative, the adequacy of trained staff, public exploitation and their concerns about when they die were all found to be significantly associated with their attitudes toward deinstitutionalization.

There was very strong agreement from the family members that community residences were better than institutions because they allowed mentally retarded persons like their relative to live more like "normal" people do. The researcher concluded that the normalizing nature of the community residences may have been an appealing feature of deinstitutionalization or community living for the family member.

The family members' strong disagreement with the statement that it would have been better for their family if their mentally retarded relative had stayed in the institution caused the researcher to conclude that most respondents felt deinstitutionalization had little or no negative effect on their family.

The researcher also concluded that most family members felt their mentally retarded relative had lived a better quality of life since being discharged to the community residence. Strong disagreement was found with the statement that their mentally retarded relative lived a better quality of life when s/he lived at the institution.

There was moderate disagreement from the family members that their mentally retarded relative received better care and supervision in the institution than s/he received in the community residence. The researcher concluded that many family members may have felt that their mentally retarded relative received better care and supervision in the community residence.

The family members' moderate agreement with the statement that they had a stronger relationship with their mentally retarded relative since s/he was discharged to the community residence caused the researcher to conclude that deinstitutionalization may have been successful in promoting stronger relationships between many family members and their mentally retarded relatives.

The researcher concluded that many family members either didn't know or were undecided as to how adequately trained the staff of either the institution or the community residence were. There was low disagreement and even lower agreement with the statement that institutional staff were better trained than staff of community residences.

There was moderate disagreement from the family members that institutions were better than community residences because they protected the mentally retarded. The researcher concluded that many family members either felt the protection offered by the institution was not a feature which made it more appealing than the community residence or that community residences protected the mentally retarded as adequately as did the institution.

The researcher concluded that many family members were or may in the future be concerned that the public may take advantage of their mentally retarded relative. Low disagreement was found with the statement that they were concerned that the pulic may take advantage of their mentally retarded relative now that s/he lives in the community setting.

The researcher also concluded that many family members were or may in the future be concerned about what will happen to their mentally retarded relative when they are no longer alive. The researcher concluded that many family members were concerned about who would assume responsibility for their mentally retarded relative after they had died. Moderate agreement was found with the statement that the family members were concerned about what will happen when they die.

6.2 LIMITATIONS

Since the study involved individuals discharged from one institution, the external validity was restricted.

Positive bias may have been induced by the fact that the questionnaire's covering letter was written on an institutional letterhead and included an endorsement from the institution's Chief Social Worker.

Although the questionnaire was anonymous, the influence of "social desirability" and the "acquiescent response set" tendencies may have been sources of differences in scores among the respondents on the questionnaire statements.

The apparent variable associations may have been spurious because variables such as sex, age, level of retardation, amount of visitation and length of institutionalization may have been involved, but were not statistically tested.

The degree to which the instrumentation was effective in determining the family members' attitudes toward deinstitutionalization was difficult to determine since it was not pre-tested on the actual sample.

6.3 RECOMMENDATIONS

Deinstitutionalization or community placement should not come as a surprise or shock to the family members of the mentally retarded. It is recommended that family members, during intake or admission procedures to the institution, be informed and prepared that the time may come when their relative may be discharged to a community placement. As community placement becomes more inevitable, the social worker should begin to explore the family's feelings about community placement with the ultimate goal being the family's acceptance of the value of community placement. Social work involvement with the families of the mentally retarded should therefore not be limited to intervention at the time of admission or discharge.

The findings of this study suggested that the amount of information and preparation received by the family members was associated with their attitudes toward deinstitutionalization. It is recommended that families of the mentally retarded about to be discharged therefore be informed and prepared well in advance about the discharge.

The findings of this study also suggested that the amount of say or control the families felt in the discharge process was associated with their attitudes toward deinstitutionalization. The researcher recommends that the family should, when appropriate, participate in the selection of their mentally retarded relative's community placement. It is recommended that the individual's family members visit the community residence before discharge. This visit will allow them to view, assess and ultimately understand first-hand, the concept of community placement.

Although family involvement in deinstitutionalization is recognized as a potential resource system in the transition from institution to community residence, it is recommended that the level of their involvement be determined on an individual basis.

The findings of this study have confirmed the suggestions by the literature that parents of the mentally retarded are concerned about what will happen to their relative when they are no longer alive. The researcher recommends that the siblings of the mentally retarded individual be involved in the pre and post-discharge procedures as much as possible in order that they may be prepared for increased involvement when their parents die.

It is recommended that social workers recognize that deinstitutionalization may pose a potential crisis for families of the mentally retarded. The guilt that may surface should be addressed where the family members, especially parents, should be assured that deinstitutionalization does not infer that they made a mistake in institutionalizing the mentally retarded relative.

It is recommended that social workers working with families of the mentally retarded recognize that in many cases they have justifiable concerns regarding community living for their mentally retarded relative. The findings of this study suggested that many family members were concerned about issues such as public exploitation and what would happen to their relative when they die. Pre-placement counselling should address issues of this nature and should include assurances that the mentally retarded relative will continue to receive quality care, services, programmes and supervision. The social worker should also address any questions about the issue of continuing accountability. Education and counselling will help the family members develop realisitc expectations and concerns.

The researcher recommends that social work involvement with the families of the mentally retarded not terminate after community placement. Rather, social work involvement with the family should be on-going as deemed necessary by either the family or the social worker.

It is recommended that the institutional social worker personally introduce the new community social worker and thoroughly explain his/her function as the community or follow-up worker. It is also recommended that the social worker stress his/her availability in the event that problems may arise.

The findings of this study suggested that family members may justifiably be concerned about public exploitation. The researcher recommends that mentally retarded individuals be educated to assert themselves, as necessary, as part of their pre-discharge training.

It is recommended that further research attempt to identify variables which may influence family members' attitudes toward deinstitutionalization.

It is also recommended that a similar study with the use of interviews or open-ended statements be done in order to identify the specific concerns of family members concerning community placement.

Exploratory research in order to describe the family members' attitudes toward deinstitutionalization before and after the discharge is recommended.

Finally, further research in order to articulate familial concerns regarding deinstitutionalization is also recommended. Realisitc and practical concerns regarding deinstitutionalization should be defined and ultimately recognized by policy developers. Continued community service development and public education may reduce these concerns.

Appendix A

COVERING LETTER

Ontario
Ministry of
Community and
Social Services

Oxford
Regional
Centre

P.O. Box 310
Woodstock, Ontario
N4S 7X9
(519) 539-1251

Woodstock, Ontario,
May 1981.

Dear Sir or Madam:

During the past several years, many mentally retarded persons have been discharged from large insititutions such as the Oxford Regional Centre, and then placed in smaller residences located in the community.

As part of the requirements of my Master of Social Work program at the University of Windsor, and with approval of the Oxford Regional Centre Research Committee, I am researching the attitudes of families of mentally retarded individuals toward deinstitutionalization or community living.

I understand that a relative of yours has been a resident at the Oxford Regional Centre, Woodstock, and is now living in a community setting. I would appreciate your consideration in completing the enclosed questionnaire. It is short and easy to complete, and can be returned in the enclosed envelope.

I would like to assure you that confidentiality of your responses will be maintained. Names and any identifying data will not be available to this researcher. Your responses will be anonymous.

Your help in aiding me to complete this study is greatly appreciated and the results of this research will no doubt help professionals to better serve mentally retarded persons and their families in the future.

Thank you for your time and co-operation.

Yours sincerely,
Mark W. Benner
Mark W. Benner, B.S.W.,
Researcher.

We have agreed to co-operate in this worthwhile study because we believe it will be helpful in planning services to families of our residents. We guarantee that no names will be kept or made available to anyone. If you have any questions regarding any phase of this study, please contact me at the above address.

Thank you.

Yours sincerely,
Michael E. Connell
Michael E. Connell, M.S.W.,
Chief Social Worker,
Oxford Regional Centre.

Appendix B

FOLLOW-UP LETTER

Ontario
Ministry of
Community and
Social Services

Oxford
Regional
Centre

Woodstock, Ontario
N4S 7X9
(519) 539-1251

Woodstock, Ontario.

Dear Sir or Madam:

In early May, a questionnaire was sent to you as part of a research project which is attempting to determine attitudes of families of mentally retarded individuals toward deinstitutionalization or community living.

This study cannot be completed until all questionnaires have been returned and to date, many persons have not responded to the questionnaire. If you have not yet responded, it would be greatly appreciated if you would take time to complete this short questionnaire and return it in the enclosed stamped envelope by June 10, 1981.

May I point out again that you are <u>not</u> required to include your name and that you or your responses will <u>not</u> be identifiable by this researcher.

Thank you for your assistance in helping to complete this study.

Yours sincerely,

MB/ab

Mark Benner, B.S.W.

Appendix C

QUESTIONNAIRE

INSTRUCTIONS:

Thank you for taking the time to answer this short questionnaire. This questionnaire should be completed by ONE person, preferably by the family member most involved with the mentally retarded person. Should there be another family member who lives at another address who would be in a better position to complete the questionnaire, please DO NOT complete this questionnaire, but kindly supply their name and address and return the unanswered questionnaire in the enclosed stamped envelope.

Alternate Relative: -
Name: ____________________
Address: ____________________
Relationship: ____________________

Please answer ALL QUESTIONS and return this questionnaire in the enclosed stamped envelope by MAY 22, 1981.

1. What is your relationship to the discharged mentally retarded person? ____________ (ie. mother, uncle etc.)
2. What city do you live in? ____________
3. What is the name of the residence or group home where your mentally retarded relative now lives? ________
4. What is your age? _____
5. On the average, how often did you visit your relative when he/she lived in the institution? ___times per year.
6. On the average, how often do you visit your relative now that he/she lives in a community residence? ___times per year.
7. The FIRST idea of having my relative discharged from the institution and placed in a community setting came from:
   1. ____the relative himself
   2. ____myself
   3. ____an institutional social worker
   4. ____another institutional employee. Specify _____
   5. ____other (specify) ____________
   6. ____don't know
8. My FIRST reaction when I learned that my relative was to be discharged to a community setting was:
   1. ____I was happy about the idea
   2. ____I was not happy about the idea
   3. ____I had mixed feelings
   4. ____No reaction/didn't know

To what extent do you agree or disagree with each of the following statement? For each statement check ( ) only one response.

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	Don't Know
9. I feel that I had enough say or control concerning the discharge of my relative.	( )	( )	( )	( )	( )	( )
10. My relative was ready to leave the institution when he/she was discharged.	( )	( )	( )	( )	( )	( )
11. My relative, despite his/her level of retardation, can still learn more.	( )	( )	( )	( )	( )	( )
12. I feel the institutional staff adequately informed and advised me regarding the discharge of my relative to the community residence.	( )	( )	( )	( )	( )	( )
13. My mentally retarded relative is capable of living successfully in the community.	( )	( )	( )	( )	( )	( )
14. My relative has made significant progress since being discharged from the institution.	( )	( )	( )	( )	( )	( )
15. Now that my relative lives in the community residence people may take advantage of him/her.	( )	( )	( )	( )	( )	( )

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	Don't Know
16. Now that my relative is living in the community setting I am concerned about what will happen to him/her when I am no longer alive.	( )	( )	( )	( )	( )	( )
17. I was NOT given enough preparation and information regarding the discharged of my relative.	( )	( )	( )	( )	( )	( )
18. There are more services and professionals available to my relative now that he/she lives in the community residence.	( )	( )	( )	( )	( )	( )
19. Institutions for the retarded do not provide as good care or programs as do community residences.	( )	( )	( )	( )	( )	( )
20. My relative reached his/her potential while living in the institution and is incapable of learning much more in the community residence.	( )	( )	( )	( )	( )	( )
21. Community residences are better because they allow mentally retarded persons like my relative to live more like normal people do.	( )	( )	( )	( )	( )	( )

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	Don't Know
22. My relative did NOT receive enough training at the institution before being discharged to the community residence.	( )	( )	( )	( )	( )	( )
23. My relative lived a better life when he/she was living in the institution.	( )	( )	( )	( )	( )	( )
24. I have a stronger relationship with my relative now that he/she lives in the community residence.	( )	( )	( )	( )	( )	( )
25. My relative had more friends when he/she lived in the institution.	( )	( )	( )	( )	( )	( )
26. My relative is happier when he/she is with other mentally retarded persons.	( )	( )	( )	( )	( )	( )
27. I am concerned that the public will never accept my mentally retarded relative.	( )	( )	( )	( )	( )	( )
28. Institutions are better than community residences because they protect the mentally retarded.	( )	( )	( )	( )	( )	( )

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	Don't Know
29. The community residence provides more opportunities for growth and learning than the institution did.	( )	( )	( )	( )	( )	( )
30. My relative received better care and supervision in the institution than he/she now receives in the community residence.	( )	( )	( )	( )	( )	( )
31. It would have been better for my family if my relative had stayed in the institution.	( )	( )	( )	( )	( )	( )
32. Community residences give more personal attention to the retarded than do institutions.	( )	( )	( )	( )	( )	( )
33. Institutional staff are better trained than staff of community residences.	( )	( )	( )	( )	( )	( )

34. My PRESENT feeling regarding the fact that my mentally retarded relative is living in a community residence is:

1. ____I am happy about the idea
2. ____I am not happy about the idea
3. ____I have mixed feelings
4. ____No reaction/don't know

Thank you for taking the time to answer this questionnaire.

<u>COMMENTS</u>:

Appendix D

CASE REVIEW SCHEDULE

CASE REVIEW SCHEDULE

1. Code number ____________________
2. Year of birth of discharged person ____________________
3. Sex of discharged person ____________________
4. Level of retardation ____________________
5. Number of years institutionalization ____________________
6. Number of months since discharge ____________________
7. Relationship of next-of-kin ____________________
8. Place to which discharged ____________________
9. City to where discharged ____________________

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REFERENCE NOTES

Note 1: London Area Mental Retardation Working Group. Mental retardation population and service, London Area. June, 1981.

VITAE AUCTORIS

Mark William Benner was born on October 1, 1955 in Woodstock, Ontario. After completing his elementary and secondary education in the same city, he pursued a Bachelor of Arts degree in Psychology at King's College, The University of Western Ontario, London. Upon graduation in 1977 he was employed as a Mental Retardation Counsellor at the Oxford Regional Centre, Woodstock, Ontario, for two years.

In 1979 he was admitted to the University of Windsor School of Social Work and graduated with a Bachelor of Social Work degree in 1980. In September, 1980 he began the Master of Social Work programme at the same university and he expects to graduate in October, 1981.

Mr. Benner's field placements were with the Windsor Association for the Mentally Retarded and the Wayne County Children's Centre, Child Day Treatment Programme in Detroit, Michigan.