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The influence of kin support and parental attitudes on the care of deinstitutionalized developmentally-disabled children

Susan Carol Herrick

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Herrick, Susan Carol, Ph.D.

University of New Hampshire, 1987

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THE INFLUENCE OF KIN SUPPORT AND PARENTAL ATTITUDES
ON THE CARE OF DEINSTITUTIONALIZED
DEVELOPMENTALLY DISABLED CHILDREN

By

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A DISSERTATION

Submitted to the University of New Hampshire
in Partial Fulfillment of
the Requirements for the Degree of

Doctor of Philosophy
in
Sociology

December 1987
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November 30, 1987
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Susan Carol Herrick
1987
For
Elyse Carol Herrick
Valerie Antoinette Parker
F. Herrick Herrick
Acknowledgements

There is a proverb that says, "Iron sharpens iron, and one man sharpens another." I thank the members of my committee for sharpening me, for their encouragement, and for opening up new avenues for discussion.

To thank Dr. Murray A. Straus, I can but draw the parallel of Cordelia and King Lear. The elaborate accolades of his two other daughters seemed towering in comparison to the laconic response of the third. Like Cordelia (if one may liken one's dissertation chair to an academic father), I cannot eschew such descriptors as pedagogue, patient guide, methodologist of steely acumen, paragon for the ability to focus on what is essential and dispense with what is not (making completion feasible and the goal clear)—for I have benefitted from all these qualities. However, I can think of no other single word more apt, that fully embodies these qualities, that I, as a graduate student, privileged to study under Dr. Straus, could use to pay him tribute than the word, mentor.

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knowledge of rural-urban sociology and ethnicity provided insights into the New Hampshire families who participated in this study.

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Completing a dissertation becomes a leitmotif of one's life, as other obligations vie for one's attention. It becomes a traveling companion, a friend, a nemesis, but always a presence that imposes itself not only upon the writer's a consciousness, but upon the writer's society, until they, too, are involved, urging for closure,
denouement, the final chord. Thus, when I was appointed Assistant Professor of Sociology at Drew University, and moved from Newmarket, New Hampshire to Madison, New Jersey, there were many who came to the fore:

Dr. Jonathan Whittier Reader, the Chair of the Sociology Department, my friend and advocate, who introduced me to the Great Swamp, a refuge not only for wildlife but for rookie professors.

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this greeting made me realize that Bill might be just the person to help me. Only a true computer technite and a man of generous spirit, would or could lend me his "spare" terminal so that I could dial into the ol' DEC 10 from my little Newmarket cloister, at graduate students' rates of course (i.e., gratis).

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ABSTRACT

THE INFLUENCE OF KIN SUPPORT AND PARENTAL ATTITUDES
ON THE CARE OF DEINSTITUTIONALIZED,
DEVELOPMENTALLY DISABLED CHILDREN

by

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University of New Hampshire, December 1987

Are there characteristics of the handicapped child and/or his family which correlate with parents' perceptions of positive kin support? How does kin support affect the child's placement outcomes? How does the child's locus in the historical context of the deinstitutionalization movement influence his/her communitization?

To answer these questions, 93 families whose children were residents at Laconia State School and Training Center for mentally retarded people in New Hampshire were engaged in face-to-face interviews between 1984 and 1985. Each parent was read a list of possible resource groups (family, friends, neighbors, co-workers, other parents, clergy, doctors, and "others") and asked how frequently each gave assistance. Parents were asked who was the most supportive and to rate the level of supportiveness of extended kin, on a Likert-type scale as it related to their child.

Using multiple regression analysis, findings suggest that, at the time of community placement, the most significant variables correlated with perceived positive kin support are the child's gender, diagnosis, year of placement and the proportion of sisters living in the household.
Follow-up interviews or parents and their kin revealed the type of support offered, often depended upon families' developmental cycles. Though men and women relatives provide different types of support, at different times, their support seems to have a catalytic rather than a direct effect upon the mother's ability to identify and utilize available community resources. The data lend further credence to the increasing evidence of the benefits of identifying handicapped families' kin support networks, not only in terms of intervention and treatment but in terms of "communitization." This term is introduced as the logical political next step after the deinstitutionalization and normalization movements. It is argued that kin are the likely candidates for furthering this process since they reside midway between society-at-large and the handicapped families themselves. Policy implications of this study are discussed with regard to Moroney's notion of "shared responsibility" (Moroney, 1986) and Litwak's "principal of matching" (Litwak, 1985).
CHAPTER I

THE INVOLVEMENT OF EXTENDED KIN IN THE CARE OF DEVELOPMENTALLY DISABLED CHILDREN: AN OVERVIEW

The purpose of this study is to examine the effects of kin support on the care of developmentally disabled children, in the context of the deinstitutionalization movement still in progress in the United States. This movement represents the culmination of over a century of ideological changes with regard to deviants. It has resulted in the reduction of institutional censuses across the country (Conroy, 1985a). As an end-goal, however, deinstitutionalization is unsatisfactory.

"Communitization" (Mallory, 1986a) has become the term used to describe the logical next phase in realizing the principles of normalization (Nirje, 1976) as the ideological foundation laid down in the 1970s. Communitization means the integration of developmentally disabled people into the community. This does not simply mean a house on Main Street, USA, but a sharply increased probability that handicapped people will have daily contact with members of the rest of the community which will eventually lead to the lowering of the consequences of stigma. The process involves the socialization of an entire nation with regard to this small segment of its population (about 3%).

The importance of extended kin in this socialization process is not to be underestimated, even though in industrial society, families tend to live neolocally and in nuclear units. Litwak (1985), Farber, (1981) and others (e.g. Bott, 1971; Young and Willmott, 1957)
have shown that modern families still have a great deal of contact with extended kin. This being the case, extended kin of handicapped children are likely candidates in furthering communitization. As I will discuss later in this introduction, parents and professionals have begun to include informal networks in the care and treatment program planning of developmentally disabled people, especially children. What I am arguing is that extended kin reside midway between society-at-large and the handicapped families themselves, and, therefore, can expedite de-stigmatization and community integration.

It is in this context that we ask the question: What are the effects of kin involvement on the communitization of developmentally disabled children? Since kin are potentially a major source of help with family problems, the question, in this research is: Which families are most likely to perceive themselves as supported by their kin? Furthermore, does this perceived support, or lack thereof, contribute to communitization outcomes? These questions are important to an immediate understanding of how families cope with major difficulties.

The 93 children and young adults whose families participated in this study, have all shared in common the fact that they have been, at one time in their lives, residents of the Laconia State School and Training Center (LSS) in the State of New Hampshire. They and their families have all faced the difficulties of placement in the institution and then the prospect of returning to the community. In this study, we will focus on kin support, but it should be kept in mind that we were not merely addressing an auxiliary role of kin. Underlying this familial altruism is a potentially strong political force in expediting community integration of handicapped people.
The Family and Extended Kin

The family, for purposes of this research, is defined as consisting of the nuclear family, i.e., parents and their children. This definition serves as the basis for variations, such as the single-parent family (usually single mothers and their children), the reconstituted family (Satir, 1972) consisting of either widowed or divorced persons who are married and living with their own and/or their spouse's biological children from a previous marriage; also included are foster and adoptive families.

Researchers have reached the conclusion in every decade since the 1950s, that extended kin relations of siblings and their parents, grandparents and great grandparents are still important in contributing to the functioning of the nuclear family unit in its various forms (Bott, 1957; Young and Willmott, 1957; Komarovsky, 1962; Farber, 1973; Rubin, 1976; Farber, 1981; Litwak, 1985; Fewell and Vadasy, 1986).

Kin assistance is not static. It waxes and wanes over the life cycle. Over twenty years ago, the anthropologist, Meyer Fortes (1962), argued that nuclear and extended families and patrilocal and matrilocal residences are part of a developmental cycle which is represented by residence but that these are only points in time in the cycle. The "isolated" nuclear unit is one with ties to extended kin which change over the life cycle of family members and in historical time. For example, when children leave their families of origin to found their own families of procreation, there is still documented evidence of exchange of goods and services in helping the new couple establish their household (Kennedy and Stokes, 1982). There is a common joke in our culture which says, "If it weren't for weddings and
funerals, we'd never see our relatives." This is simply the observation that families expand and contract over the life cycle, rallying when support is needed and living their own lives the rest of the time.

Litwak and Szelenyi (1968) and others have shown that physical distance among family members, due to greater mobility in post-industrial society, has not vitiated kinship ties. Farber (1981) has made us aware that reduced actual face-to-face contact of nuclear families with kin should not cause us to conclude that kinship is becoming a "relic." He presents data confirming the symbolic, normative power of kin which continues to act as a strong psychological and emotional connection among kin, although actual contact is determined by differential opportunities and competing interests. Before we look at how kin influence family processes, let us briefly outline the main functions of the family.

Family Functions

To insure healthy functioning, the tasks the family fulfills have been variously identified in the literature as: the physical, emotional, social, spiritual and biological maintenance and growth of family members for their mutual development (Duvall, 1971; Rodgers, 1964; Ackerman, 1966). To this list may be added the ability to meet "the challenge of both internal and external change" (Minuchin, 1974; see also Glasser and Glasser, 1970).

Caplan (1976) emphasizes the feedback guidance system function of the family. He enumerates the various aspects of this function: The family acts as 1) a source of ideology; 2) a mediator in problem solving; 3) a source of practical service and concrete aid; 4) a
millieu in which rest and recuperation take place, where one can be oneself. Robert Frost, whose private life of domestic violence was veiled by his public poetry, said: "Home is where they have to take you back" (Stafford, 1974); 5) the family is the primary group where validation of one's identity occurs; and 6) where one gains emotional mastery. Emotional mastery involves dealing with negative emotions, such as anxieties, depression, anger, guilt, etc., by providing a variety of means to deal with frustration (in healthy families) via hope, respect and love based on past experiences and an accumulation of cultural wisdom and ideology in the form of tradition and religion.

Even though family tradition and religion may not be sources of concrete knowledge specifically addressing the problems of handicapped people, these forms of social support can provide mollifying reassurance and can pave the way for clear thinking and courageous problem solving. One of the strengths of the family is that it does evaluate and steer its members to make choices, and to weigh the costs and benefits of anticipated outcomes. In other words, value judgments are crucial to family problem solving. Caplan observes: "In an era when the dominant philosophy of clinicians is non-judgmental, it may be well to emphasize that a non-judgmental approach inside the family in our culture is not necessarily of value."

**Kin Support**

In order for the above outlined tasks to be accomplished, social support is necessary and rests on an even more fundamental foundation of love and caring. Caplan points out that social support is forthcoming only when certain requirements are met. These include the variables of intactness, stability, integration, common language
and free communication. Caplan speculates that a family may be optimally supportive only if its members accept its ideology and code of behavior, including the obligations of mutual concern for each other, as well as the social mission of the family in monitoring and controlling individual behavior (1982:215).

Cobb (1979) has identified four types of support: social support, instrumental support, active or mothering support; and material support. He further identifies three components of social support which he deems as the "most important" of the four types. Social support consists of: 1) emotional support, leading the recipient to believe that she is cared for and loved; 2) esteem support, leading to a belief in one's own value as a person; 3) network support, which leads the recipient to believe "she has a defined position in a network of communication and mutual obligation." Instrumental support or counseling involves the guiding of persons to better coping and/or adaptation. Presumably Cobb is referring to what Caplan has identified as "advice," grounded in knowledge and experience passed from one generation to another, in the form of religious and cultural traditions, for example. Active support or mothering, states Cobb, is "what mothers do for infants and what nurses do for patients." Finally, there is material support of goods and services. Other researchers might prefer to reduce this taxonomy to two types: affective and instrumental, in which social support and what Cobb calls instrumental (advice) fit into the affective category and in which active support (such as material exchanges) fit into the category of instrumental support. Cobb releases us from laboring over these distinctions by noting that, though we may find these categories theoretically elegant, they are, in practice, confounded. Cobb
oberves that the latter three types of support, i.e., what he calls instrumental, active and material support, "may involve or imply social support. . . . This is important as a source of bias in research, but is entirely appropriate for it is [his] belief that social support is more important than all others put together" (1982:190).

Cobb buttresses this argument with documented evidence that social support affects development, the ability to cope with crises, and the reduction of the likelihood of depression. Lack of social support has also been associated with the onset of tuberculosis, arthritis and coronary disease. He further notes that age-adjusted mortality rates are reduced among those who have supportive networks including spouses, close friends, and relatives, church membership, informal and formal group associations. Cobb and his colleagues have hypothesized that social support "operates to facilitate stress reduction by improving the fit between the person and the environment."
They have further theorized that esteem support and emotional support raise levels of self-confidence so the individual is more adaptable to the circumstances that she/he faces. Family network support, the form of social support of interest in the present study, contributes to a sense of participating in decision-making on the part of the mother of the handicapped child. It is therefore hypothesized that family social support influences directly or indirectly, the placement outcomes of the child. This is addressed in Chapters 6 and 7.

Family Problem Solving and Coping of Handicapped Families
"Coping" is the term usually applied to the form of problem solving when a crisis is being faced which taxes adaptive resources
directly related to the welfare of the family or individual who faces the crisis. Having a developmentally disabled child in the family is identified as taking on crisis proportions when a major change in the demands in the quantity, quality and intensity of caretaking required of the family and the community is involved.

With the introduction of a developmentally disabled person into the kin network, we can expect certain ties to be changed and the family developmental cycle to be slowed down (Farber, 1959). There are reports by articulate lay and professional people, who are parents of developmentally disabled children (e.g., Featherstone, 1980; Turnbull, 1984), who have documented their time-consuming efforts in developing a family routine. Everything takes longer. When milestones toward independence have not been reached, such as walking, toileting, and feeding, there are necessarily limits placed upon other activities.

Dr. Evelyn West Ayrault, a psychologist and herself handicapped by cerebral palsy, has observed: "the family with a handicapped member is a handicapped family." Handicapped families need more help to function. McCubbin and his colleagues (1982) have identified eight categories of hardships faced by families of children with cerebral palsy: 1) altered relationships with friends due to stigma which in turn produces isolation; 2) major changes in family activities due to reduced flexibility in routines and recreation; 3) concerns over medical procedures and treatments; 4) medical expenses; 5) medical consultations; 6) specialized childcare needs related to limited community resources such as convenient, available respite care; 7) time commitments due to special care in and out of the home, e.g.,
strains which include a tendency toward overprotectiveness of the child, regarding his/her care and safety, the danger of this child's rejection, denial of disabilities, extended parenthood due to arrested or thwarted development (e.g., extra cleaning and housework) the effect of the child on siblings, especially the concern of their neglect because of caretaking demands made on the parents. To these tasks may be added the complaints of parents, studied by Simeonsson and Simeonsson (1983), of being required to withstand interrupted sleep; physical or structural adjustment of the home; and the sheer physical exertion of lifting, bathing and diapering people who literally cannot carry their own weight without some form of aid.

When, to the executive functioning of parents is added the job of facilitating and motivating biological and sensory development of the child above and beyond what is normally required and when what is required is often not well understood or known, even to professionals, we can safely assume that the adequate functioning of the family as outlined above is threatened. Mitchell points out that "[t]he extent to which these tasks of the family of the handicapped child are satisfactorily mastered is probably a function of the type and degree of the child's handicap as well as resources available within and outside the family" (1973:66). The family is said to be "at risk" of isolation not only because of possible shame at having an "imperfect" child, but because, practically, reaching out to others takes time which is tied up with caregiving (Mori, 1983:49).

Featherstone (1980), who has written an account of her experiences raising her own disabled child, noted the contrast between being a mother of a normal child and the mother of a disabled child in
their respective relationships with their own mothers. The mother of a normal child goes through the same traumas and routines of her own mother and her grandmother before her, but the mother who discovers her child is disabled finds "she steps outside the mainstream. Routine advice becomes irrelevant; few friends and neighbors have faced this problem . . . ." Finally, McCubbin's research group (McCubbin, et al. 1982) mentions the lack of understanding on the part of extended family members making them unable to appreciate the concerns of the parents and siblings of the child.

Practitioners and parents alike have observed that parents must take the lead in shaping the attitudes of family members toward their handicapped child. Parents who insist that their disabled child be included in family gatherings or the entire family does not attend, are more likely to have their child accepted by relatives and the child's siblings (Ayrault, 1977). Suelzle and Keenan (1980:58-62) reported that siblings and husbands comprised the regular support group for mothers of handicapped children and that grandparents attended to social needs, such as birthdays, photographs, etc., and, in the higher income families, provided emotional support. They found that about 25% of their sample of families with developmentally disabled children (n=317) received help from kin with their special children. They also found that grandparents tend to accept the child's disability and to agree with parents' mode of dealing with their children's treatment. However, mothers were on their own as far as decision-making was concerned regarding treatment plans for their handicapped children. What I argue in Chapter 7 is that mothers who
have support from their kin network are better able to face these dilemmas than mothers without such support.

In the past ten years or so, articles by researchers and practitioners have called for greater cooperation among professionals and families and kin of handicapped children (Anderson, 1982, David, 1978). Too often professionals unwittingly create a gap between the parents of the child and their kin. As they intently train parents in the individualized treatment program, but not their kin, parents become experts and kin feel inadequate to offer help, (Blacher, 1984).

Recently new programs had been developed to address this problem. Gabel and Kotsch (1981) describe their Family Infant and Toddler (FIT) Project at George Peabody College of Vanderbilt University. Project FIT incorporates an educational outreach to the focal family and extended kin on a bimonthly basis, holding meetings in the evening. Participating parents have been satisfied that this approach served to improve understanding, enabling relatives to give more support to the children and their parents. Such programs are evidence of a possible trend toward a greater cooperative effort between professionals and parents, between the State and the family.

**The Family and the State**

The notion that the child's family is the repository of resources seems glaringly obvious, but has only comparatively recently been reconsidered. Moroney (1986) has defined the family itself as a "social service" relieving the state of an overtaxing burden (1986:12). He has discussed the need to consider the prospect of "shared responsibility" between the family and the State with regard to handicapped and elderly people. (See a more elaborate discussion
The dilemma lies in determining the proportion of involvement and responsibility of these two agents. I propose that Litwak's "principle of matching" is a practical tool for such an assessment. Litwak (1985) has developed the principle of matching of task structures with group structures to tease out which responsibilities are best met by primary groups, such as the family, relatives, friends and neighbors, and which tasks are best handled by large organizations (the State).

The Principle of Matching

Litwak's principle of matching, used in this study as an heuristic device, states that helping groups offer the kind of help that matches their ability in form and function. More formally posed, the principle states: "groups will most effectively handle those tasks that are consistent with their structure" (Litwak, 1985:36). For example, tasks that are easily routinized and can be accomplished by a number of different groups, the outcomes of which can be evaluated and rewarded accordingly, are best managed by large organizations. In contrast, tasks that occur unpredictably and whose outcomes are not easily evaluated and are idiosyncratic, having many contingencies, and therefore not easily routinized, are best accomplished by primary groups (kin) that offer long-term commitments.

Litwak applied his principle of matching to his empirical study of helping elderly people in New York and Miami. He and his colleagues have demonstrated that this principle can be applied in general to the nature of kin support and specifically to other instances of family members who are in the position of extreme dependence.
Litwak argues that primary groups—kin, neighbors and friends—have not declined but that the nature of the contact among them has changed and been facilitated by technology.

Kin, according to Litwak, are best suited to tasks such as (1) checking in daily with the dependent person, usually by telephone; 2) taking the dependent person to dinner or cooking a meal; 3) bringing little household gifts; 4) telephoning to cheer up or simply to have a conversation. Neighbors generally are available for short-term emergency pinch-hitting. Friends supply moral support and understanding of one's own generation. On the other hand, though friends are companionate, they often share circumstances and troubles in common and therefore may be able to commiserate but not supply modes of solution, even if they can help to identify them. Litwak categorizes laundry, food preparation, shopping and cleaning as "marital tasks." For purposes of discussion in the present context, I prefer to call such tasks "intimate familial tasks." These consist of household chores which are usually handled by the immediate family as opposed to other relatives, neighbors or friends. While direct care and household tasks are not likely to be handled on a continual basis, it is possible for kin to assist during periods of crisis, or when kin live in close geographic proximity and such help is part of the family value system. Kin are also best suited to handle matters of health and financial welfare. These tasks require long-term commitment but not necessarily long-term daily face-to-face contact. Litwak points out that such tasks can be dealt with in periods of two to three weeks by kin who do not live in close proximity to the dependent person. Most of the families Litwak studied had the resources to make
necessary trips to handle these tasks.

While large organizations can take on uniform tasks by handling them in a routinized way, primary groups are best suited to handle tasks that do not require technical knowledge and that are nonuniform. These nonuniform tasks are characterized by 1) being unpredictable, in terms of timing and their idiosyncratic nature; 2) having too many contingencies; 3) not being easily subdivided (i.e., routinized); in addition, 4) these tasks tend not to be easily supervised or motivated by money. This last point is extremely important. The tasks, in order to be accomplished properly, require an intrinsic motivation of caring for the recipient of such services. This intrinsic motivation develops over time, with repeated face-to-face contact, through biosocial ties, and through commitment, which is based on family tradition and ideology. Regarding social class, Litwak argues that there are sufficient similarities especially of class origin, race, ethnicity, and religion, that make exchanges possible among kin.

There is empirical evidence that kin retain significant forms of identification and exchange over geographic distance. Farber's 1981 report on families in Arizona revealed that no matter what level of absolute interest families had in the maintenance of nuclear family ties (i.e. no matter their kinship orientation) infrequent face-to-face contact of less than once a month was counteracted by telephone calls and/or correspondence with one's own mother more than one's in-laws. Admittedly, because face-to-face contact has diminished due to geographic mobility, certain tasks which require proximity cannot be accomplished easily by kin. Nevertheless, the sense that one is supported by kin in some important way known to the individual in need
of services, is taken into account in the present study by asking the question: "How supportive were members of your extended family?"

Having distinguished between tasks best handled by kin, other primary groups and large organizations, we shall now look at the relationship between the family and the State from an historical perspective. The purpose here is to lay the groundwork for our discussion of deinstitutionalization in Chapter 4.

The Role of the Institution in Historical Context

At the beginning of the nineteenth century, mentally retarded people were herded apart from society into a melange of deviates of all types: The criminal, the mentally ill and the poor. In 1843, Dorothea Dix wrote her Memorial to the Legislature of Massachusetts, in which she described the horrors of ill-treatment of mentally ill and retarded persons, "literally caged like animals" (Rosen, Clark and Kivitz, 1976:3-30).

When institutions first opened in the mid-nineteenth century, the goal was to provide "culturally normative social experiences" to only the young, "improvable cases." From 1850 to 1880, practitioners believed it was possible to "make the deviant undeviant" (Wolfensberger, 1969). This was the time when Edouard Seguin was writing of his inspiration at Itard's work with the Wild Boy of Aveyron. Seguin was developing forms of treatment based on the belief that:

That which most constitutes idiocy, is the absence of moral volition, superceded by a negative will; that in which the treatment of an idiot essentially consists is, in changing his negative will into an affirmative one, his will of loneliness into a will of sociability and usefulness; such is the object of moral training. (Rosen, et al., 1976:158)
This period gave way to the plea for protection of these people from the rest of society, which Wolfensberger calls the period of "sheltering the deviant from society" (1870 to 1890). The purpose of segregation from society shifted slightly to a general protection of the "holy innocents" from the rest of society. At the same time, the populations of institutions were expanded to include persons who were more disabled. All mentally retarded persons, not only youth, were deemed to need custodial care.

By the 1880s, the reasons for segregation of mentally retarded persons had shifted to the 'protection of society' because they were considered a 'danger' to society, potentially criminal and likely to produce deficient offspring; this latter belief gave license to the practice of sterilization. Though Fernald's 1919 longitudinal study of 500 mentally retarded persons showed that the majority adjusted well to society after leaving the institution, the common belief in their inability to cope in the community persisted.

In his review of the historical changes in our culture's attitudes toward and treatment of mentally retarded people, Wolfensberger (1976) cites c. 1920 as the time in which practitioners began to accept some of the research findings that showed that mentally retarded people can actually live peaceably in the community after release from institutions. This was also the beginning of what Wolfensberger calls "a loss of rationales," which means that, though they persisted, institutions no longer had a raison d'être. The huge hollow edifices were filled with staff and "patients," rattling about the halls, who no longer knew how to make the best of the situation.
because the situation had lost its definition. New goals had to be set. Wolfensberger has observed:

All the money in the world will not change the minds of men. What we need are concepts and models. .. . The principle of normalization is gaining wide acceptance. With the acceptance of this new ideology, we are witnessing the agonized death struggle of an institution model based on the perception of retarded persons as a menace and/or subhuman organism. (1976:72)

How the goals of normalization are best achieved is still controversial, but it is clear that the development of multiple alternatives to institutional care is necessary and beneficial. A major tenet of normalization ideology is that developmentally disabled people have equal rights and protection under the law. The normalization principle encompasses numerous goals devised and first put into practice in the Scandinavian countries in the last two decades.

In his report to the President's Committee on Mental Retardation, Bengt Nirje of Sweden defined the normalization principle as having four sets of goals. Normalization means that, first, handicapped persons share in the normal rhythms of the day of privacy, work or school responsibilities and social fellowship; second, that they go through the normal stages of the life cycle--infancy, childhood, adolescence, adulthood and old age--as they are known in the particular culture in which they find themselves. The third set of goals involves the right of self-determination, to form friendships and relationships and that their lives should show the same basic economic patterns of the rest of society. The fourth goal is a provision for those persons who cannot live with their families or on their own, that their homes be located in residential neighborhoods and be of a normal size and operation. In sum, Nirje states: "The normalization
principle means making available to all mentally retarded people, terms of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life of society." (1976:231)

More than one hundred years passed before our society resurrected this belief in the potential development of all persons and developed the concepts of the ideology of normalization for developmentally disabled people. It was not until the 1930s that parents' groups began to become active in championing the rights of their disabled children. It has only been in the last fifteen to twenty years that the deinstitutionalization movement has gained momentum. Within the State of New Hampshire, only in the last ten years have parents begun to push for alternatives to Laconia State School.

On the other side of the coin, however, there are some parents in the present study who were and some who continue to be active in the LSSARC (the Laconia State School Association for Retarded Citizens) to improve conditions within the institution. One mother told us of her tireless efforts in the 1950s campaigning around the state for funds for improvements of LSS facilities and personnel. At the time of Judge DeVine's decision (in 1981), in the Garrity v. Galen case, this mother felt betrayed by the parents who were plaintiffs in the lawsuit. The situation had become polarized.

Frohboese and Sales (1980) have examined the objections to deinstitutionalization in Nebraska by gathering data from multiple sources including archives of legal proceedings documented by both plaintiffs and defendants, the Nebraska Department of Public Institutions, natural observations of public hearings and personal
interviews with parents in the opposition. They identified four categories of objections to deinstitutionalization ideology that they deem deserving of the legitimate attention of researchers, service providers, parents and policy makers alike. These are: 1) the concern that the community-based service delivery system is as yet unstable with regard to funds and programming and that services lack quality and comprehensiveness; 2) that the underlying ideology; i.e., normalization, the developmental model, dignity of risk, and the least restrictive alternative do not apply equally to all developmentally disabled persons; 3) the process utilized to effectuate deinstitutionalization ideology usurps parental power over future plans for their children; and 4) concerns about parents' ability to cope with their children in the community and at home.

These objections are intimately related to the overall definition of the relationship of the family with the State. At what point does the State replace the functions of the family? What functions should/can it replace? What functions should/can the State not replace? We will address these issues in Chapters 7 and 8.

Purpose and Guiding Questions

The purpose of this study is threefold. First, the study will trace the effects of the process of deinstitutionalization as it pertains to the participants and their families. Chapter 4 looks at how history influences parental attitudes toward community placement.

Chapters 5 and 7 address a second set of questions which have a more micro focus but have implications for social policy. It is to identify the key characteristics of families who are most likely to
perceive their kin as supportive with regard to their handicapped children. The question posed is: To what extent do socioeconomic status, ideology (beliefs in deinstitutionalization philosophy and religious belief) and family characteristics, such as its size and number of women, bear on perceived kin support?

We will examine whether or not there are special characteristics of the children themselves which correlate with kin involvement. This has to do with the question of the influence of the degree of the handicapping condition upon perceived support. Do diagnosis, medical, and behavioral problems of the child correlate with level of support? The purpose here is to identify the characteristics of families who are most likely to take an active role in the direct care of their children, as well as the coordination of services, i.e., those who will share this responsibility with the service delivery system. We also want to identify the characteristics of those families that are likely to need greater involvement on the part of the State.

Third, in Chapter 6, the study will broadly look at the correlates of successful placement for the child. However, since our interest is in how kin involvement influences these outcomes, we will ask, more specifically: Does having a supportive extended family increase the likelihood of: Deinstitutionalization? A more stable first community placement? A more positive attitude on the part of the parents toward deinstitutionalization? Stronger parental advocacy?

As will be demonstrated, kin, even those who are not involved directly with their handicapped relative, but are onlookers, do have insight into their relative's situation and have opinions informed by their observations about what is needed and could be done. Relatives
are in the unique position of being both outsiders and insiders. They are outsiders to the nuclear family and yet insiders of the kin network. They have the qualities intermediate between being the general public and being immersed in the family problem. Unlike the general public, they are eyewitnesses to the struggles of the immediate family with their disabled child, with the quest for help, and the process of communitization.

In the final chapter, we will discuss the policy implications of the research. Before we address the main issues of deinstitutionalization attitudes, placement outcomes and kin support, the next two chapters describe the details of how this study was conducted and the characteristics of the participants.
CHAPTER 2

METHODS

The present study was carried out as a subproject of a larger research, entitled "The Study of the Impact of the Residential and Educational Consequences of the Deinstitutionalization of Handicapped Children," affectionately known as Project SID (Mallory and Herrick, 1986). The criteria for the inclusion of sample members were also dictated by this larger research but in no way interfered with the answering of the questions herein addressed. These questions are:

What influences the level of perceived kin support with regard to handicapped persons? What are the correlates of placement success of developmentally disabled persons? What are the correlates of parents' positive attitudes toward deinstitutionalization?

Sample

The sample consisted of 93 people who resided at Laconia State School and Training Center (LSS) for a minimum of three weeks during the period between 1970 and 1985. All were born on or after January 1st, 1949 to insure their eligibility for educational and residential services during the fifteen-year period under consideration. This means each person would be 21 years old or younger by 1970. Sixty-eight people, the "Leavers," returned to the community prior to their 21st birthday and 25 people, the "Stayers," remained in the institution until sometime after their 21st birthday. Of 187 letters mailed to potential participants who had already left
the institution, a third were returned by the post office and nearly another third were unreturned after three mailings. In the final tally, we had received consents for 70 ex-residents, two of whom had to be dropped because they left LSS on placement before 1970 and never returned. In ten instances, we received an explanation for the denial of consent. These included family stress, such as illness or relocation, fear of intrusive questions and the misconception that the study would interfere with the treatment plan of the disabled person. One parent told us, "He's lived in a gold-fish bowl long enough! We just want to let things rest at this point." Parents of disabled persons who now resided in the community feared reinstitutionalization, while parents of current residents of LSS feared premature community placement.

An additional 110 consents were obtained from families of Stayers. Letters were mailed through the Office of Quality Assurance at LSS to all those families of people who met our cohort criteria. The response rate was nearly 100% since all families could be located and only permission to review their children's institutional records was requested. From this sample, a subsample of Stayers' families was obtained, yielding a sample size of 25. Further description of how this sample was obtained appears in Chapter 3.

Data Sources

Data for this research were generated using both quantitative and qualitative approaches. Quantitative instrumentation consisted of surveys of several sources: a) clinical records at LSS; interviews with b) service providers; and c) parents. (Though the questions used in this research were contained in much larger survey schedules, only
the questions directly relevant to this research are contained in the appendices.)

Qualitative data, in the form of case studies, were generated by follow-up interviews with parents, their relatives and in two instances the disabled persons themselves.

Table 2.1 Data Types and Sources

<table>
<thead>
<tr>
<th>Source of Data</th>
<th>LSS Record (n=93)</th>
<th>Parent Guardian (n=93)</th>
<th>Service Provider (n=68)</th>
<th>Ex-Resident (n=2)</th>
<th>Relative (n=8)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Background</td>
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<td>X</td>
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<td>X</td>
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<tr>
<td>Kin Support</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Reasons for Admission</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Medical and Behavioral Characteristics</td>
<td>X</td>
<td>X</td>
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<td>Educational and Residential Placements</td>
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<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Attitudes Toward Deinstitutionalization</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>

Table 2.1 and the following list serve as a brief overview of the data sources and methods used in this study.

Clinical Records

Appendix A shows the questions used to guide field staff in culling clinical records for information on family background, visitation, AAMD diagnoses (i.e. level of retardation established by codes
developed by the American Association on Mental Retardation; Grossman, 1974), descriptions of each participant's handicapping condition, medical and behavioral problems. Questions from the Behavioral Development Scale (BDS) developed by Conroy and Bradley (1985) were used to identify selfcare and social abilities as well as problem areas. In addition, the LSS intake notes were scrutinized for discovering the circumstances of admission.

Service Provider Interviews

Appendix B contains representative questions from the interview schedule used with service providers, most of whom were case managers, though some were teachers, speech therapists, physical therapists and nurses. Most questions were of the closed-ended, multiple choice type and addressed the straightforward questions about types of residential placement and educational services obtained after the person left LSS. The interviews were only conducted if the disabled person left LSS before his/her 21st birthday (i.e., a Leaver, but not a Stayer) and was therefore eligible for these services in the community (N=68).

Interviews with Parents

These interviews, the relevant questions from the schedule which appear in Appendix C, covered the entire span of the disabled person's lifetime. Ninety-three (93) parents were asked to describe the early years of learning about their children's disabilities, attempts to obtain services, help from kin and others, visits to LSS, as well as to supply information about their own occupational and educational background. In order to ascertain the child's educational and residential treatment experience, we asked the parents the same
questions as those we asked of the service providers. (See Section II, questions 1a through 12e of Appendix B.) Included in the survey in its entirety was the Attitudes Toward Deinstitutionalization Survey (ATDS) developed by Conroy and Bradley (1985) to assess the impact on parents of their children's return to the community and to assess parents' attitudes concerning deinstitutionalization ideology. The ATDS questions appear in Table 4.4 in Chapter 4.

**Interviews with Relatives**

From the in-depth interviews with parents, kin were identified on a scale of 1 to 5 as to their level of supportiveness of parents. (See question 26, in Appendix C.) Parents who rated their extended kin as either "somewhat" or "very supportive" (4 or 5) or "unsupportive" or "making things worse" (2 or 1) were re-contacted to participate in the case studies. In the Follow-Up Parent Network Interview (Appendix D), parents were asked to map out their family relations, using the familygram technique (Hartman, 1978), to identify relatives with whom they had the most contact and whom the researcher would contact for interviews. There is an admitted bias in allowing the parent to choose which relatives could or should be interviewed, but the entire sample was in some sense self-selected since participation was completely voluntary.

Initially ten families were chosen and asked to participate in the case studies. The criteria used to select these ten families required that a representative sampling of diagnostic categories be included, that half the parents reported their kin to be supportive and half did not, that parents were regarded by interviewers as good informants, and that they be geographically accessible.
Two families provided three relatives, one family provided two and four families provided one relative and the remaining families contacted decided to withdraw because they were unable or unwilling to cooperate at that time. Since this reduced the number of participating families, it was decided that the three families who provided the most information (and at least two relatives) would be the subjects of the case studies. (See Chapter 7.) Once identified, relatives were contacted, appointments arranged, and in-depth interviews were conducted. (See Appendix E.)

In addition, relatives' attitudes toward deinstitutionalization were measured using part of the ATDS (questions 1 through 11 in Table 4.4) as well as questions to assess socioeconomic status, ethnic and religious background.

Thoughts and feelings of the observed and the observer were recorded because they provided valuable insight toward outstanding what transpires in this process (Reinharz, 1979)—the research process as well as the process of kin support. Further details of the methods used in the case studies appear in the chapter devoted to them (Chapter 7).

The interviews with service providers and parents were of the schedule standardized type (Denzin, 1970). However, interviewers were allowed some leeway in the order in which they asked the questions and in the phrasing of questions so that the interviewees understood exactly what they were being asked. At times, the interviewer's role was to record information which was spontaneously offered by the informant before a specific question was asked, requiring the interviewer to go back and forth in the schedule, according to where a
particular item was located. Allowing for this kind of flexibility and spontaneity reduced the reactivity of the instrument.

Face-to-face interviews are preferable to mailed questionnaires for a study such as this for a number of reasons. First, even though the work is more labor intensive, it ensures that the data will be obtained within a given time period. Second, the interviewer can explain any questions and dispel misconceptions the informant may have regarding what is being asked, thereby reducing ambiguity and incorrect responses. Third, even though there is a great diversity of interviewing conditions, because of families' homes and service settings, the interviewer acts as a constant as well as an agent of social control, tending to reduce the amount of interference that might otherwise be present if the person were simply filling out a questionnaire.

Pilot Work

Each research tool was developed during a pilot phase (lasting about one month) in which successive approximations of the final instrument emerged. In developing the clinical records survey, we learned, for example, that it was not possible to identify, with any consistency, exactly who visited the disabled person during his/her stay at LSS. It was therefore decided to simply note the frequency of visitation and use this as an indicator of general social interest in the resident, even though, in several instances, kinship relations actually were identified.

Ethical Considerations

One of the most neglected aspects of research reporting is the ethical approach to the inclusion of human subjects. Since this study
involved the use of indirect forms of consent which complicated the
task of developing the research sample, the ethical concerns are
described at length.

**Informed Consent**

Informed consent requires that the participant: a) understand
what the study will involve, and b) participate without coercion.
American Sociological Association guidelines further require that
sociologists assure participants dignity of treatment and that their
right to privacy will be respected and upheld.

Most institutions have internal peer review boards as a means
of assuring that the researcher has taken all necessary precautions to
truly inform potential participants so that they can give their con­
sent with full knowledge of their involvement in the research.

The consent form, which was three pages long (and appears in
Appendix F), acted as a contract between the research scientist and
her subjects. It included: 1) purposes and procedures; 2) risks or
discomforts; 3) benefits; 4) the methods to be used to keep infor­
mation that identifies individuals confidential--e.g., locked filing
cabinets, the use of identification numbers in lieu of names for keep­
ing track of subjects in computer analyses, etc.; 5) assurance that
participation is voluntary, and 6) that there is no penalty for not
participating, withdrawing or withholding information (Smith, 1975).

**Third Party Consent**

When subjects are minors, or, as in this case, when subjects
are potentially legally incompetent, consent must be obtained through
parents or legal guardians. Participants under the age of 18 automa­
tically were considered under their parents' guardianship; others had
been assigned legal guardians by the Office of Public Guardian (OPG). However, there was a remaining group of people over the age of 21, who had not been adjudicated as incompetent, and, who, therefore, were legally their own guardians, even though they still lived at home where their parents acted as their guardians. In the final report to the Spencer Foundation, Mallory noted, "almost all of the parents contacted believed that they still had legal authority over their adult children." Rather than disturb the status quo, we acted as if these parents were the guardians. Mallory, explained further:

We believed that to bypass the role and concern of the parent would unnecessarily introduce confusion and stress. For us to introduce the notion that the parent no longer had any legal relationship to their child, and that we could enter into their lives without the parents' permission, was seen as intrusive. We were also concerned that we establish positive relationships with parents so they would participate as respondents to our interviews. Because the service providers also seemed to be acting as though the parents were still guardians, we wanted to act in a consistent fashion. Interestingly, none of the state agencies, community staff, or institutional staff, raised this issue as a concern. It was one we identified and resolved internally. (Mallory and Herrick, 1986).

Obtaining Access to Informants

Public agencies and parents' groups are under obligation to protect the privacy of their constituents. Therefore potential participants could not be contacted directly. No agency can release a person's name without consent. This required then that alternate means of contacting potential participants be developed.

The ethical approaches used in this study were first approved by the University of New Hampshire internal review board. The next step was to approach the Director of Quality Assurance (Dr. Frank McAloon) at Laconia State School and Training Center and request
cooperation in soliciting consent from parents and guardians of those disabled persons "eligible to participate" in the study.

The initial determination of which present and which former residents of LSS were "eligible" participants was made by a graduate student of the research team who had been hired as a staff member at LSS. This student reviewed all admission record cards for dates of birth and admission. Because the resulting list could not be legally used by the research team, the people on the list were contacted by the Offices of Quality Assurance and Community Integration at LSS. They agreed to mail a cover letter, signed by Dr. McAloon (see Appendix G), our consent forms and an explanation of the study to the guardian of each person on the list.

In approaching an institution, it is important to observe the hierarchy of personnel and the proper chain of command. In this particular case, the Director gave us entree to the records, but inadvertently side-stepped the supervisor of the record keepers. In hindsight, we should have asked if there were an immediate supervisor. So for a while there was some ill-feeling that could have been avoided.

The LSS staff completely cooperated in the mailing out of the letter describing the research, the consent form and stamped, self-addressed envelope for easy response. A large portion of letters were returned unopened; many were evidently lost, or received, but not honored with a response. This was not particularly surprising since addresses obtained from old institutional records were often obsolete. It was therefore necessary to try other avenues to reach potential participants, as well as to gain support for the study so that when the field staff approached service providers and parents,
they would understand the purposes of the study and be willing to cooperate.

Community Networks. Though consent had been received from parents who had been contacted by the State School, so that the study was underway, further outreach was necessary. These strategies included appealing to regional agencies (in New Hampshire this is known as the case management system), representatives of non-government service agencies, and parents' Associations for Retarded Citizens (ARCs). Group and agency leaders were telephoned in order to set up a time for us to speak before their constituents. Each presentation consisted of the following: a brief description of the study, efforts to maintain anonymity and a discussion of the impact of the study upon future policy changes in the state.

Service Providers. In order to obtain cooperation from service providers, I presented a brief description of the study at one of their state-wide monthly meetings held in Concord, New Hampshire, by the Division of Mental Health and Development Services. In that first meeting with case managers who came from the 12 regions of the service delivery system (see figure 3.1), my presentation was met with a mixed response. The previous speaker was the new psychiatrist at the head office who had raised some hackles around the room with his lofty tones to a very overworked group of people. So now I was another professional coming along to make demands while I soared in the heights of academic etherea never to be scathed by their difficulties.

Service providers expressed several concerns: 1) that our research was in reality an evaluation of their competence; 2) that our interviews would require inordinate demands on their already crowded
schedules; 3) that we did not address their immediate concerns of service delivery and therefore their participation was not worth their time.

At these times, one hopes to find a common agenda. One seasoned social worker came to my and the study's rescue when he rallied support for research that apparently was more on the side of proving the necessity of community services than anything that had come their way in a long time. I could feel my entire body return to equilibrium in a grateful sigh of relief that I hoped did not reveal my former dismay.

OPG. As mentioned earlier, some of these young adults had been assigned public guardians. The Office of Public Guardian met with us and, when they understood the purposes of the research, they completely cooperated, provided that we did not involve parents who had been out of the picture for a long time. This seemed an outrageous request to me personally because any time parents want to assume responsibility for their own children it would seem a positive step and a saving of taxpayers' money, but we didn't argue, since such an occurrence was unlikely and in fact did not happen.

Parents. During the meetings of the regional ARCs, we discovered that parents were most concerned about three issues: 1) who funded the project; 2) whether the research would serve as someone's dissertation; 3) whether, as participants, their children would benefit directly.

It was important to these parents that the research not be funded by the New Hampshire State Division of Mental Health and Developmental Services nor any agency of the Federal Government; the
former because of the fear that services they had fought hard to obtain would be withdrawn, and the latter for reasons unascertained.

The parents' second concern had to do with not wanting to be "guinea pigs" or the object of academic ogling for the frivolous purpose of one person's career advancement at their expense. This was dealt with by assuring parents that the researchers and interviewers conducting the study were people of integrity who had personal commitments to the cause of handicapped children and their families. The Principal Investigator was identified as a professor of special education, involved in policy issues with regard to handicapped children. The Project Director was identified as a family sociology doctoral student, whose former involvements had been in the care of institutionalized persons and their families. The interviewers were all persons directly involved with handicapped children: A mother of a developmentally disabled child; an active leader in the regional AAMD; a special education teacher; and a special education coordinator.

The third concern was more difficult to answer. It was not possible to promise that the study would directly benefit the outcome of a particular individual, but it was hoped, the study would call the attention of policymakers to the need to further develop community resources for handicapped children and their families. Nevertheless, when one father determined that our study would not directly relieve difficulties in his son's placement situation, he told us we would get no help from him!

Meeting with parents at these ARC meetings served in guiding the research to include more meaningful questions and as an orientation for the future one-to-one interviews.
In one episode in this networking saga, one of the more active members who had been involved in the litigation against the State School and who, up until that point, had denied consent for her child to participate, changed her mind as a result of a miraculous encounter. This parent, suddenly, in the midst of an ARC meeting, had discovered that one of her diamond earrings was not in place. She gasped. The room was immediately transformed into a flurry of activity to locate the sizeable gem.

Having had a similar experience with an earring of no less personal value, I assured the woman that Providence had been merciful to me on one particular occasion which I related to her in vivid detail which amazed the listener and restored her to a hopeful anticipation of the return of the lost object.

The next morning, this parent called the office to relate that indeed a miracle had occurred and the earring was found waiting for her on the doorstep! She further stated with great enthusiasm that she would send her consent by the next mail and cooperate in any way she could to contribute to the success of the project.

The Contact Packet. Since we had to rely on third parties to reach sample members, it was imperative to provide them with a means of responding. To meet this need, the "contact packet" was devised. This consisted of: 1) a letter signed by the leader of the organization, endorsing the project; 2) an announcement letter describing the project, the staff involved, the precautions taken to ensure anonymity and confidentiality; 3) a small postcard in which the parent could indicate that we may or may not contact him/her and a space for the address and telephone number; and 4) a return envelope.
In sum, the outreach procedures involved making personal presentations, a myriad of telephone calls, and vast quantities of correspondence.

Establishing Community Relations—Taking off the White Lab Coat

It was imperative to live up to the ethical contract with the participants of the study who did not always understand the fine legalistic distinctions devised to protect scientific skins—or perhaps they understood only too well! For example, even though each family read a 3-page consent letter, they did not always realize they did not have to answer potentially upsetting questions; they just reacted and became upset. One father would not answer the standard sociological question: "What was your occupation at the time your child entered LSS? His response was: "None of your damn business! What does this have to do with my son's treatment at the school, anyway?" I tried to explain that part of the study required that we obtain a little background information about the participants' families and that indeed his background should have nothing to do with his son's treatment. Sociologists always ask this question; it's stock in trade. When I tried to explain that all information was kept confidential, the father replied: "Yeah, everybody from the secretary on up will know my business. That's not confidential! Confidential is when I tell you something and you don't tell anyone else!"

This is an example of the kind of field data which is written on the researcher's gut for the rest of her life! It does not fit into the study of the question, yet if this instance is placed only in the private archives of the researcher, a valuable insight about this man's experience goes unshared. This man's high sensitivity coincided
with the extreme handicapping condition of his son. The threat of closing LSS was a great source of stress for this father, which was conveyed in his reactions to the questions. This family did not answer even 50% of the questions directly, but gave me clear evidence of their great difficulty with their son's circumstances. I was caught in the dilemma of the desire to obtain data and the desire to make the probing as painless as possible. [See Reinharz (1979) for a discussion on the importance of the points of view of the researched as well as of the researcher.]

Limitations of the Study

The drawbacks of interviews are that 1) they are measures taken at one point in time; and 2) information is subject to the exigencies of the memory of the respondents. In order to compensate for these shortcomings, institutional records were examined which provided an historical context for the data we gathered from informants. In addition, if parents had any records of events, written at the time of their occurrence, parents were asked to consult them before or during the interview. In interviewing relatives, it was also possible to cross-check information given by parents to better establish time frames, sequences of events and the details of events.

The other drawback of the interview method is that it is open to recall and viewpoint biases. For example, one parent, in his opening statement about his son's educational career, said his son received "no education!" and "hardly any services!" Later in the interview, however, the father proceeded to tell the interviewer about several schools his son had attended. The father's opening gambit had
more to do with his current frustration at his present situation (the son was no longer eligible for educational services, though the father believed his son could still benefit from them) than with his son's educational history which was the focus of the questions being asked. Had reliability checks not been built into the interview, i.e., asking about education at two different points in the interview, this would not have been revealed.

Aside from the many correlates of memory bias and decay—elapsed time, frequency of the event, level of importance or significance to the individual, etc.—the interview is limited in the way questions are phrased. In most portions of the interview schedule, closed-ended questions were asked with multiple choice and likert-type answers.

Multiple choice questions of the Likert-type do not allow for the spontaneous answer and require the respondent to pigeonhole his/her thinking to fit the question. For example, respondents were asked to say whether they "strongly agree, somewhat agree, neither agree nor disagree, somewhat disagree or strongly disagree" with the concept of deinstitutionalization. Often the responses ran something like: "Well, I agree, but only if it means Bill will get one-to-one supervision. Otherwise, I'm for it." The question as asked does not allow for such qualifying statements.

Though the ability to compare our data with those of other researchers by incorporating their multiple choice questions (Conroy and Bradley, 1985) in the present study was gained, valuable sources of insight into parents' true opinions and concerns might have been lost. Therefore, interviewers were instructed to press the respondents
to choose a particular answer, but also instructed to write, verbatim, the unsolicited comments made by the parents.

As mentioned at the outset, this research is in the context of a larger study called Project SID—an acronym for "Study of the Impact of Deinstitutionalization on the Educational and Residential Consequences of Handicapped Children." Project SID was originally conceived by Dr. Bruce L. Mallory of the Early Childhood Special Needs Program in the Education Department at the University of New Hampshire. The purpose of Project SID was to discover the educational and residential outcomes of developmentally disabled persons discharged from Laconia State School and Training Center before their 21st birthday, that is, while they were still eligible for educational services.

As Project Director of Project SID, I had the privilege of including questions in the interviews which pertained to my own interest in kin support. As with all research, inclusion of variables, especially those not directly linked to the focal questions, becomes a matter of negotiation, weighing the costs in time, labor and money. Since the Project SID interviews ranged from a minimum of one and half hours to four hours in length, elaboration of the exact type of support, from whom and from what available pool of kin (geographic location, e.g.) and during what time periods, would have added considerable length to an already long interview schedule.

This placed constraints on the number of questions directly related to this present study that could be included in the questionnaires. For example, a more thorough interview would have included questions regarding the times that relatives were most helpful: What
kinds of support did you need or want? What did you receive? When? Who helped? Where did these relatives live? Etc. Thus, a disadvantage of the present study is that it is part of a larger study which has other agendas. However, this context saved time and effort and alleviated the stress on parents of being approached twice for different, but related, researches. Just as there are many experiments housed on a single satellite when it is launched, it is certainly highly economical, whenever possible, to accommodate several related researches simultaneously. To some extent these limitations were counteracted by the use of case studies.

There are other limitations. The sample is voluntary and therefore a self-selection bias is introduced. The testimony of the kin interviewed in this study may well be correlated with factors related to a willingness to participate, such as a general helping attitude. Because of the small sample size (N=93), another drawback is that not all types of kin relations are included equally. Thus, results are necessarily inconclusive.

Strengths of the Study

The methodological strengths of the study are that both qualitative and quantitative data are used to study kin support. The correlates of support and obstacles to support are identified using multiple regression. In addition, the actual process of kin giving support over time are identified by the relatives themselves. Thus we are not relying solely upon parents' reports to understand this process.

It is hoped that a third contribution is made by this study in calling attention to the heuristic value and generalizability of Litwak's "principle of matching" to another population of dependent
persons and to its utility in sorting out the relationship between the family and the State.

A fourth strength is that the study gives further impetus to the shift in focus from the "patient" to the whole family, including the extended network, not as a larger body to be "fixed," but as a system seeking to maintain health. If the network is understood, professionals may view it as an asset rather than as just one more complication and hindrance to their work.
CHAPTER 3

CHARACTERISTICS OF THE CHILDREN AND THEIR FAMILIES

The 93 families involved in this study are comprised of two samples whose differing experiences should not be ignored. As will be demonstrated in later chapters, the families of children who left Laconia State School (LSS) early enough to be eligible for educational services, had somewhat different experiences, with regard to admission, length of stay at LSS, visiting patterns, etc., from the families of children who stayed into adulthood. These different experiences resulted in differences in attitudes regarding the deinstitutionalization movement. These differences highlight the dialectics of the movement and so are included in this chapter. To do otherwise would be to misrepresent the families.

Leavers and Stayers

The two samples involved in this study were drawn from the population of the Laconia State School residents who were born on or after January 1st, 1949, and whose period of residence at LSS fell between January 1, 1970 and June 30, 1985.

The first sample, from hereon referred to as "Leavers," includes those whose first placement in the community fell in this time period but before their 21st birthday. This group was comprised of those persons who were eligible for educational, as well as residential services upon leaving LSS (n=68).

The second sample, from hereon referred to as "Stayers," includes 25 persons drawn from a larger sample of 110 persons,
who stayed at LSS past their 21st birthday, making them ineligible for educational services when and/or if they returned to the community. Practical constraints required us to select a smaller sample than the original 110 persons who stayed at LSS after their 21st birthday, in order to set up parent interviews. The procedures for obtaining the 25 Stayers consisted of developing a list of children whose parents had retained custodial or guardianship rights or who had remained closely involved in their children's lives. Members with public guardians, non-related guardians, or those who had no on-going contact with their parents were not included in this pool of parent interviews. This process generated a list of 55 potential families. By selecting every third name on the list, a random sample of eighteen families was drawn. If a family was unavailable to be interviewed, the next family on the Stayers' list was contacted. Seven additional families were included who had come to us desiring to be interviewed, resulting in a sample (of 25 families) contaminated by self-selection.

The schedule standardized interview discussed by Denzin was used (1970:129). The questions in the Stayers' parent interview were identical to those we asked of Leavers' parents except with regard to placement and discharge. The questions in the Stayers' parent interview about services and placement were omitted since placement would have occurred after the individual's 21st birthday.

Stayers were not eligible for educational services. Leavers were eligible for educational as well as residential services by the time they left LSS. It is the latter group that will be the focus of the discussion on the effects of kin support.
The distinction between Leavers and Stayers is important in examining how or whether kin support is related to long-term institutionalization or not. Since 18 of the 25 Stayers were still at LSS at the time of the study, it is important to see whether there are other characteristics that further distinguish the groups.

Table 3.1 Characteristics of Leavers and Stayers

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<tr>
<th></th>
<th>Sex</th>
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<th>Year*</th>
<th>Range</th>
<th>Mean age at First Community Placement*</th>
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<td>8.2</td>
<td>1970</td>
<td>1958-1979</td>
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<td>Stayers</td>
<td>68% male</td>
<td>9.2</td>
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<td>1955-1976</td>
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*p<.02

Table 3.2 Mental Retardation Diagnoses of Each Sample (%)

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<th></th>
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<td>35.3</td>
<td>22.1</td>
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<td>5.9</td>
<td>7.4</td>
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<tr>
<td>Stayers</td>
<td>(n=25)</td>
<td>-</td>
<td>-</td>
<td>28.0</td>
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<td>Second Diagnosis</td>
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<td>Stayers</td>
<td>(n=24)</td>
<td>4.2</td>
<td></td>
<td>25.0</td>
<td>37.5</td>
<td>33.3</td>
</tr>
</tbody>
</table>

From Table 3.1, it can be seen that a major difference between Leavers and Stayers is their year of admission to LSS. Though they entered the institution at about the same age, the Stayers entered
five years earlier; they are, on average an older cohort. This places Stayers in an historically somewhat earlier period vis-a-vis the trend toward deinstitutionalization.

Table 3.2 shows the distributions of diagnoses for mental retardation at two points during residence at LSS for each sample. The Stayers' group is comprised of a greater proportion of persons diagnosed as severely retarded, whereas, the distribution of Leavers' diagnoses tended to be skewed toward the moderately retarded range, when first assessed, closest to the admission date.

We culled the records for a second diagnosis closest to the first community placement for Leavers and closest to the 21st birthday for Stayers. (Since Stayers were still in the institution, for comparative purposes, the 21st birthday was chosen as a reasonable cut-off point at which they would have still been eligible for child-related services had they been placed in the community.) Generally, the distribution for each sample shifted to the severe to profound range in the second diagnosis. This finding is consistent with abundantly documented evidence that people living in institutions over long periods of time tend to deteriorate in performance (e.g., Blatt, Ozolins and McNally, 1979).
### Table 3.3 Behavioral and Medical Characteristics (in Percentages)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Leavers n=68</th>
<th>Stayers n=25</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>A. Behavioral Characteristics</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Little or no difficulty walking</td>
<td>76.5</td>
<td>84.0</td>
</tr>
<tr>
<td>Speech easily understood or slightly difficult</td>
<td>41.2</td>
<td>33.3</td>
</tr>
<tr>
<td>Dresses independently or with help</td>
<td>67.6</td>
<td>60.0</td>
</tr>
<tr>
<td>Feeds self independently</td>
<td>73.5</td>
<td>68.5</td>
</tr>
<tr>
<td>Toilets independently</td>
<td>52.9</td>
<td>52.0</td>
</tr>
<tr>
<td>Never or rarely aggressive</td>
<td>50.7</td>
<td>70.8</td>
</tr>
<tr>
<td>Interacts with others or with encouragement</td>
<td>78.5</td>
<td>72.7</td>
</tr>
<tr>
<td>Extreme unresponsiveness**</td>
<td>16.7</td>
<td>50.0</td>
</tr>
<tr>
<td>Stereotypical behavior*</td>
<td>35.3</td>
<td>48.3</td>
</tr>
<tr>
<td>Some writing skills</td>
<td>29.4</td>
<td>29.6</td>
</tr>
<tr>
<td>Some reading skills*</td>
<td>19.1</td>
<td>11.1</td>
</tr>
<tr>
<td><strong>B. Medical Characteristics</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>23.5</td>
<td>20.0</td>
</tr>
<tr>
<td>One or more major medical conditions*</td>
<td>26.5</td>
<td>66.0</td>
</tr>
<tr>
<td>Significant sensory loss</td>
<td>29.2</td>
<td>28.0</td>
</tr>
</tbody>
</table>

*p < .05  **p < .001 (df=91)

Behavioral and Medical Characteristics

In the comparisons that follow, it will be apparent that Leavers and Stayers are more similar to each other than they are different. The purpose here is to provide evidence that social attitudes regarding handicapped people has more to do with historical context than actual characteristics of persons.
Table 3.3 compares the two samples on a number of behavioral and medical characteristics identified in the literature to be particularly salient with regard to communitization and hypothesized to influence kin support, which will be examined in Chapter 5.

For the most part, the groups were similar. Over two-thirds of each sample were able to walk with little or no difficulty, and were able to feed and dress themselves with little or no assistance. About half of each group were completely self-sufficient with regard to toileting. Over 70% of each group were considered able to interact socially with others and close to a third of each group had some writing skills.

With regard to reading, stereotypical behavior (e.g. non-purposeful handwaving) and unresponsiveness, Leavers were, on the whole, rated more positively ($p<.03$). In addition, there was some suggestion that Leavers were, on average, more aggressive than Stayers, though the difference was not significant ($p<.13$).

Less than one fourth of each group were diagnosed as having cerebral palsy which limited or precluded activities. Somewhat less than a third of each group showed significant sensory (auditory and/or visual) loss.

Table 3.4 Requests for Admission Initiated by Parents, Physicians and Social Workers

<table>
<thead>
<tr>
<th>Sample</th>
<th>Parents</th>
<th>MD*</th>
<th>MSW**</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leavers</td>
<td>86.8%</td>
<td>36.8%</td>
<td>36.8%</td>
</tr>
<tr>
<td>(n=68)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stayers</td>
<td>96.0%</td>
<td>64.0%</td>
<td>4.0%</td>
</tr>
<tr>
<td>(n=25)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* $p<.02$  ** $p<.002$
Although parents did not present medical problems as a chief concern when applying for their child's admission, each group had one or more major medical conditions (e.g. scoliosis, Prater Willi syndrome, etc.) with Stayers having proportionally over twice as many people medically involved as Leavers (p<.05).

Requests for Admission

In order to ascertain possible differences between the two samples with regard to circumstances of admission, we examined the LSS records for details about who made the initial request for admission and any descriptive statements, usually made by parents, to the intake worker at the time. Table 3.4 shows that requests for admission were initiated, for the most part, by parents with auxiliary assistance from the children's physicians and social workers. The data show that social workers were more active in the admission process with Leavers while the children's physicians were more likely to play a major role with Stayers.

That parents should be the initiators of their children's admission is not particularly surprising, since 83.8% of Leavers lived at home at the time of admission; the remainder lived with foster parents (5.9%) or in other residential treatment centers (10.3%) just prior to admission. For Stayers, 84% lived with their foster parents, with a relative, or in a special school or other facility, just prior to admission.
Table 3.5 shows the circumstances in which admission to Laconia State School took place. The percentages do not add up to 100% because as many items as were applicable were selected. The most common reasons for admission were behavior problems, family problems and the depletion of the mother's coping resources. Where the two samples differed

<table>
<thead>
<tr>
<th>Circumstance</th>
<th>Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Leavers (n=68)</td>
</tr>
<tr>
<td>Behavior Problems</td>
<td>61.8</td>
</tr>
<tr>
<td>Medical Problems</td>
<td>14.7</td>
</tr>
<tr>
<td>Legal Problems</td>
<td>4.4</td>
</tr>
<tr>
<td>Other Residence Unavailable</td>
<td>16.2</td>
</tr>
<tr>
<td>Local Education Unavailable</td>
<td>23.5</td>
</tr>
<tr>
<td>Child Dangerous</td>
<td>17.6</td>
</tr>
<tr>
<td>Family Financial Problems*</td>
<td>14.7</td>
</tr>
<tr>
<td>Recommended by LSS Staff</td>
<td>19.1</td>
</tr>
<tr>
<td>Evaluation</td>
<td>16.2</td>
</tr>
<tr>
<td>Mothers Coping Resources Depleted</td>
<td>36.8</td>
</tr>
<tr>
<td>Family Stress</td>
<td>26.5</td>
</tr>
<tr>
<td>Respite Care Unavailable</td>
<td>10.3</td>
</tr>
<tr>
<td>Other Siblings Affected*</td>
<td>10.3</td>
</tr>
<tr>
<td>Child Abuse/Neglect*</td>
<td>13.2</td>
</tr>
<tr>
<td>Special Arrangements</td>
<td>0.0</td>
</tr>
</tbody>
</table>

*p<.10 (df=91)
the most were in four particular circumstances: Siblings being affected, financial difficulties in supporting the disabled child, in the use of special arrangements for admission, and child abuse and/or neglect. The latter was suspected by admitting staff at the State School to a greater degree among families of Leavers than of Stayers. These findings are consistent with the assumption that less severely retarded and physically impaired children are more difficult to care for because they are more capable of emitting problem behaviors that are viewed as destructive, oppositional or disruptive. A higher frequency of such behaviors would be expected to correlate with a higher incidence of abuse.

In about a third of each group, clinical records showed that parents requested admission of their child because the mother's coping resources were depleted. Yet the need for respite care was reported in only seven records in the Leavers' sample (10.3%) and one record in the Stayers' sample (4.0%). This may possibly be related to the historical context of the respite care policy in practice at Laconia State School at the time. As one mother related to us in an in-depth interview:

[Laconia State School] had a respite program. . . . You could have 30 days a year but it was a one-shot deal. And I thought . . . who wants to take their kid and dump him at the State School for 30 days? God, I'd have given my eye-teeth for 30 days but I hated to leave her there. If you only took an hour or a day and that was all you wanted, that was it for a whole year! You couldn't split it up. . . . So we didn't use it. . . . You just don't take a kid that lives at home and put em' in an institution for 30 days!. . . . I didn't need 30 days at one shot.
Another precipitating circumstance was the effect of the handicapped child upon his/her siblings; more parents of Stayers complained that other siblings were affected than the parents of Leavers (p<.10).

One mother explained that her husband still could not talk about his feelings about his handicapped daughter and that, as a family, they had decided that their other children would suffer great hardship if their disabled child remained with the family. The mother said that her other children would probably not have been able to attend college and live normal lives if this child had lived at home. As will be explained in the section on socioeconomic status, the families of Stayers, were, on the whole, much more upwardly mobile than those of Leavers. Thus the presence of a developmentally disabled child poses a threat to goals of economic and social advancement. What is particularly noteworthy with regard to circumstances of admission, is that medical problems were not a chief complaint of either population. From other reports in the literature, this is not unusual. Featherstone (1980) points out that it is not the medical problems per se that are difficult; it is the fact that a child with more severe problems in functioning takes so much of parents' time away from their other children that causes families to consider institutionalization as a necessary alternative to home care when no other community care exists. A substantial proportion of each group did complain that local education was not available for their children.
Figure 3.1 Map of New Hampshire Showing DMH/DS Regions
"X" marks the location of LSS.
Region

Figure 3.1 shows the State of New Hampshire as it is divided into 12 regions by the service delivery system of the Division of Mental Health and Developmental Services. Generally speaking, Leavers tended to come from regions 3, 7, and 10, i.e., areas around Laconia, Manchester, Derry, Salem, and Plaistow, what can be considered the central and southwestern regions of the state. Stayers tended to come from the south and the southwestern regions, around the towns of Manchester (Region 7), Nashua (Region 6) and Keene, Greenfield, and Peterborough (Region 5) which are centers of small businesses and industry.

Family Characteristics

The data for describing the characteristics of participating families of Leavers were obtained through the combined reports of parents, case managers and service providers, and Laconia State School records. When there were discrepancies among these sources, parents' reports were favored except in instances of chronological information, wherein written documents took precedence over human memory. For example, fathers' occupation reported to the intake worker at the time of their children's admission to LSS was deemed more accurate than the parent's recall in an interview.

Socioeconomic Status

Straus and Urban (1978) have argued that family SES is increasingly affected by women's participation in institutions of higher learning, the professions, as well as in the labor force.
They state:

[T]he traditional practice of controlling for socioeconomic status by using only the SES of the male breadwinner is inappropriate for a majority of dependent variables. In some cases it is the husband's and in some case the wife's characteristics which are most predictive of variation in social phenomena. Given this knowledge, the superior method of controlling for family socioeconomic status involves treating husband and wife SES as separate variables entered simultaneously into a regression analysis.

On the basis of this argument, it was decided that at least in initial analyses, measures of both husbands' and wives' SES scores would be included. The Nam-Powers Socioeconomic Status Score based on the 1970 U.S. Census code was used to obtain a measure of socioeconomic status for the two samples (Miller, 1983:290-300). This was chosen over the more commonly used Duncan Socioeconomic Status Index because the Nam-Powers scale assigns a separate score for men and for women in the same occupation, thereby providing a built-in weighted prestige differential. Fathers' and mothers' occupations at the time of the children's admission and at the time of first community placement or (in the case of Stayers) at the 21st birthday were obtained (see Section B of Appendix C) and then assigned the appropriate Nam-Powers score.

Mothers' work profiles differed dramatically from those of fathers. During their children's admission and first community placement, few mothers were engaged in gainful employment. Therefore, in order to get a better picture of their occupational status, it was necessary to look at their employment before marriage and their most recent occupation.
Table 3.6a Socioeconomic Characteristics of Leavers and Stayers

<table>
<thead>
<tr>
<th>Sample</th>
<th>Nam-Powers Occupational Status Score</th>
<th>First Sample</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Fathers' Score</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>mothers' Score</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>admission</td>
<td>placement</td>
<td>at age 21</td>
<td>Before</td>
</tr>
<tr>
<td>Leavers</td>
<td></td>
<td>45.3</td>
<td>52.3</td>
<td>42.1</td>
<td>42.9</td>
</tr>
<tr>
<td></td>
<td></td>
<td>SD=26.3</td>
<td>(n=63)</td>
<td>(n=50)</td>
<td>(n=50)</td>
</tr>
<tr>
<td>Stayers</td>
<td></td>
<td>58.6</td>
<td>60.5</td>
<td>49.3</td>
<td>51.0</td>
</tr>
<tr>
<td></td>
<td></td>
<td>SD=21</td>
<td>(n=24)</td>
<td>(n=11)</td>
<td>(n=21)</td>
</tr>
</tbody>
</table>


Table 3.6b Socioeconomic Characteristics by Status Categories

<table>
<thead>
<tr>
<th>Status Category</th>
<th>Fathers' Status</th>
<th>Mothers' Status</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Admis'n 1st Placement</td>
<td>Marriage Recent</td>
</tr>
<tr>
<td>A. Leavers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>(n=63) 27.0%</td>
<td>(n=50) 20%</td>
</tr>
<tr>
<td>Medium-Low</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medium-High</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td></td>
<td></td>
</tr>
<tr>
<td>B. Stayers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>(n=24) 4.2%</td>
<td>(n=11) 9.1%</td>
</tr>
<tr>
<td>Medium-Low</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medium-High</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
In cases where a particular occupation did not appear on the Census list of occupations, Hollingshead's Two Factor Index (Miller, 1983:303-308) was used to determine the relative position of the occupation which was then interpolated. In some cases ambiguity necessitated the datum be coded missing; in cases of retirement or unemployment, no score was assigned and was coded "not applicable." In general terms, the Nam-Powers Status Score ranges from 1 to 100 and can be divided, for practical understanding, into the categories shown in Table 3.6a.

Generally, both populations can be considered upwardly mobile. By comparing the fathers' occupation at the time of their children's admission with their occupation at the time of the children's first community placement, we found that occupational status scores rose. The average Nam-Powers score increased 7.0 points for Leavers (t=1.31; p<.10, df=111) and 1.9 points for Stayers.

Since the number of mothers working at the time of their children's admission or at placement were few, we considered their scores before marriage and their most recent occupation as a means of comparing the mother's contribution to the family's status. Consistent with husbands' scores, wives of Stayers, on the average, had higher scores than did wives of Leavers. Table 3.6b shows the proportion of parents in each of four occupational categories. At admission, a significantly larger proportion of Stayers' fathers are in the medium-high and high categories than fathers of Leavers (t=2.21; p<.03; df=85). All other comparisons were suggestive of Stayers' higher status but were not statistically significant (using student's t).
Table 3.7 Highest Level of Parents' Education at the Time of Children's Admission (Percentages)

<table>
<thead>
<tr>
<th>Education At Admission</th>
<th>Leavers' Fathers (n=65)</th>
<th>Leavers' Mothers (n=64)</th>
<th>Stayers' Fathers (n=24)</th>
<th>Stayers' Mothers (n=25)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Some Grade School</td>
<td>9.2</td>
<td>9.4</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>2 Completed Gr. School</td>
<td>12.3</td>
<td>7.8</td>
<td>4.2</td>
<td>4.0</td>
</tr>
<tr>
<td>3 Some High School</td>
<td>16.9</td>
<td>28.1</td>
<td>16.7</td>
<td>32.0</td>
</tr>
<tr>
<td>4 Completed H.S.</td>
<td>24.6</td>
<td>34.4</td>
<td>29.2</td>
<td>32.0</td>
</tr>
<tr>
<td>5 Some College or Training</td>
<td>29.2</td>
<td>14.1</td>
<td>25.0</td>
<td>28.0</td>
</tr>
<tr>
<td>6 Completed College</td>
<td>1.5</td>
<td>4.7</td>
<td>16.7</td>
<td>4.0</td>
</tr>
<tr>
<td>7 Some Graduate School</td>
<td>1.7</td>
<td>1.6</td>
<td>4.2</td>
<td>-</td>
</tr>
<tr>
<td>8 Graduate Degree</td>
<td>4.6</td>
<td>-</td>
<td>4.2</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>$\bar{X}=3.9$</td>
<td>$\bar{X}=3.6$</td>
<td>$\bar{X}=4.6$</td>
<td>$\bar{X}=3.9$</td>
</tr>
<tr>
<td></td>
<td>SD=1.7</td>
<td>SD=1.3</td>
<td>SD=1.4</td>
<td>SD=1.0</td>
</tr>
</tbody>
</table>

Education

The majority of Leavers' fathers completed high school, including a substantial proportion who attended college by the time their children were admitted to LSS. The data from the Stayers subsample suggested that these families were generally better educated than the families of Leavers. Stayers' fathers and mothers tended to have at least some college experience with a greater percentage completing college than Leavers' parents. Consistent with these findings is the fact that this group also was comprised of more professionals, according to their Nam-Powers Scores.

The national average in 1970 for all white persons 25 years of age or older for completing high school was 54.5% (U.S. Bureau of the
Census, 1985: Table 219). The samples in this study are somewhat above the national average, except for Leavers' mothers who are about 12% below the national average. Of Leavers' fathers, 61.6% completed high school by their children's first admission, and 79.3% of Stayers' fathers had completed high school.

Religion

Of the 56 Leavers' families who answered our questions about religion (see questions 28-30 in Appendix C), only one family said they had no religious affiliation; half of the sample identified themselves as Roman Catholic while the rest identified with a specific sect of Protestantism (Congregational, Baptist, and Evangelical comprising the largest groups). We asked, "How important is your religion to you?" and about frequency of attendance. To the first question, 65.5% responded that their faith was either very or extremely important. Another 32.8% reported attending services once a week and 8.6% reported attending two or more times a week. The majority (51.8%) attend a few times or less per year.

Stayers (n=25) was comprised of 33.3% Roman Catholics and 37.5% Protestants (Congregational and Methodist being the largest sects represented). Six persons (about 25%) reported affiliation with smaller Protestant sects such as Seventh Day Adventists, or simply "Born Again Christian;" one person (4.1%) was affiliated with Judaism. Similar to Leavers, two-thirds of Stayers stated that their religion was very or extremely important, with 41.7% attending services at least once a week and 37.5% attending only a few times or less a year. Census data for New Hampshire residents (for 1980) show that 44.2% were Christian church adherents (this includes both Protestants and
Catholics) with 0.6% identifying themselves as Jewish (U.S. Bureau of the Census, 1985: Table 78). Gallup poll results of 1984 for the United States show that 39% of the White population 18 years or older attended services within seven days of the poll. These comparisons suggest that the informants for this study are significantly more involved in religion than the population-at-large and that this is especially true of Stayers' families.

Race and Ethnicity

As is typical of New Hampshire, the families were racially homogeneous. Seventy-four per cent and 15.5% of Leavers' parents considered themselves white Americans or of French Canadian or French origin, respectively. Stayers' parents consisted of 70.8% white Americans with another 20.9% claiming French Canadian or French identification. However, if one estimates French origin by examining the surnames of the 93 families, 37% emerges as the more likely figure for describing the participants. The underestimate is most probably due to disclaimers on the part of families, a practice with a long history in New Hampshire.

As part of their desire to assimilate completely into the dominant culture, having experienced prejudice and other barriers to upward mobility, Franco-Americans have adapted English as their language, inter-married with non-French-speaking peoples and abandoned their separatist orientation known as "survivance" (Samson, 1982). It is therefore not surprising that the parents in this study identified themselves as "White Americans" even though their parents or grandparents were of French extraction.
What is important here is that, despite assimilation of the participants in this study, ethnic influences may not have been totally dissipated with respect to kinship. Ethnic ties are extremely important. Toennies' concept of Gemeinschaft is the term for the shared meanings and understanding that come with the territory of ethnic identity with its common language, customs, traditions, and religious beliefs (Toennies, 1961). Even among assimilated persons, the shared heritage remains thematic in their lives.

Because of the limited data addressing this issue—I did not ask questions which would properly measure depth of ethnic identity or ethnic themes—I can only speculate as to the Franco-American influences which may have contributed to a sense of felt obligation binding the kin networks together. However, other studies of Franco-Americans in New England have reported the strength of family ties and obligations which lend credence to the assumption I am making regarding kin support patterns. Brault, for example, observes:

Often it is said that the third generation in America—the grandchildren of immigrants—cultivates an ethnic identity that the second generation was eager to lose. This holds true for many Franco-Americans. For some, ethnic values are an antidote to alienation, preoccupation with consumer goods, drugs, sex, technology, or other ills that affect modern society. Many discover for the first time what it means to belong when they begin to frequent Franco-American circles, attend family gatherings in New England or French Canada, or learn of the hardships and indignities experienced by their parents or ancestors.

Franco-Americans who approach their ethnicity selectively are another recent phenomenon. Genuinely interested in certain elements of their heritage... they may pay little or no attention to other facets of their culture, in particular the French language and the Catholic faith. Informed observers point out that other American ethnic groups—for example, Greeks and Jews—have a highly developed sense of pride or solidarity that does not necessarily
depend on the language loyalty or religious affiliation. Franco-Americans may reject many of the values the group holds dear yet continue to exhibit a strong attachment to the milieu from which they sprang or to their French-Canadian forebears.... [T]his kind of awareness or identification with the Franco-American group should not be dismissed as token or symbolic ethnicity. (Brault, 1986:159-160.)

Rural Living

Another feature that may contribute to strong kinship ties within this sample is the fact that New Hampshire has much of its population still living in small towns. It may be speculated that the participating families in this study have stronger familial bonds than in other parts of the nation because they live in New Hampshire, which is comprised of small towns that are racially homogeneous and often contain several generations of families within them. These ethnic and geopolitical features, in turn, make for a climate of Gemeinschaft as opposed to the Gesellschaft of more urban environments. We shall see in Chapter 5, that the majority of the families in this study claim their kin to be supportive with regard to their developmentally disabled children. However, we will look more closely at the correlates of this support to see which family and child characteristics may inhibit or stimulate this support.

Family Size

The average household is comprised of two natural parents, the child in our study, and three other siblings. These families are twice the size of the national average reported in 1970, when 17.7% of white families had two children; 10.5% had three children; and only 8.8% had four or more children (U.S. Bureau of the Census, 1986: Table 64). Of Leavers' families, 30% had four or more children; and 41% of Stayers' families had four or more children.
Of the 58 Leavers' families who answered this question, twelve reported that they had at least one other developmentally disabled child besides the one in our study. There were three families who had 2, 3, and 4 disabled children, respectively, in addition to the one in our study. Of Stayers' families (n=25), two parents reported they had one other disabled child who also went to LSS.

Summary

Our participating families typically consisted of 2 natural parents, four children, one of whom was developmentally disabled and had spent several years at Laconia State School. The families were of western European stock, educated, upwardly mobile, with fairly strong religious ideals. It was speculated that as much as a third of all the families in this study may be Franco-American and that these ethnic ties in combination with small-town living, may also play a part in strengthening kin support.

Though overall, the groups were quite similar, Leavers had a greater proportion of less retarded individuals than the Stayers who also had somewhat more major medical conditions. A major difference between the samples, which has significance for our examination of parental attitudes toward deinstitutionalization, is the fact that, in general, Stayers entered LSS five years earlier than Leavers.

I believe it can justifiably be said that the two groups, of Leavers and Stayers, were more similar than different with regard to behavioral and medical characteristics. This comparison was made in order to prepare the reader for the arguments presented in the
following chapter. In Chapter 4, I will show that deinstitutionalization has had more to do with civic attitudes pervasive in a given historical period than with the children's diagnostic categories or levels of handicapping conditions.
CHAPTER 4

PLACEMENT DECISIONS,
DEINSTITUTIONALIZATION,
AND PARENTAL ATTITUDES

In this chapter, the many issues that parents faced in seeking admission of their children to Laconia State School and Training Center (LSS), in dealing with institutional residence, and in confronting the deinstitutionalization process and community placement will be discussed. It is the purpose here to not only describe response patterns and attitudes, but to bring to light the impact of historical context on parents' concerns as they arose. Mallory has observed:

Although parents have always fought for improved services for their handicapped children, they did not take the lead in calling for the deinstitutionalization process that began in the 1960s. . . . In general, parents have resisted community placement out of concern that their children would be made to live in unsafe, inadequate facilities where lack of supervision and exploitation would be more likely to occur than in an institution. Parents were also fearful that they would be required to assume legal, financial, and psychological responsibility for their children. (Mallory and Herrick, 1986).

In light of the pain and grief associated with the early stages of diagnosis and institutional placement, and the many intervening years when families adjusted to living without their severely handicapped child, the possibility of involuntary reintegration of the child into the family was viewed with great trepidation. As we shall see in the later discussion, the move to place children out of LSS was not initiated or supported by most parents whose children lived there. However, we shall also see that the drastic and involuntary changes that occurred from 1970 to 1985 caused significant changes in parents'
attitudes toward community care. Our discussion will focus on the issues which make deinstitutionalization so complex. In a final section, we will examine the correlates of parents' positive response to normalization ideology.

Initial Placement Decisions

The median admission year to LSS was 1970 for Leavers and 1966 for Stayers. Even at these late dates, alternative residential and educational programs were not available in most regions of the State of New Hampshire. As reported elsewhere (e.g., Suelzle and Keenan, 1980), placement in the institution is usually a difficult decision fraught with guilt and feelings of helplessness and frustration. However, a subtle distinction emerges between the two samples regarding this decision process. Parents of Leavers tended to encounter barriers to their child's admission which they had to overcome, whereas Stayers' parents were more often encouraged at the outset to institutionalize their disabled offspring. Whereas for the second group, this impetus tended to come mostly from professionals; Leavers' parents tended to receive advice from other family members and neighbors, as well as professionals. This supports the observation that Stayers' families were somewhat higher in socioeconomic status, which correlates with a greater reliance upon professional input. As already outlined in Chapter 3, though Stayers were somewhat more severely handicapped, leading to more frequent contact with a variety of professionals and greater likelihood of consensus concerning the decision to institutionalize, the decision itself has more to do with historical climate. This historical climate dictates how different levels of handicaps are treated and the services available.
The majority of all the participating parents were the ones who first initiated admission of their children to LSS. Though families of Leavers and Stayers each had difficulties with the admission process, there were some qualitative differences that were revealed in in-depth interviews.

It must be remembered that, in general, Leavers' parents applied for their children's admission at a later point in history, when there were already beginning to be constraints on the census at the State School. Figure 4.1 shows the dramatic decline in the LSS census of children for the fifteen years from 1970 to 1985. This graph has many other regional counterparts and reflects the national trend (Conroy, 1985a). All the 68 Leavers left during this period. As constraints increased, in a climate of great public criticism, admission to the State School became increasingly difficult. By 1970, deinstitutionalization had begun. The school began to refuse new admissions. Parents had to plead a desperate cause to gain their children's admission since alternatives to the institution did not exist.

Though both groups of parents spoke of the mother's coping resources being depleted and of the significant behavior problems presented by their children, it appears that Leavers' parents were more likely to use these reasons to press for admission. One mother threatened, "If you don't take him, you'll have to admit me to New Hampshire Hospital!" (the State psychiatric facility.) A father reported, "It took nine years to get Carl into LSS for a four day per week, four-month program" [for toileting and self-care]. Carl had been on the waiting list since one year of age but didn't get in until
Figure 4.1 Decline in Population of Children at LSS, 1970-1985
*Based on data for July 1 of each year, both resident and community populations
his father complained to the central office in Concord, the State capital, stating that his wife was "on the verge of a breakdown."

At times extreme measures seemed to be the only solution. A surrogate mother told us her charge was abandoned as an infant at LSS by the child's father who, at the time, had become a widower. The father sought admission on an evaluation basis and never returned.

In contrast, Stayers' parents seemed to experience pressure early on to institutionalize their children. On the whole, their children were placed at LSS at an earlier point in history when community placement was barely contemplated in the public mind. Doctors were more adamant about institutionalizing mentally retarded children. "Better put him away. He's an idiot," admonished one physician. In another painful recollection, a mother was told by the family doctor, "Get her out of the house as fast as you can. What is the use of cutting off the puppy dog's tail by inches"? But even physicians manifested difficulty in advising parents. A mother told us: "At first the doctor said, 'Take him home and love him'; later he said, 'Put him in the State School.'"

Since Leavers tended to be somewhat more active than their Stayers' counterparts and entered LSS at a later point in history, reflective of the ambiguity of transitional periods. At this time mainstreaming ideas were taking root, though not all facilities and programs were fully capable of implementing these ideas; Leavers' parents reported that they were subject to social pressures from relatives, teachers, their children's schoolmates and neighbors. One parentsaid pressure from teachers and the teasing of schoolmates made keeping her child at home increasingly difficult. In another
instance, parents were told by the school district that LSS was the "only" place their daughter could be evaluated in order to be accepted for any program in the state. Another mother explained the painful shunning of her neighbors. "The townspeople were hateful to her. . . . They wanted to get rid of her--Vicky was an undesirable in town."

Dennis was not learning in school, having seizures and was teased by other students. Family members blamed Dennis' mother for his seizures and his problematic behavior, saying she spoiled him when she should have disciplined him. Finally, a woman in her husband's office, whose child was at LSS, suggested to Dennis' father that Dennis might benefit from placement there.

Though in a third of the cases of Leavers, the physician was a key figure in the admission to LSS, other family members also encouraged parents to admit their disabled relatives. A mother, whose husband and father-in-law were both ex-residents of LSS, reported that a cousin had urged her to place her daughter.

A mother in the Stayers' group explained: "We polled extended family members to see what they thought. When a paternal aunt and her husband had agreed to keep all the kids except Gerard in case of [our] death--that was the deciding factor!"

At one point in history when there were only two choices, home or the institution, parents experienced great frustration. When one mother could no longer handle her daughter at home because of the child's terrible behavior and because there were no other possibilities, the family placed her at LSS. The frustration, however, of witnessing her child's rapid regression forced the mother to quickly take her home. "I had to toilet train her all over again!" she told us.
Due to the fact that Stayers entered LSS earlier in New Hampshire's history of service delivery, today, their parents are most vulnerable to feelings of guilt for placing their children in the institution. The current social context of deinstitutionalization ideology makes for painful hindsight. Many of the mothers we interviewed would tell us "We did what the doctors told us to do" or "There were no group homes in those days!" One mother told me, "Now that Belinda [aged 24] is in the group home, she is so happy. She has her own room. . . . She has privacy the way she never did at Laconia." There was a tone of remorse in the mother's voice that belied the question, "Why didn't this happen sooner?!

Leavers' parents placed their children in LSS at a time when institutions were beginning to be criticized, but also at a time when alternatives were not yet developed. For neither group was the decision to seek their children's admission to LSS an easy one and once their children were there, it was not always easy to visit.

Visiting Patterns

Visitors to Laconia State School are required to report to the administration building before going to the units and cottages to visit residents. The visits are recorded at the time and kept in a file separate from the residents' medical and behavioral records. Since visitors are not always consistently identified, no distinction was made—in recording data—as to whether the visitors were kin or others, though for the most part, they were relatives, according to the reports of staff and parents. In some instances a resident was visited by LSS staff or community staff preparing the resident for
placement. These data give a rough indication of social involvement of the children's networks.

Table 4.1 Total and Average Number of Visits Per Year by Sample In Comparison with Length of Stay at LSS

<table>
<thead>
<tr>
<th></th>
<th>Leavers (n=67)</th>
<th>Stayers (n=21)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Total number of visits during stay at LSS</td>
<td>18</td>
<td>20</td>
</tr>
<tr>
<td>Median</td>
<td>18</td>
<td>20</td>
</tr>
<tr>
<td>Mean</td>
<td>37.0</td>
<td>31.7</td>
</tr>
<tr>
<td>SD</td>
<td>53.4</td>
<td>30.1</td>
</tr>
<tr>
<td>B. Average Yearly Visits</td>
<td>6.9</td>
<td>3.2</td>
</tr>
<tr>
<td>C. Average Length of Stay at LSS (years)</td>
<td>5.4</td>
<td>10.0</td>
</tr>
</tbody>
</table>

Table 4.1 compares the visits received by Leavers and Stayers. Stayers, when comparing average yearly visits, were not visited nearly as often as Leavers. When we compare means and medians, however, differences from Leavers are less dramatic. Most likely this is due to the fact that nearly a third of this smaller sample of Stayers included individuals whose parents volunteered to participate in the study and in general were more interested in their children, than is typical of an institutionalized population that is older. As will be shown in Chapter 5, the majority of this group of Stayers' parents reported that their extended kin were extremely supportive. These parents often spontaneously mentioned their relatives (especially grandparents) visiting the disabled children at the State School as evidence of support. (See Chapter 7.)

In general, we found that the longer the stay at LSS, the fewer the visits. This is not a new finding. It is one of the sad
correlates that make institutions so insular. Another is distance. It was not uncommon for a parent to tell us, "We'd visit more if it didn't take two hours to get there." Or, "It's not that I don't want to visit Larry, it's just that it's so depressing to see the other residents." A mother of a very severely involved child, who required 24-hour physical attention told us the sight of her son was too painful to her. These parents did not gain the sympathy of LSS staff. When a parent broke through his/her inertia to make a visit, the staff, who were keeping score, often conveyed their scorn, making subsequent visits even more difficult and unlikely.

Table 4.2 Parent Interview Informants (Percentages)

<table>
<thead>
<tr>
<th></th>
<th>Leavers</th>
<th>Stayers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Father</td>
<td>10.8</td>
<td>8.0</td>
</tr>
<tr>
<td>Mother</td>
<td>50.8</td>
<td>64.0</td>
</tr>
<tr>
<td>Both Parents</td>
<td>20.0</td>
<td>28.0</td>
</tr>
<tr>
<td>Foster Mother</td>
<td>4.6</td>
<td></td>
</tr>
<tr>
<td>Foster Father</td>
<td>1.5</td>
<td></td>
</tr>
<tr>
<td>Both Foster Parents</td>
<td>1.5</td>
<td></td>
</tr>
<tr>
<td>Other (relative, guardian)</td>
<td>10.8</td>
<td></td>
</tr>
</tbody>
</table>

Parents' Attitudes Toward Deinstitutionalization

The two main methods of data collection which inform this discussion are the Attitudes Toward Deinstitutionalization Scale (ATDS) developed by James Conroy and his colleagues (Conroy and Bradley, 1985) and in-depth interviews conducted in the period between 1984 and 1985. Table 4.2 shows the distribution of informants whose attitudes we assessed. In addition, anecdotal material made
available from a survey conducted by two parents in 1979 will be presented to shed light on issues revolving around opposition to deinstitutionalization.

Table 4.3 Parents’ Assessment of the Impact Upon Family Life Of Their Children’s Return to the Community

<table>
<thead>
<tr>
<th>Area of Impact</th>
<th>Leavers (n=63)</th>
<th>Stayers (n=25)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>S.D.</td>
</tr>
<tr>
<td>Your own social life</td>
<td>2.9</td>
<td>1.2</td>
</tr>
<tr>
<td>Your job</td>
<td>3.0</td>
<td>.7</td>
</tr>
<tr>
<td>Your spouse’s job</td>
<td>3.1</td>
<td>.5</td>
</tr>
<tr>
<td>Family home recreation</td>
<td>2.9</td>
<td>.9</td>
</tr>
<tr>
<td>Your time alone</td>
<td>2.9</td>
<td>1.2</td>
</tr>
<tr>
<td>Your time with spouse</td>
<td>2.9</td>
<td>1.0</td>
</tr>
<tr>
<td>Time with other children</td>
<td>3.0</td>
<td>.9</td>
</tr>
<tr>
<td>Family vacations</td>
<td>3.0</td>
<td>1.1</td>
</tr>
<tr>
<td>Your own general happiness*</td>
<td>3.9</td>
<td>1.2</td>
</tr>
<tr>
<td>Your child’s happiness**</td>
<td>4.3</td>
<td>.9</td>
</tr>
<tr>
<td>Child’s relation with you</td>
<td>3.7</td>
<td>1.1</td>
</tr>
<tr>
<td>Child’s relation with your spouse</td>
<td>3.6</td>
<td>.9</td>
</tr>
<tr>
<td>Child’s relation with siblings</td>
<td>3.5</td>
<td>1.0</td>
</tr>
<tr>
<td>Child’s relation with others*</td>
<td>4.1</td>
<td>1.0</td>
</tr>
</tbody>
</table>

*p<.05    **p<.001

ATDS: Impact Scale

The Impact Scale consists of a list of fourteen routine family activities. (Table 4.3). The parent is asked to judge to what extent these activities change as the result of his or her child being placed in the community. Leavers’ parents answered in retrospect and Stayers’ parents were asked to respond according to how they anticipated their lives might change as a result of their children returning to the community.

On a scale of 1 (change for the worse) to 5 (change for the better) the parent responded to the following items: His or her own
social life, job, spouse's job, family home recreation, time alone, time with spouse and with the other children still at home, family vacations, own general happiness, the parent's assessment of the developmentally disabled child's happiness, and the latter's relationship with the respondent, the spouse, with siblings and with others. Table 4.3 displays the means and standard deviations for each item in the Impact Scale for each sample.

Though, overall, the median response was 3, i.e., no change, with regard to family activities, some concerns were detected. Both groups of parents thought their children's placement might impinge upon their time alone. While Leavers' parents showed some concern for their social life, family recreation and their time with their spouse, Stayers' parents were concerned that placement would interfere with their time spent with their other children. However, unlike Leavers' parents, Stayers' parents gave a small indication that family recreation at home might improve as a result of their child's placement. Rudie and Riedl (1984) have shown that parents are not able to anticipate the benefits of community placement, but that once placement has occurred, parents express happiness with the outcome.

With regard to emotional issues and social relationships, parents showed high sensitivity to community placement. Mothers in both samples perceived or anticipated a change for the better with regard to their children's relationship to others as well as to family members. Leavers' mothers saw their children as much happier now that they were in the community. Though we asked about mother's happiness
first, often mothers would spontaneously tell us that since they saw their children were happier, they were happier as well.

**Cohort Differences.** The year 1978 marks a turning point in the rights of handicapped people. It was the year P.L. 94-142, the Education for All Handicapped Children Act of 1975 went into effect. It also marks the period when parents in the State of New Hampshire were mobilizing for a lawsuit against the State School in the Garrity v. Gallen case. Therefore it seemed reasonable to test whether we could expect any differences between pre- and post-1978 cohorts with regard to a child's return to the community, i.e., whether positive changes insuring educational services would affect parents' outlook. The results, in fact, did show that parents whose children left LSS after 1978 were statistically more likely to say their own general happiness had changed for the better (Chi-sq=11.26; p<.03; df=4) and that their children's relationship with them had improved as a result of leaving the institution (Chi-sq=10.04; p<.05; df=4).

These results suggest that as the prospect for increased services becomes more secure, parents will respond with increased satisfaction. What I am trying to demonstrate in this chapter is that parents in New Hampshire are not merely reactionary and self-seeking, but their resistance to deinstitutionalization is founded upon the very real concern about adequate alternatives to the institution. As these alternatives become more stable, I believe we will see a growth in parental support for community options. In the next section, we will look more closely at how parents view the practical and ideological issues of deinstitutionalization.
Table 4.4 Parents' Attitudes Toward Deinstitutionalization**

<table>
<thead>
<tr>
<th>Statement</th>
<th>Leavers (n=63)</th>
<th>Stayers (n=25)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>Mean</td>
</tr>
<tr>
<td></td>
<td>S. D.</td>
<td>S. D.</td>
</tr>
<tr>
<td>1. Child has reached development limits</td>
<td>3.8</td>
<td>3.2</td>
</tr>
<tr>
<td></td>
<td>1.5</td>
<td>1.2</td>
</tr>
<tr>
<td>2. Same residence for life*</td>
<td>3.1</td>
<td>2.3</td>
</tr>
<tr>
<td></td>
<td>1.5</td>
<td>1.6</td>
</tr>
<tr>
<td>3. Open setting to match skills*</td>
<td>3.8</td>
<td>3.2</td>
</tr>
<tr>
<td></td>
<td>1.3</td>
<td>1.6</td>
</tr>
<tr>
<td>4. Community workers competent*</td>
<td>3.5</td>
<td>2.8</td>
</tr>
<tr>
<td></td>
<td>1.3</td>
<td>1.3</td>
</tr>
<tr>
<td>5. Community funds are secure</td>
<td>2.1</td>
<td>2.0</td>
</tr>
<tr>
<td></td>
<td>1.2</td>
<td>1.3</td>
</tr>
<tr>
<td>6. Needed services are available</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Financial burdens lifted</td>
<td>3.4</td>
<td>3.4</td>
</tr>
<tr>
<td></td>
<td>1.5</td>
<td>1.2</td>
</tr>
<tr>
<td>8. Normalization*</td>
<td>4.7</td>
<td>3.5</td>
</tr>
<tr>
<td></td>
<td>.6</td>
<td>1.4</td>
</tr>
<tr>
<td>9. Least restrictive alternative*</td>
<td>4.8</td>
<td>4.0</td>
</tr>
<tr>
<td></td>
<td>.5</td>
<td>1.3</td>
</tr>
<tr>
<td>10. Deinstitutionalization*</td>
<td>4.7</td>
<td>3.1</td>
</tr>
<tr>
<td></td>
<td>.9</td>
<td>1.9</td>
</tr>
<tr>
<td>11. Discharge decision*</td>
<td>4.5</td>
<td>2.9</td>
</tr>
<tr>
<td></td>
<td>1.2</td>
<td>1.6</td>
</tr>
</tbody>
</table>

*p<.05

**The items in the table refer to the following statements to which the respondent answers "strongly agree, somewhat agree, neither agree nor disagree somewhat disagree or strongly disagree."

1. I believe that my relative has reached his/her educational and psychological development and will not progress much beyond the level he/she is at now.

2. When my relative lives away from home, I prefer that he/she remain in the same place his/her entire lifetime.

3. When my relative lives away from home, I prefer that he/she move from a more protected residential setting to a more open setting as he/she achieves greater self-help skills.

4. Persons who work in community living arrangements are knowledgeable and skillful enough to handle situations which may arise with regard to your developmentally disabled relative.

5. I believe that funding for community arrangements is secure and permanent.

6. I believe that all services needed by my developmentally disabled relative are available to him/her in the community.

7. I believe that my family has not had to assume added financial burdens for the care of my relative since he/she has been (or will be) living in the community.

8. Normalization means that, as much as possible, developmentally disabled persons are given normal opportunities for living, working, and school. In thinking about what your relative will need in the future, how much do you agree with this concept?
Table 4.4 (continued)

9. The Least Restrictive Alternative says that developmentally
disabled persons should be allowed to live in places which are much
like normal homes as possible. In thinking about what your relative
will need in the future, how much do you agree with this concept?

10. Deinstitutionalization is the moving of developmentally
disabled persons from the institution into places in the community.
In thinking about what your relative will need in the future, how much
do you agree with this concept?

11. When your relative was (is) selected for movement from LSS
to the community, how agreeable were you (will you be) to this deci­
sion?

ATDS: Deinstitutionalization Ideology

The second part of the ATDS consists of eleven ideological
statements concerning deinstitutionalization as applied to the infor­
mant's developmentally disabled child. The parent was asked to
respond to each statement with "strongly agree, somewhat agree,
neither agree nor disagree, somewhat disagree," and "strongly
disagree." Table 4.4 shows the mean scores for both groups for each
item. Note that the higher the score, the more the agreement with
the principles of normalization. Thus, for example, strongly
disagreeing with the statement that the child has reached his/her
developmental limit or with the statement that the child should live
in the same home for a lifetime, is coded 5 while strongly agreeing is
coded 1. Each item will now be discussed in turn.

Developmental Model. For the first statement, "I believe my
relative has reached his/her highest level of educational and psycho­
logical development and will not progress much beyond the level he/she
is at now," the mean score was 3.8 for Leavers and 3.2 for Stayers.
Optimism that their children could still progress was not significantly
influenced by the child's diagnosis. Further analysis revealed that
parents of severely retarded children strongly disagreed with this statement in 63.6% of the cases, and 50% of parents of profoundly retarded children also did not believe their children had reached their full potential.

These findings are in sharp contrast to those of Latib, (Conroy and Hoss, 1984). The Pennhurst families agreed with the statement, i.e., that the children had reached their limit. The authors concluded that the families in their sample were not responsive to the developmental model which stresses the notion that all people can grow and learn.

Assuming that the results are true, there are two possible explanations for the discrepancy between our findings and those of Latib's and Conroy's. It could be that since our respondents are the parents of a younger cohort than the parents of the Pennhurst population (we limited our sample to residents born in or after 1949 and the Pennhurst study included all residents), they were still hopeful for their children's growth and development. The other reason could be that history has had an impact and our parents have had more exposure to, and therefore more opportunities to adopt, a developmental perspective.

Least Restrictive Alternative (LRA). Three statements were posed pertaining to the concept of the least restrictive alternative. These appear as items 2, 3 and 9 in Table 4.4.

In general, parents responded more conservatively to item 2 than items 3 and 9. In our in-depth interviews, especially with Stayers' parents, there was a concern expressed for the need for a stable environment which promotes familiarity and good orientation to
surroundings so that their children can develop and improve in functioning. Since Stayers' parents scored lower on items 2 and 3, our interpretation here is that we can expect greater concern on the part of the parent for stable long-term placement, the greater the child's impairment and the longer the period of institutional residency.

We asked parents to what extent they favored the concept of the least restrictive alternative as it would apply to their children (item 9). Over 90% of all Leavers' parents and 79.2% of Stayers parents, regardless of their child's diagnosis, supported the concept.

Though both groups were in favor of placement in the least restrictive alternative, interpretation of this concept demands careful scrutiny. While parents of younger, somewhat less disabled children may interpret it to mean living in a small group home in the city, parents of more disabled persons tend to have a different view. One mother, whose son had recently been placed in a group home at the age of 24, explained:

When they took the fences down [at LSS], my heart sank. It meant that James and his friends were not as free to roam. The staff kept them closer to their building. You know, sometimes, fences are the least restrictive alternative! They took the fences down for the sake of appearances, not for the sake of the residents.

Normalization, Deinstitutionalization and the Discharge Decision. Referring to items 8, 10 and 11 in Table 4.4, the two samples differ greatly with regard to these concepts and this decision. While Leavers' parents were vigorously in favor of normalization, deinstitutionalization and were very agreeable to the decision to discharge their children into the community, Stayers' parents were extremely cautious. Though they ratified the concept of normalization, as a group they were ambivalent toward the concept
of deinstitutionalization and did not favor a decision to discharge their children.

In order to understand why Stayers' parents were split with regard to deinstitutionalization (50% were in favor and 49% opposed), the data were further analyzed to reveal some underlying factors.

Table 4.5 Stayers' Parents' Responses to Deinstitutionalization As a Function of Child's Placement and Diagnosis

<table>
<thead>
<tr>
<th>Opposed (n=10)</th>
<th>In Favor (n=9)</th>
<th>Unsure (n=4)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Prof. Severe</td>
<td>Prof. Severe</td>
</tr>
<tr>
<td>Still at LSS</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>On Placement</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Discharged</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

First, it was hypothesized that the higher the level of retardation, the less optimism there would be toward community placement. Jack Melton (1985), the former superintendent of the Laconia State School, noted that, in his experience, parents' attitudes correlated with their children's diagnoses. Our data bear this statement out. There is a relative decrease in optimism regarding community placement as the level of retardation increases.

However, Table 4.5 shows that despite the diagnosis of the child, if the child is already in the community, Stayers' parents find it easier to accept the concept of deinstitutionalization. These parents told us that though they were initially opposed to community placement, now that they had seen it happen for their children, they slowly began to see its benefits. As one father put it: "I'll believe it when I see it." In other words, a change in policy
(reflective of historical climate) had its impact upon parents' attitudes.

It should be mentioned that for Leavers' parents, attitudes toward deinstitutionalization, the least restrictive alternative, and the notion that their children have not reached their developmental limits have not changed over the period from 1970 to 1985. These parents were consistently supportive of normalization ideology and were optimistic regarding their children's developmental progress.

**Community Services: Competence, Finances and Availability**

Four statements of the ATDS addressed issues directly related to community services. These are items 4, 5, 6 and 7 in Table 4.4.

**Competence.** Item 4 reads: "Persons who work in community living arrangements are knowledgeable and skillful enough to handle situations which arise with regard to your developmentally disabled relative." This statement divided along group lines. While Leavers' parents were fairly optimistic, Stayers parents remained skeptical. The parents, who in 95% of the cases believed their children required 24-hour per day supervision, were concerned that community workers did not have the skills or experience to match those of workers at Laconia State School.

Though confidence was expressed by Leavers' parents, it was not without reservations. One mother commented:

People who advise have little or no experience. New teachers: They have lots of theory but no common sense! Most teachers have had no experience with mental retardation.

Parents, especially those of more severely involved children, are not overly anxious to send their children into the community.
Parents' skepticism is based on reality—a reality that is corroborated by service providers themselves who admitted to me that they are not adequately trained to handle "surprise" situations, i.e., behavioral problems that certain clients are not reputed to have. Leavers' parents also showed differences by cohort. Parents of children placed after 1978 were more confident in community workers than the pre-1978 cohort. For the most part, reluctant parents we spoke to were willing to take a "wait and see" attitude toward community group homes.

Funding. Another factor contributing to parents' reservations about community placement has to do with the financing of group homes (item 5 in Table 4.4). We asked parents whether they believed funding for community living arrangements were secure and permanent. About 68% of Leavers' parents strongly or somewhat disagreed with this statement and about 73% of Stayers' parents disagreed.

Regarding the statement (item 7 in Table 4.4), "I believe that my family has not had to assume added financial burdens for the care of my relative since he/she has been living in the community [or when he/she lives in the community]," most parents were in agreement. There were some instances, however, which suggested that where families were quite involved with their children who were now living in the community, they also shouldered more of the financial responsibility. (See the case histories of Cheryl Bonaventure and GG Lawson in Chapter 7.) Moroney (1986) has pointed out that the deinstitutionalization movement has been a burden on families because of the lag in the creation of comparable services in the community.
Availability of Services. We asked parents to respond to the statement (item 6 in Table 4.4), "I believe that all services needed by my relative are available to him/her in the community." Here we are addressing the belief that only the institution can provide the necessary services. As expected, Stayers' parents still believe there are services the community cannot provide. However, Leavers' parents are also skeptical.

Parents of the pre-1978 placement cohort were only 42.8% in agreement with this statement, in contrast with the post-1978 cohort which was 77.8% in agreement. (See section on Cohort Differences.) This suggests that once again historical context plays an important role in shaping opinion. A father and mother who made the decision to take their son out of LSS, because of "terrible care and overmedication," stated "Deinstitutionalization is going too fast. There are not enough services in the community to support the clients coming out." They too expressed the fear that funding will remain too low and then not be there to support community integration.

Correlates of Positive Attitudes Toward Deinstitutionalization

In this chapter, we have examined some of the causes of parental resistance to their children's leaving the State School and assessed current attitudes toward the practical and ideological issues concerning the movement. In order to corroborate these findings and to determine more systematically the major correlates of positive attitudes toward deinstitutionalization (DI Attitudes), a linear regression model was used. The dependent variable was the average score on a DI
Scale comprised of items 8, 9, 10, and 11 in Table 4.4 (i.e., normalization, least restrictive alternative, deinstitutionalization, and the discharge decision). The scale has a standardized alpha coefficient of .81. The independent variables tested in the model included children's gender, diagnosis, father's education, mother's current age, importance of religion, kin support, total number of siblings (recall that one of the reasons for admission to LSS, for Stayers, was the concern for the other children in the family), importance of religion, parents' beliefs about the service delivery system, etc., i.e., all the other items listed in Table 4.4.

Results showed that the significant positive correlates of the ratification of DI ideology have to do with parents' belief that community homes are permanent and securely funded and that community workers are competent (items 2, 4 and 5 in Table 4.4). The two variables which tend to lower the DI ideology score are mothers' age and the importance of religion. As a group, older mothers and more religious parents would tend toward more conservative views. Both age and religion are generally considered to inhibit the acceptance of change. (As to why these have a dampening effect is a matter for much greater theoretical and empirical consideration.) These latter results should not serve to prejudice the reader against older religious persons, however, as enemies of progress. Without a tempering influence, there can be no real solution, only one faction dictating to another. The equation yielded an Rsq of .52, an adjusted Rsq of .40 and an F coefficient of 4.18 (p<.001). Using backward elimination, the five significant variables (i.e., items 2, 4, 5, mother's age and religion) yielded an Rsq of .45, an adjusted Rsq of .40 and an
F value of 9.4 (p≤.001). These findings were based on a sample size of 62.

It should be noted here, that parents' DI attitudes were uncorrelated with kin support (r= -.13; p≤.10). However, we shall see in the case studies that parents' attitudes do have a positive influence upon relative's attitudes toward normalization concepts.

Parental Opposition to Deinstitutionalization

In the face of the impending lawsuit against LSS, a husband and wife, who were opposed to the closing of the institution, sent out a questionnaire in 1979 to 490 families whose relatives were at LSS. Their motivation was the concern that the lawsuit was only representing a vocal minority of parents who wanted to close LSS. Thus, they were determined to poll as many parents as they could. When Mrs. Watson consented to participate in our study, she came forward with all the returned questionnaires she had received in late 1979 and early 1980.

The questionnaire invited comments from those surveyed and thereby provided a forum for parents to express not only their reasons for opposition or support of deinstitutionalization but for other comments, complaints and expressions of frustration and bewilderment. Parents who believed their children required 24-hour supervision for medical and behavioral reasons were in the forefront of the opposition. Their children were severely retarded and would not benefit from being in the community and would most likely suffer abuse. Other parents were opposed because of the disruption in theirs and their children's lives. LSS is "home." The problem of the burden of the handicapped child returning to aging parents was also raised.
These responses are valuable data contributing to our further understanding of objections to deinstitutionalization as a blanket policy. Here is one of the responses that is typical of the New Hampshire version of a scenario that has been played out in its many forms throughout the United States.

Mrs. Thayer's comments present a well thought out analysis of the situation faced by parents whose children resided at the school at the time the questionnaires were mailed.

Each person's response to this "questionnaire" I feel quite sure will be colored by his (her) own situation as it regards the retarded member of their family: 1) to the degree of brain damage and severity of retardation; 2) the length of time the resident has been institutionalized . . . ; 3) to the age of the parents and the sibling of the Laconia resident; and 4) the stage and circumstances of life the rest of the family happens to be in.

I am in favor of continuing the School and in line with above paragraph hope this will be the final determination as: 1) our resident is severely brain damaged though physically almost normal; 2) has been institutionalized since before she was three years old (she is now twenty-two); 3) and 4) the parents are in their late fifties having had four children late in the mother's childbearing years and are now putting two [children] through colleges and a third, the youngest child, will go to college next fall. The father could not adjust ever to an abnormal child in the household as he is even now devastated by the tragedy of a retarded daughter and still cannot even talk about it without emotional strain.

... I sincerely believe that for much less severely retarded persons, a more "everyday" life in the community is more beneficial for them if there are excellent services in communities for special education, job training, etc. and support groups for young parents—all parents for that matter. [Emphasis in original.]

The Watson's questionnaire revealed a number of concerns about deinstitutionalization. Parents expressed concern that their children were being uprooted and their children's friendships and social bonds with caring staff and volunteer grandparents were being ignored. Aged
parents feared a responsibility they could not manage. Some relatives wrote the Watsons, explaining how they wanted and were actively seeking alternatives to LSS.

From our interviews conducted six years after the Watson survey, we see similar concerns regarding deinstitutionalization still being expressed. One mother told us she was opposed to deinstitutionalization because:

I'm afraid of what can happen to him outside--what's around him--not him. In the community he can't move independently. At LSS he moves around independently.... I have a fear of George not being taken care of if something happens to us. That's why we put him at LSS. LSS is his home and he's being uprooted.

A father expressed his concerns this way:

Most people don't know how to cope with the situations--to confront them on the street, in a store. "Look at this retard." "Why do we have that type in the community?" You hear all kinds of comments and they're all negative.... If he were moving to [the next town over] or a little closer to home, I'd be for it but if it were another community I'm not sure--if it were a community used to retarded kids.... Not unless they prove to me that he's capable of handling the situation.... I think they're pushing these kids into the community too fast. Of course, I realize that some need to be in the community to develop their limited skills, but, I don't think they should push them out of LSS.... I think they're trying to eliminate a service.

In sum, parents saw the institution as a place of protection and permanence--a place where parents would not have to worry about attitudes in the community, or their children's future and they could die in peace.

Social Growth as a Result of Deinstitutionalization

In this section, two levels of social growth are discussed: That of the ex-residents and that of persons with whom they come in contact.
Deinstitutionalization simply means movement out of the institution. It does not automatically signify communitization. This latter term is applied to the second phase of planning toward normalization goals (Mayeda and Sutter, 1981). Communitization implies integration, that is, social exchange and mutual socialization. In sum, I am talking about our social growth, the social growth of society.

Parents were asked to note changes in their children's abilities and to give their opinions as to the reasons for these changes (either positive or negative). They most often attributed improvements in their children's functioning to programming that specifically addressed a particular problem. This was true of self-care skills, hearing, vision and speech. However, they also regarded the "normal home environment," the "exposure to people and social activities," maturation and a "secure and loving home" as positive influences. One parent observed, "Nancy has grown more since her living in the group home than she ever did in 20 years. She has grown most in the past year!"

Another parent reported:

Because of the program at the Moore [Community] Center, he has learned more in the past two years than in all other years of his life. [Donald] is more at ease . . . has calmed down to appreciate other people and things. . . . The program my son is receiving is fabulous. I could not ask for anything better. He has learned so much in the past two years.

One couple described their delight with their daughter's progress in the community. They told us that, in the Christmases of '82 and '83, Margery did her own shopping (with staff) for presents for her parents and was very proud and happy and involved in the Christmas spirit for the first time. Our field notes read:
Margery's mainstreamed home economics class put on a dinner at a corporation. Each student had to say his/her name afterward; Margery did this along with 'normal' peers and her parents were so surprised! Her parents have Margery to dinner once a week and home for Christmas and her birthday.

There is a paucity of commentary on the importance of the presence of developmentally disabled people in the community for the social growth of the rest of society! Historically, one of the reasons formulated for institutionalization of mentally retarded people was for the "protection" of society. It seems useful to explore further reversals in rationale to include the reversal of this notion of protection to the notion of the benefit of interaction with people who are disabled.

Parents gave us insight into the benefits of having the company of their children. An example from field notes:

Charlie now goes to the Salvation Army. He is learning to be an SA soldier. He belongs to the Grange, [though] he would like a job. These parents enjoy Charlie's company; they are proud of him and the fact that he is self-supporting with his SSI pension as a disabled dependent.

(Notice, here, that these parents have framed SSI as a means of "self-support," thereby allowing their son the dignity of independence.)

Field notes in another case, where parents adopted their child when the child was about 12 years old, revealed: "Both parents feel that having Ramona as their daughter has helped them both to be more sensitive and understanding in their jobs and to be very strong advocates on behalf of their daughter and all developmentally disabled people."
Summary and Conclusions

Parents in our study have lived through sweeping historical changes in the treatment of their children. From a time when professionals urged institutionalization to the present impetus toward communitization, these parents have, for the most part, adjusted.

The two samples were compared on a number of key points.

1. Leavers' parents had to fight to place their children at LSS, whereas Stayers' parents were urged to place their children there. This was due to the fact that Stayers were, on average, entering LSS five years earlier than Leavers.

2. Once institutionalized, Stayers were visited less often than Leavers. This means that those children who require institutional care, for whatever reason, are likely to be cut off from society. Smaller community facilities may increase the likelihood of family contact and the opportunity for social integration into the dominant culture and not the subculture of a 'total' institution (Goffman, 1961) such as LSS. Burton Blatt and others (1979) have more than adequately argued this point which is reiterated here to emphasize that the problem is still with us.

3. Regarding attitudes toward deinstitutionalization and its impact, in general, parents reported that community placement is, or would be (in the case of Stayers) a positive change, especially in their children's relationship with all members of the family and with others. Leavers' parents saw their children's happiness as greatly improved. Stayers' parents tended not to be able to anticipate the outcome.
4. It was hypothesized that if historical context makes a difference in peoples' attitudes, then a change in policy should show an effect. Specifically the year of the implementation (1978) of the Education for All Handicapped Children Act of 1975 should result in differences between pre-1978 and post-1978 discharge cohorts from LSS. Indeed parents whose children left LSS after 1978, were more optimistic about their children's placement than parents whose children were placed before 1978. In Chapter 5, we will examine the effects of this law on kin support.

5. With regard to normalization ideology, we found that both groups supported the concepts of the developmental model, normalization and the least restrictive alternative. But with regard to deinstitutionalization, the two groups diverged, with Leavers' parents strongly in support and Stayers' parents strongly opposed. However, of the latter group whose children were actually now placed in the community, five out of six were in favor of deinstitutionalization. This suggests that once parents actually experience their children's successful community placement, their opposition melts. "Seeing is believing."

6. The two groups of parents were identical in their view that funding for community facilities is neither secure nor permanent. However, Leavers' parents did believe that the services their children needed were available in the community. Stayers' parents were less confident in community services and personnel.

7. An attitude scale was developed to measure the extent to which parents were in favor of normalization concepts. The best predictors of a high score on this scale were parents' beliefs that the
service delivery system could provide adequate and secure care for	heir children in the community. Attitudes tended to be less posi­
tive, the older the mothers and the more religious the parents.

8. In examining the main issues regarding the opposition to
deinstitutionalization, results from a 1979 survey conducted by two
parents whose child was at LSS at the time, and the comments from the
interviews we conducted between 1984 and 1985, revealed that much of
the same concerns about deinstitutionalization are still contributing
to parental resistance.

Parents are still concerned that the closing of LSS may be pre­
mature and that a failed placement may leave them burdened with the
financial, physical, and emotional care of their disabled children.
Elderly parents still assume that there are only two alternatives:
home or large institution. No longer able to care for their children,
they fear their children will not have a secure and safe place to
live, after they are dead, if their children leave the institution.
Other parents were concerned about the lack of community acceptance of
their children. However, parents, whose children have had successful
placements in good programs in the community, have described their
satisfaction in seeing their children improve in skills, social deve­
lopment and blossom with happiness.

Change in historical climate cannot be under-estimated as the
necessary first step in the process of communitization. In general
parents favor the goals prescribed by normalization ideology. They
have been encouraged by P.L.94-142 as any social group would be when
its members' rights are protected by law. Their understandable
caution lies with the need of proper community implementation of this law, which takes planning, organization, and money.

In the chapters that follow, we will look at the correlates of kin support and see how and whether attitudes and kin support affect successful community placement outcomes. We will look at these issues quantitatively in Chapters 5 and 6 and then qualitatively in Chapter 7.
The purpose of this chapter is to determine the correlates of perceived kin support. Are there characteristics of the handicapped child and/or his family which correlate with parents' perceptions of positive social support from members of the extended family? What are the differential influences of these characteristics?

Human Resources of Handicapped Families

In order to obtain a picture of the human resources available to the parents in our study, we asked them several questions about the sources of assistance they could draw upon over the years. Each parent was read a list of possible resource groups and asked to tell us how frequently members of each of these groups gave assistance. This list included family, friends, neighbors, co-workers, other parents, clergy, doctors and "other." Parents were asked to tell us who, in this list, was the most supportive and, finally, to rate the level of supportiveness of extended kin. This rating was obtained by asking the question: "Would you say that the support you have received from extended family members as it related to your developmentally disabled child, has been: extremely supportive, somewhat supportive, mildly supportive, not supportive at all; [or would you say] it made things worse?" (See Appendix C.) This variable was recoded so that, in the regression model, the most positive answer received a score of 5 and the most negative, a score of one.
Of non-kin, friends, neighbors and other parents were the most frequently available. Parents reported that friends supplied daily and weekly support, whereas neighbors were somewhat less available (or less relied upon). Some of the parents had found moral support and information from other parents of developmentally disabled children (e.g. in monthly gatherings at their children's school or at meetings of the local Association for Retarded Citizens.)

Parents of Stayers had little or no contact with regional services providers. The latter usually become involved as community placement becomes imminent but not before. Parents of Leavers, on the other hand, gave their write-in votes to local staff in their county hospital or private center for services for developmentally disabled people. Twenty-seven per cent reported they received valuable assistance on at least a monthly basis.

The responses overwhelmingly pointed to the family as the greatest resource. Forty-nine per cent of Leavers' parents said they received daily assistance from their families and another 8.5% received at least weekly assistance in the form of babysitting, chauffeuring or advice by telephone. Stayers' parents reported 39% daily help and another 7.5% reported help from their families on a monthly basis. While Leavers' parents said their immediate families were most helpful, Stayers' parents said they received the most support from extended kin.

Of Leavers' parents, 40.4% reported their kin were extremely supportive; another 8.8% chose "somewhat supportive;" 19.3% chose mildly supportive; 22.8% said kin were "not supportive at all"; and 8.8% said kin involvement "made things worse." Of parents of Stayers
54.2% said their kin were "extremely supportive"; 20.8% said kin were "somewhat supportive"; 16.7% chose "mildly supportive" and 8.3% said kin were "not supportive at all". Having examined the variable, Kin Support, in its context of other primary groups and evaluated it for sufficient variability, we now turn to the regression equations to discover the significant correlates of perceived kin support.

Regression Models of Kin Support

The Regression Equation

In the explanation of equation 1, each independent variable will be described in terms of its hypothesized relationship to the dependent variable, its operationalization, and the rationale for its initial inclusion in the equation. As analysis proceeded, some of these variables were dropped from the equation and others added as will be explained. Furthermore, though, at the outset, the equation is presented as linear, scatterplots, tests of normality of the distributions of residuals and bivariate correlations, were used to detect the possible non-linear functions and multicollinearity.

The regression equation is of the following form:

\[ Y = a + B_1X_1 + B_2X_2 \ldots + B_kX_k + e \]  

(1)

Where

- \( Y \) is a measure of kin support,
- \( a \) (alpha) is the Y intercept,
- \( B_1-k \) are regression coefficients,
- \( X_1-k \) are the independent variables hypothesized to be correlated with kin support,
- \( e \) is the error term representing unexplained variance.

**Y, Kin Support.** The question used to measure kin support appears at the outset of this chapter. The main limitation of
measuring kin support by the use of a one-shot survey question is that parents' perception of kin support is subject to the influences of the vicissitudes of hindsight. For example, the present emotional tenor of a parent's relationship with extended family members may color his/her assessment of overall support rendered over a period of years. The time frame, "over the years," is vague and varies from one family's situation to the next. One parent may assess kin support given during the child's early years while another may emphasize a time closer to the present. Yet to call for a general evaluation of any relationship is not an unusual occurrence in human experience. We are continually weighing our relationships in terms of past and current shared events. We are likely to maintain friendships that are rocky at present on the basis of past events that make us eternally grateful. We eschew others because of an action which overrides any kindness that a person may have bestowed in the past. Marsdan and Campbell (1984) found that the best measure of friendship ties—if we can liken kin support to friendship—was the person's own assessment of "closeness" or intensity of friendship and not any objective measures of frequency of contact or duration of the relationship. Since "felt" or "perceived" support is an entirely subjective experience, perceived kin support is judged to be the best measure available of this variable. In Chapter 7, case material will shed light on the nature and processes of kin support, who gave it, and during what periods of time.

Note that throughout the discussion, this variable is referred to from hereon by the shorthand term "kin support," but it must be
kept in mind that the variable is actually the parents' report of
their evaluation of the level of support.

As originally posed, the hypotheses are as follows:

**X1, Family Size.** The larger the family size, the greater the
kin support. One way X1 is measured is by parents' reports of number
of people living at home at the time of their children's admission and
at first community placement.

It is reasoned that large families, though generally lower in
material resources engender more social support in the kin network.
Bahr has noted that, "In general, there seems to be a direct asso­
ciation between number of children and affirmation of kin obligations"
(1976:76). However, he points out that mothers of large families have
experienced greater difficulty in meeting these obligations due to
their responsibilities at home. Even though this may result in fewer
exchanges, these felt obligations most likely produce a climate of
greater support.

**X2, Age of Mother.** The younger the mother at the birth of her
child, the greater the kin support. The mother's age at the birth of
her child is determined by the year of the mother's birth subtracted
from the year of the child's birth. It is reasoned that younger
mothers are more likely to have contact with their relatives in order
to obtain and receive support than older mothers.

**X3, Father in the Home.** When the child's parents are married
to each other, there is more support. The variable was dichotomized
where 0 signifies "not married to child's father" and 1 signifies
"married to the child's father" (measured both at the time of
admission and at the time of placement.)
Marital stability has been found to be an important resource with regard to the reduction of stress. Most authors have found that married persons experience somewhat less stress than unmarried persons—even though stress in married women is higher than in married men, it is still lower than that of unmarried women (Dohrenwend, et. al., 1980). With the addition of a disabled child, marital stability is at greater risk among marriages that are already unstable (Farber, 1959, Gath, 1978). There is also a possibility that the presence of the father in the home will have a differential effect upon kin support depending upon the gender of the child. This will be explored later in a separate section of this chapter.

**X4, The Proportion of Sisters in the Family.** The greater the proportion of sisters, the greater the kin support.

Since women are still the primary caregivers in this society (Yanagisako, 1977; Genovese, 1983), it was reasoned that the greater the number of females in the family, the greater the potential resources for care of the handicapped child. However, a measure of the sheer number of sisters is highly correlated with family size ($r=.63$, $p<.001$). By using a proportion, we reduce the risk of multicollinearity but preserve the important key feature of the hypothesis, that, when it comes to support, females are the main contributors. This variable has three versions: the proportion of sisters in the household at the time of admission and the time of placement and the total proportion of siblings who are sisters, at home or not. By using this last measure, it is possible to test whether sisters per se or sisters in the household is most important. Sisters who have moved out of the household are still considered part of the kin network and
may, because they have reached adulthood, be even more likely to be in a position to offer support to the family.

**X5, Socioeconomic Status (SES).** The higher the SES, the less the kin support. SES is measured by the fathers' and mothers' occupations as listed in the 1980 U.S. Census occupation codes and then assigning this code the respective Nam-Powers Status Score (see Chapter 3). There are several measures of the variable that were tested: the fathers' score at children's admission to LSS and at the time of the first community placement, and the mothers' score before marriage and her score of her most recent occupation; the mothers' and fathers' levels of education were also used as indicators of SES.

Originally it was reasoned that at higher SES levels, there is a greater tendency on the part of the families to rely on professionals when dealing with the difficulties concerning their disabled child. This reliance was expected to reduce kin support. Professionals (Gabel and Kotsch, 1981) and parents (e.g. Featherstone, 1980) have reported that professionals tend to focus on the child or, at best, work with the mother and the child around programming and treatment. This causes mothers to become "experts" to such an extent as to create a gap between her and the rest of her family.

Another measure of SES is level of education. Since education tends to be correlated with the ability to use resources (Farber, 1968), we might expect that the more educated parents are, the more support they might obtain from their families. Among working class families, for example, Komarovsky (1962) found that high school graduates seemed to have more congenial relationships with their own parents and with their parents-in-law than less educated people.
X6, Importance of Religion. The greater the importance of religion, the greater the reported level of kin support. Importance of religion is measured by the question "How important is your religion to you?" with a five-point ordinal scale of response categories. (See Appendix C, Section B, question 29.)

Glock and Stark (1965) have pointed out that there is general agreement among the various religions that religious commitment should have consequences for the daily life of the believer. The religious outlook has been also identified among family theorists as a family coping resource for redefining the situation of raising a handicapped child with greater optimism (McCubbin, et. al., 1982). Should results support this hypothesis, such confirmation may not be due to any differences in actual support, but may be due to the response on the part of the parents of greater thankfulness (as an attribute of religiosity).

X7, Child's Gender. If the child is a girl, kin are more likely to be supportive. Farber (1959) has shown that disabled boy children are more likely to be institutionalized and that there is a greater sense of futility on the part of their parents. It is reasoned that this overall disappointment carries over its influence to kin. This disappointment may also tend to preclude parents' desire for support from kin and/or influence their perception of kin as unsupportive as in the psychological phenomenon of projection.

X8, Diagnosis. The greater the retardation, the less the kin support. As measured by the reported AAMD (American Association on Mental Deficiency) diagnosis in the LSS clinical records, diagnosis is
one indicator of level of intelligence and concomittant behavioral and medical problems.

As retardation increases, there is a greater likelihood of extended professional involvement which tends to preclude informal interventions (Blacher, 1984:32). Originally a number of other medical and behavioral characteristics were tested in the equation, such as level of speech impairment, the number of major medical conditions, the child's abilities with regard to ambulation and various self-care skills, such as toileting, dressing and feeding. However, all these variables are highly correlated with the AAMD diagnosis. Therefore, this latter variable was chosen as the most parsimonious representation of the child's medical and behavioral profile.

X9, Year of First Community Placement. The more recent the year of placement, the greater the kin support. This variable is measured by the year of the child's first community placement reported and corroborated by LSS clinical records, service provider and parent interviews.

This variable is particularly important because it enables us to take into account the effects of historical context upon family interaction. By 1978, New Hampshire began to enforce PL94-142. Thus, children leaving LSS in most recent years, have been recipients of more professional services in the community (Mallory and Herrick, 1986). As deinstitutionalization and normalization ideology take hold, it is expected that informal support will increase.

X10, Stayers. Stayers is a central variable that is introduced into the equation to test whether kin support is influenced by the different experiences of families of Leavers and Stayers (described in
Chapters 3 and 4). The variable is measured by coding the identification numbers assigned to Leavers as 0 and coding those of Stayers as 1.

**Data Sources**

Except for child's diagnosis and year of placement, which were obtained from the LSS records and service provider interviews, all variables are measured using data from the parent interviews. (See Table 4.2.) It should also be mentioned that the sample size is reduced in the regression equations due to missing data.

**Regression Method**

Regression analyses were conducted by entering all the independent variables simultaneously because this is the simplest and most direct method of determining the relative correlational strengths among the variables hypothesized to influence kin support.

At the outset, it should be cautioned that interpretations of results are tentative owing to the small size of the sample and the fact that participants were not chosen completely randomly, as explained in Chapters 2 and 3. (Stayers in this study, for example, are fairly typical of the population that stayed past their 21st birthday at LSS, but their parents tended to be somewhat more involved in overseeing their children's progress than is typical of those of the LSS population of stayers.) In no way are the results to be generalized to developmentally disabled people-at-large or even all institutionalized people. However, the results presented here may be compared to the national experience. Readers familiar with the results of similar studies will find these results to be in keeping with national trends.
<table>
<thead>
<tr>
<th>Independent Variables</th>
<th>At Admission</th>
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<tbody>
<tr>
<td>Diagnosis</td>
<td>-.14</td>
<td>-.27*</td>
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<tr>
<td></td>
<td>(-.20)</td>
<td>(-.36)</td>
</tr>
<tr>
<td>Female Child</td>
<td>.29*</td>
<td>.46***</td>
</tr>
<tr>
<td></td>
<td>(.84)</td>
<td>(1.38)</td>
</tr>
<tr>
<td>Father in the Home</td>
<td>.12</td>
<td>-.20</td>
</tr>
<tr>
<td></td>
<td>(.48)</td>
<td>(-.67)</td>
</tr>
<tr>
<td>Year of Admission/Placement</td>
<td>-.14</td>
<td>.50***</td>
</tr>
<tr>
<td></td>
<td>(-.04)</td>
<td>(.13)</td>
</tr>
<tr>
<td>Proportion of Sisters in the Household</td>
<td>.02</td>
<td>.26***</td>
</tr>
<tr>
<td></td>
<td>(.06)</td>
<td>(.93)</td>
</tr>
<tr>
<td>Mothers' Education</td>
<td>.26+</td>
<td>.11</td>
</tr>
<tr>
<td></td>
<td>(.32)</td>
<td>(.13)</td>
</tr>
<tr>
<td>Fathers' SES</td>
<td>-.05</td>
<td>.26</td>
</tr>
<tr>
<td></td>
<td>(-.003)</td>
<td>(.02)</td>
</tr>
<tr>
<td>Mother's Age at Child's Birth</td>
<td>.07</td>
<td>.03</td>
</tr>
<tr>
<td></td>
<td>(.02)</td>
<td>(.01)</td>
</tr>
<tr>
<td>Importance of Religion</td>
<td>.08</td>
<td>-.03</td>
</tr>
<tr>
<td></td>
<td>(.09)</td>
<td>(-.03)</td>
</tr>
<tr>
<td>Family Size</td>
<td>-.004</td>
<td>.11</td>
</tr>
<tr>
<td></td>
<td>(-.003)</td>
<td>(.10)</td>
</tr>
<tr>
<td>Rsq</td>
<td>.26</td>
<td>.56</td>
</tr>
<tr>
<td>Adj Rsq</td>
<td>.12</td>
<td>.44</td>
</tr>
<tr>
<td>N=</td>
<td>66</td>
<td>48</td>
</tr>
<tr>
<td>F=</td>
<td>1.91+</td>
<td>4.69***</td>
</tr>
</tbody>
</table>

+p<.10  *p<.05  **p<.01  ***p<.001
Kin Support at Time of Admission and Placement

Table 5.1a shows the results of two models of regression, with kin support as the dependent variable produced by entering simultaneously all hypothesized relevant variables. These models include independent variables pertaining to the time of admission of the child to LSS and the time of placement from LSS to the community. They are: Father in the home, the proportion of siblings who are sisters living in the household, father's SES, mother's education, mother's age at the time her child's birth, the importance of religion, and the size of the household. The variables describing the child's characteristics are gender and diagnosis.

Wherever possible a separate measure of the independent variable was used at time of admission and time of placement. Thus, father in the home, year of admission/placement (which places the models in historical context), proportion of sisters in the household, and family size were measured at the two time periods. The importance of religion, father's SES, mother's education, and the child's characteristics were identical in both equations in order to prevent drastic reductions in sample size. For example, by the time children were placed in the community, many fathers had retired, so father's SES at placement would have caused missing data in the correlation matrix upon which the regression runs were based.

The regression coefficients in Table 5.1a, indicate that at the time of admission, kin support is significantly correlated with the child's gender and the mother's education. When the child is a girl, kin support is likely to be greater than when the child is a
boy. The results also suggest that, at the time of admission, the higher the mother's level of education, the greater the kin support, all other influences held constant (Adj. Rsq.=.12; p<.10).

Furthermore, it appears that fathers' presence in the home has a more positive effect for support when the child is young than at placement.

At the time of placement, the variables significantly correlated with perceived level of kin support are gender, diagnosis, year of placement, and the proportion of sisters living in the household. These variables explain nearly half the variance of the dependent variable (Adj. Rsq.=.44). From these four coefficients (using standardized betas), the following statements can be made: 1) when the child is a girl, kin support is likely to be higher than if the child were a boy. 2) As the child's retardation increases, kin support decreases. For example, if one child is diagnosed mildly retarded and another is diagnosed profoundly retarded, the parent of the profoundly retarded child is more likely to report a lower estimation of kin support than the parent of the mildly retarded child. 3) The later the year of community placement, the greater the kin support, all other variables held constant. 4) The greater the proportion of sisters in the household, the greater the kin support.

All the independent variables in the equations are correlated with kin support in the expected direction. Let us look at the statistically significant independent variables outlined above in turn.

**Gender**

The hypothesis that families of female handicapped children will receive greater kin support is upheld. This finding is
consistent with the fact that there are generally more males in institutions than females. Linsky (1970) has shown that males who are mentally ill are more likely to be placed in an institution than females. MacMillan has observed, "In virtually every program serving children with learning and behavior problems, there are more males than females. Mental retardation is no exception: The number of males diagnosed as mentally retarded exceeds the number of females. . . ." (1982:69) These differences are attributed to genetic and socialization differentials.

It is believed that often severe and profound retardation are the result of recessive genotypes which increase the likelihood of these conditions among males. However, sex role socialization differentials compound treatment difficulties for males. Since boys are socialized to be more aggressive (Maccoby and Jacklin, 1974), retarded boys are likely to become more unmanageable than docile, well-behaved, retarded girls. This situation most likely precipitates earlier detection resulting in earlier and longer institutionalization for boys than girls.

Another explanation may be that it is easier to care for and support a child who is a girl because of the differential expectations our society has with regard to males and females. Females are generally not expected to take on roles which require ambition, independence, physical and mental robustness, all stereotypical male attributes (Chafetz, 1974). Cumming and Cumming (1972) have noted that men who have been hospitalized for mental illness, "probably do not have as much leeway in the occupational world." This suggests, again, that males have a narrower repertoire of roles available to
them that they are expected to fill and that once these avenues are seemingly closed, the social network also becomes more limited. These authors hypothesized that men would have a greater difficulty than women in becoming destigmatized because of their different role expectations. These authors reasoned:

Women . . . do not always have to reach a certain minimum of effectiveness in their core roles. . . . Some women may only have to refrain from raising tension in the home and from representing the family in a devalued way outside in order to begin the undoing [or destigmatization] process. (Cumming and Cumming, 1972:455.)

I believe these authors' insights are applicable to the experience of the developmentally disabled person as well since he/she faces deinstitutionalization and and the concurrent burdens of stigma. These authors presented evidence that, for men, the re-integration process could be expedited by the presence of women in the kin network. Data from a small sample suggested that women, other than wives or mothers (who were considered "too close" to their husband's or son's distress) e.g., aunts or grandmothers, seemed to be essential. This suggests that single mothers of handicapped sons who lack female relatives in their network or human resource pool are especially in need of social as well as material support. Moreover, their findings suggest that we may need to build into our programming activities a means of expanding the role repertoire of handicapped youth and men.

Another explanation for the finding that kin support is correlated with females and not with males is that, for the most part, women are the caregivers. It is easier for them to care for female disabled children than for males because in this one aspect, there is similarity between caregiver and receiver; caregivers may assume there is a measure of predictability of the child's behavior.
In sum, the greater institutionalization for males is attributed to: 1) their higher biological vulnerability; 2) greater aggressive behavior; and 3) greater role expectations (Vitello and Soskin, 1985). Related to this last point is the possible interaction effect of father's presence and the child's gender. This will be discussed further in a later section of this chapter.

Diagnosis

With regard to diagnosis, we see that the greater the retardation, the less the likelihood of kin support. The complexity and profundity of medical and behavioral difficulties as retardation increases does make the task of caretaking more formidable. Each level of retardation brings with it a host of idiosyncratic problems which require more professional involvement (Turnbull, et. al., 1985). In these instances parents become more and more the experts and kin become more and more bewildered as to how to offer help. Mori (1983) has suggested that the greater the level of retardation, the greater the social isolation of the family merely because their time is taken up with greater caretaking. It may very well be that support differs in kind as well as amount at the different levels of retardation. This needs to be empirically examined.

Year of Placement

The hypothesis that the later the year of community placement, the more the kin support, is also upheld. I believe this result is related to the increase in acceptance of normalization principles in our society. The relatives I interviewed generally were in favor of deinstitutionalization, normalization and the least restrictive alternative living situation for their handicapped kin. (See Chapter 7.)
(If we ever in the future champion the institution as the best solution for treatment of developmentally disabled persons, we will be guilty of willful cruelty! It will be because we choose to ignore what we have learned to be true, that developmentally disabled people can grow and develop in the community.)

**Proportion of Sisters**

The results lend support to the hypothesis that the greater the proportion of sisters home at the time of placement the greater the perceived kin support. Since proportion of sisters is not significantly correlated with kin support in the first equation, at admission, it may be that sisters are too young at the time to offer any major social support.

**Socioeconomic Status**

As a measure of overall family socioeconomic status, mothers' education at the time of admission influences kin support in a positive direction, not originally hypothesized. Originally, I argued that the higher the SES, the lower the support because higher status families tend to rely more heavily on professionals. I assumed that the use of professional services precludes the use of primary groups. Litwak offers an explanation of why, though there may be differences in social status among kin, certain kinds of tasks, such as household and marital or intimate familial tasks, such as laundry, personal hygiene and the like, are accomplished by kin regardless of social status. Litwak argues that the mechanisms of multicultural operate in these instances:

that even when kin have to manage tasks that include class differences, the fact that kin (i.e., parents,
children and siblings) shared a common class position at one time . . . provides a common cultural bridge . . . [so that] people retain the common bases even when learning new ones (1985:126).

Accordingly, this positive correlation between mothers' education and kin support may be due to the greater ability of higher status persons to make use of networking both in connecting to professional networks as well as family and also simply because, despite the likelihood of greater geographic distance from kin, the greater the resources, the greater the ability to overcome this barrier with the use of transportation and other technology.

Table 5.1b Correlates of Kin Support Controlling for Leavers and Stayers (at Admission)

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>Regression Coefficient Standardized</th>
<th>Regression Coefficient Unstandardized</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis</td>
<td>-.19+</td>
<td>-.27</td>
</tr>
<tr>
<td>Female Child</td>
<td>.35**</td>
<td>.99</td>
</tr>
<tr>
<td>Father in the Home</td>
<td>.11</td>
<td>.46</td>
</tr>
<tr>
<td>Year of Admission</td>
<td>.08</td>
<td>.02</td>
</tr>
<tr>
<td>Proportion of Sisters</td>
<td>.04</td>
<td>.14</td>
</tr>
<tr>
<td>Mothers' Education</td>
<td>.12</td>
<td>.15</td>
</tr>
<tr>
<td>Fathers' SES</td>
<td>-.02</td>
<td>-.001</td>
</tr>
<tr>
<td>Mothers' Age at Child's Birth</td>
<td>.01</td>
<td>.004</td>
</tr>
<tr>
<td>Importance of Religion</td>
<td>.03</td>
<td>.04</td>
</tr>
<tr>
<td>Family Size</td>
<td>.01</td>
<td>.01</td>
</tr>
<tr>
<td>Stayers</td>
<td>.34*</td>
<td>1.00</td>
</tr>
</tbody>
</table>

Rsq= .33
Adj Rsq= .20
N= 66
F= 2.43*

+p<.15  *p<.05  **p<.01
Correlates of Kin Support: Stayers vs. Leavers

In Table 5.1b an additional variable is considered in the equation. In order to compare the correlates of kin support between Leavers' and Stayers' families, a dichotomous variable was created, where 0=Leavers' and 1=Stayers. Since Stayers' families became involved in the service delivery system approximately 5 years earlier than Leavers' families, I wanted to see if this historical fact had any impact on kin support, using the regression model. Only the time of admission was considered because most of the Stayers were still at LSS at the time the study was conducted, therefore, placement was not relevant.

From the table, we see that the constellation of significant correlates shifts somewhat. Rather than child's gender and mother's education (as in Table 5.1a), child's gender and diagnosis become more salient. Moreover, when the child is a Stayer, he/she is more likely to have kin support than when the child is a Leaver. The fact that the coefficients for diagnosis and child's gender become larger (more negative and more positive, respectively), suggests that the diagnosis of Stayers becomes more of an issue than for Leavers. In the last chapter we discovered that Stayers were somewhat more severely developmentally disabled and had more major medical conditions which would contribute to less kin involvement for Stayers than Leavers. This contradictory result requires closer scrutiny. Anticipating our discussion in Chapter 7, Stayers' families reported that they received a great deal of support from kin. Since, for the most part, I did not obtain data on the type of support, the following explanation is tentative. It may be that what Stayers' families reported as support was
kin's support of the decision to institutionalize the child. In Chapter 3 we learned that Stayers' families were more concerned about the effects of the disabled child on the other children. This might preclude social support within the nuclear family, motivating the mother to seek support from relatives outside the home. Since the institution is used as a substitute for the home, support would be less in the form of goods and services, and more in the form of emotional strength. Leavers' families, on the other hand, were more oriented toward concrete aid, in the form of goods and services, since their children spent more time at home than Stayers. With the anticipated return of the child to the home and community, the nuclear family rallies its internal supports and coordinates more closely with professionals while kin may be relegated to a more auxiliary role.

Kin Support as a Function of Father's Presence and Child's Gender

Though the correlation coefficients for father's presence in the home (Table 5.1a) are not statistically significant, the change in sign from positive to negative, from admission to placement, raised a question as to why this should occur.

One possible explanation is that fathers tend to be a conservative influence upon the care of their children. Nemzoff (1979) found that the fathers in her study of developmentally disabled children, tended to look after the financial and educational planning of their children. (What I am suggesting here is that holding the purse strings, not only is an exercise of power but tends to require more deliberate planning and therefore is conservative.) Fathers in our sample also played this role and often expressed skepticism with
Table 5.2 Kin Support as a Function of Father's Presence and Child's Gender

<table>
<thead>
<tr>
<th>Overall Kin Support</th>
<th></th>
<th>Girls</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Boys</td>
<td></td>
<td>Girls</td>
</tr>
<tr>
<td></td>
<td>Mean = 3.36</td>
<td>S.D. = 1.43</td>
<td>Mean = 4.26</td>
</tr>
<tr>
<td></td>
<td>n = 50</td>
<td></td>
<td>S.D. = 1.06</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Admission</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Father Present</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean = 3.78</td>
<td></td>
<td>S.D. = 1.30</td>
<td></td>
</tr>
<tr>
<td>n = 68</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fathers and Sons</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean = 3.38</td>
<td></td>
<td>S.D. = 1.36</td>
<td></td>
</tr>
<tr>
<td>n = 37</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mothers and Daughters</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean = 4.26</td>
<td></td>
<td>S.D. = 1.06</td>
<td></td>
</tr>
<tr>
<td>n = 31</td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Placement</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Father Present</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean = 3.69</td>
<td></td>
<td>S.D. = 1.32</td>
<td></td>
</tr>
<tr>
<td>n = 55</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fathers and Sons</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean = 3.27</td>
<td></td>
<td>S.D. = 1.36</td>
<td></td>
</tr>
<tr>
<td>n = 34</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fathers and Daughters</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean = 4.38</td>
<td></td>
<td>S.D. = .92</td>
<td></td>
</tr>
<tr>
<td>n = 21</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| Father Absent               |            |                        |            |
| Mean = 3.31                 |            | S.D. = 1.65            |            |
| n = 13                      |            |                        |            |
| All Other Conditions        |            |                        |            |
| Mean = 3.98                 |            | S.D. = 1.33            |            |
| n = 42                      |            |                        |            |
| All Other Conditions        |            |                        |            |
| Mean = 3.33                 |            | S.D. = 1.43            |            |
| n = 48                      |            |                        |            |

|                      |            |                      |            |
|                      |            |                      |            |
|                      |            |                      |            |
|                      |            |                      |            |
regard to the availability of services in the community. Their attitudes may have had a dampening effect upon kin support.

Another explanation may be that kin involvement lessens over time so that mothers tend to rely more on their husbands as time goes by. In Chapter 7, we shall see that the relatives interviewed, did, in fact, report that their involvement (though not their interest and concern) decreased over time. The reasons for this decrease are discussed in that chapter.

A third explanation may be that there is an interaction effect of father's presence and the child's gender. If indeed there is an interaction, we would expect that the kin support rating for fathers and sons would be lower than all other permutations of fathers' presence (or absence) and children's gender.

Table 5.2 shows how this hypothesis was tested. The 93 participants were simply divided into groups as indicated and their means and standard deviations compared. Immediately we see (as we found in our regression models displayed in Tables 5.1a and 5.1b), that overall kin support is lower for boys than for girls. When we look at kin support in relation to fathers' presence at admission and placement, we see that fathers' absence has more of a negative impact upon kin support at the time of admission than at the time of placement.

Now when we compare the combination of fathers and sons and fathers and daughters (i.e. both are in the home), we see that when the child is a girl, the family receives the most kin support than in all other conditions and that this is true at the time of admission as well as at the time of placement. There is therefore evidence for an
interaction effect of fathers and sons which dampens kin involvement. Let us speculate as to why this might be so.

We have already seen that males are more likely to be institutionalized than females. We have also cited evidence for fathers' conservative influence. I would suggest that the reasons this combination gives these results lies in the extent to which fathers define their expectations for their sons along stereotypic lines. When fathers require that their sons be able to become breadwinners like themselves, there is little room for alternatives much less handicapping conditions. There is evidence, for example, that when fathers themselves lose their ability to be the breadwinners of the family--due to disability--those fathers who define themselves as heads of household and who have religious convictions, are more likely to maintain an active role in their families than those who narrowly define themselves as breadwinners and have few if any outside interests (Power, 1979). Fathers' stereotypic definitions and expectations may carry-over with regard to sons' roles.

Summary and Conclusions

Family characteristics which correlate with perceived kin support are marital stability (i.e., fathers' presence in the home) at admission, a high proportion of sisters at placement, diagnosis, gender, year of placement and mothers' education.

Marital stability is measured by father's presence in the home, though included in both admission and placement equations, was found to be salient for admission only. This makes sense since kin support varies over the life cycle. As we shall see in the case studies, kin
support was greater during the child's early years than in the later years. When parents are no longer married to each other in the child's early years, this disruption may interfere with any attempt at support on the part of kin.

The proportion of sisters at admission was not found to be a strong correlate of kin support, but at placement it was significant. The proportion of sisters still living at home, but now older, are able to provide more support than at the time of admission.

The child's diagnosis was found to have a negative effect upon kin support. The greater the retardation, the less the support, as predicted. This suggests that as the child's medical and behavioral characteristics manifest more profound involvement, kin are less equipped to handle caregiving tasks. The structure of the task does not match the structure of the primary group.

Another explanation may be related to the findings of Emerson (1966). In a participatory observation study of group decision-making in the American Everest Expedition of 1963, Emerson noted that when the outcome (reaching the summit) was defined as less certain, climbers' motivation and energy to persevere was maintained. Emerson postulated that goals "tend to be defined in 'regions of uncertainty,' and that goal-oriented motivation is maximized and maintained overtime as a function of prolonged uncertainty" (1966:227).

Analogously, when children's diagnosis indicates profound retardation, relatives may sense that outcomes for the child are certain and negative. In order to increase uncertainty, and thus maintain kin involvement, it would be necessary for relatives to have more information about the developmental possibilities of very
involved children. This might increase the uncertainty about the child's future, or, in lay terms, increase the hope that the child will progress with increased intervention and thus prevent the relatives from "giving up."

I observed the staff at LSS who work with the most profoundly retarded children in the school. These children were non-verbal, non-ambulatory and completely dependent upon others for their lives. Yet, the staff would tell me they could see their charges' responses, their signals of likes and dislikes in the subtlety of an eyeblink in any given situation. Overall, this staff's involvement was sustained by optimism in the face of the pessimistic prognoses of these children. Emerson states that this type of response (giving an opposite response to any given statement; e.g., optimism when confronted with pessimism is one of the mechanisms by which uncertainty is maintained.

Other findings, presented in this chapter, showed that if the child were a girl, kin support is likely to be greater than if the child were a boy. It was argued that differential expectations along gender lines play a part here and that since caregivers are more likely to be women, they are likely to be more comfortable taking care of disabled girls than boys, all other variables held constant.

It was found that the year of placement was more important than the year of admission in influencing kin support. Not only may the increase in public awareness and support of normalization ideology positively influence kin support, but other factors influencing placement may be operating. For example, in most recent years, there has been greater pressure for the institution to lower its census. This
may be deemed as a crisis among families which may arouse greater reliance upon the coping resources of the kin network. These findings alert us to the fact that families with severely or profoundly involved children, especially boys, and families where the child's parents are no longer married to each other, are at risk of lack of support from the kin network. What the results suggest is that the family may need help in reviewing their network and reconsidering who the available resources are, if not from among kin, then from among other primary groups as well as from among professionals. The kin of families with more involved children may require education and help in understanding their relatives' difficulties and how they may be able to assist. Understanding the nature of the disability and its treatment and programming may promote more appropriate social support. Simply being able to share the parents' experience intelligently increases support.
CHAPTER 6

REGRESSION MODELS OF SUCCESSFUL COMMUNITY PLACEMENT AND POSITIVE IMPACT

Practitioners, educators and policymakers alike are advancing the idea of the inclusion of the kin network as a means of increasing the likelihood of successful implementation of treatment programs and to generally provide relatives with information that can augment parents' efforts in meeting the needs of their disabled children (Gabel and Kotch, 1981, Genovese, 1983; Mallory, 1986b). In a sense, we might view this present study as a preliminary investigation of the baseline effects of kin support before professionals in the State of New Hampshire have attempted to co-opt family networks into their programming plans.

In Chapter 4, we saw that parents are very concerned about their children's living situations in their children's old age. Parents want to be certain that their children have the proper care when they, the parents, are no longer able to provide it themselves. On whom can they rely? Perhaps we can get a handle on this question by looking at some of the correlates of a successful first placement out of the institution.

Having examined the issues around parents' attitudes toward deinstitutionalization and the correlates of kin support, we now look at the question: To what extent does kin support influence the care of handicapped children? There are two aspects of this question that will be examined. The first is: To what extent does kin support influence the success of the first community placement? The second
is: To what extent does kin support influence the impact of the child's return to the community on family routines? Could we expect, for example, that when kin are perceived as supportive, parents are more likely to see their child's return as having a positive impact?

**Kin Support and Placement Outcomes**

There are two regression equations, that is, two models, that will be examined. However, since they each contain most of the same independent variables, I will present the hypotheses associated with each dependent variable together to avoid repetition as much as possible.

As in Chapter 5, the linear equation is of the form:

\[ Y = a + B_1X_1 + \ldots + B_nX_n + e \]

where \( Y \) is the dependent variable, either \( Y_1 \), Successful Placement or \( Y_2 \), Positive Impact; \( a \) is some constant; \( B_1X_1 \) through \( B_nX_n \) are the differentially weighted effects of the independent variables; and \( e \) represents unexplained variance.

The twofold hypothesis being tested in this chapter is: The greater the perceived kin support, the more likely placement outcomes will be successful and have a positive impact upon the family.

**The Dependent Variables**

\( Y_1 \), **Successful Placement**. It is never a simple matter to measure success. One man's success is another's idea of mediocrity. Yet, at the very least, we can say that success is the attainment of certain goals. The degree to which the goals have been met is a measure of the degree of success. When we speak of a successful first
community placement of a developmentally disabled person, a number of criteria should be met. These are based on the comparatively recent goals set by the principles of normalization. Broadly speaking, the longer a person is able to stay in one place, and outside of the institution, the more successful the placement. Thus, the first criterion is stability of residence. Two measures of stability were the length of stay in the community and whether or not the person returned to LSS. Of course, mere stability is not necessarily proof that where one is placed is conducive to growth and development, but the underlying assumption is that the community is qualitatively better than the institution.

A second criterion of success is that a person resides in a living situation which has a small number of people, since most of America live in households which contain not more than four or five people. Thus, the fewer the number of persons with whom a disabled person lives, the more "normalized," i.e., the more successful the placement outcome. Reports from service providers and parents of Leavers were used to estimate the size of the household of the placement situation.

A third criterion was whether or not a person attended school, whether in a mainstreamed classroom, a special class in a regular school or special school. Receiving an education to which all handicapped people under the age of 21 are entitled, is unquestionably a mark of success. The nature and quality of that education is more difficult to evaluate and was not considered in this study.
Finally, a fourth criterion is how long the person received educational services during the first placement. An expedient measure of the success of a program is simply whether or not the child can stay in it. At the very minimum, it means a child is interacting or at least, exposed to an additional person several times a week for the purpose of developing skills. Even if skills are never developed, the goal of normalization that states that the "daily rhythm of life" includes work for adults and school for children is met. Now that individual education plans (IEPs) are required by law, it is hoped that the dreary prospect of special education being reduced to babysitting is obviated.

The most important criterion for measuring success is glaringly absent. It is the handicapped person's own assessment of success. This criterion is often neglected, I think, because it is difficult to measure. Sigelman and her colleagues (1983) have been developing interview techniques in order to better understand the desires and thoughts of developmentally disabled people. These authors report that as retardation increases, the difficulty in interpreting results also increases. However, there are issues that are readily apparent and require no interpreter. The following is an illustration.

When I was working in the record room at LSS, I heard a voice wailing in the corridor. Following the sound, I saw a young woman, wearing a bicyclist's helmet, presumably for protection from falling and the like. Through her tears, the woman told me her friend was leaving LSS, and she would never see her friend again because the friend was going away, presumably the friend was being discharged.
In a more formal interview with a severely retarded young man residing in one of the more advanced units (each person had his/her own room) on the LSS grounds, while awaiting placement, I learned that he and his girlfriend were sad because they wanted to live in the same group home. They each were awaiting community placement. With only one opening pending and only one group home in that particular town, their prospects appeared unlikely. Using the criteria outlined above, if this man were placed at the group home in this town where he would attend a sheltered workshop, the placement would be considered a complete success. But would it be for the young man? This is a criterion that I realize is lacking in my own study, and I present this for other researchers to consider when attempting to measure successful placements.

Given these limitations, the criterion variables used to measure success of placement were 1) staying in the community (i.e., Did the person return to LSS? Where 0 = yes and 1 = no); 2) length of stay in the first placement; 3) number of residents at the placement; 4) whether or not the child went to school; 5) length of time the child stayed in the educational program. Data from these variables were converted to z-scores and averaged together to create a scale, Successful Placement, with a mean of zero and a standard deviation of .547.

Y2. Positive Impact of Child's Return to the Community. Another means of assessing the effect of community placement on families, is to consider the impact of the disabled person's return to the community upon family routines. The purpose here is also to discover to what extent kin support bears on such an outcome.
Positive Impact is measured by an average score of the responses to the fourteen questions (variables) presented in Table 4.3. The scale has a standardized alpha of .89. Briefly, in review, the parent is asked to respond to questions about how his child's return to the community would affect his/her own social life, family vacations, the child's relationship with family members, the parent's own and the child's happiness, etc., using a scale of 1 to 5. ("Change for the worse" is given a value of 1; "no change" a value of 3; and 5 signifies "change for the better.")

The Independent Variables

The accompanying hypothesis is posed as each variable is operationalized.

**X1, Kin Support.** The greater the kin support, the more successful the placement and the more positive the impact (referred together as "placement outcomes"). Kin Support is measured by parents' report of their perception of how supportive their extended family members have been with regard to their handicapped child. The scale varies from 1 to 5, where 5 signifies extremely supportive, and 1 signifies making things worse.

It was reasoned that parents who have greater family resources such as social support from relatives, will have better problem solving skills (an intervening variable not measured in this study) and so will be better able to obtain services.

**X2, Proportion of Sisters.** The greater the proportion of sisters in the family, the more positive the placement outcomes. This variable is a measure of the proportion of siblings who are sisters including those no longer living in the household.
It is reasoned that female family members serve as caregiving resources and so would increase the likelihood of success and positive impact.

X3, Family Size. The larger the family, the more positive the placement outcomes. The rationale is the same as in X1 and X2.

X4, Father in the Home. When the child's mother is still married to the child's father at the time of placement, placement outcomes will be more positive than when she is not. This variable is measured by parents' report of mother's marital status at the time of placement and was dichotomized, where 0 = not married to child's father and 1 = married to child's father.

Marital stability is reasoned to be a positive influence upon the child's placement outcomes since fathers tend to handle the role of planning for their children's futures (Nemzoff, 1979).

X5, Child's Diagnosis. The greater the retardation, the less positive the outcomes. Diagnosis is that reported in the LSS records at the time of admission. The effect of this variable is difficult to predict. If the child with severe or profound retardation is discharged to the community, it may mean that sufficient preparations have been made for his/her reception into the community so that negative effects are attenuated. We know that some of the most severely retarded children are being placed in group homes and that this trend is increasing (Mallory and Herrick, 1986).

X6, Child's Gender. When the child is a girl, placement outcomes will be more positive than when the child is a boy. As already pointed out in Chapter 3, boys are seen as more difficult to handle than girls--they are more likely to be institutionalized (holding
level of retardation constant) and are likely to stay for longer periods—so it is expected that their return to the community will be fraught with more difficulty.

**X7, Father's Education.** The more educated the father, the more positive the placement outcomes will be. Education is measured by parent's report, in categorical form, of the number of years of education, where 0 = none; 1 = less than 8 years; 2 = 8 years; 3 = some high school; 4 = completed high school; 5 = some college, technical or military training; 6 = completed college; 7 = some graduate work; 8 = graduate degree.

We have seen that Stayers' parents were more conservative in their views toward deinstitutionalization (Chapter 4) and more concerned about the effects their retarded child would have on their other children and that these families also tended to be more educated and professional (Chapter 3). However, by including Attitudes Toward Deinstitutionalization (DI) ideology, it will be possible to tease apart the separate effects of these two variables. Intuitively, one would expect that more educated people would be more in favor of community placement than less educated people.

**X8, Mother's Current Age.** The older the mother, the less positive the placement outcomes. Mother's age is measured by parents' report of her birth year which is then subtracted from 1985. Older mothers will be more skeptical about placement in the community because they are likely to have been urged by professionals (e.g. their family physician) to place their children in LSS as the only solution to their children's treatment. Conroy (1985b) has argued that Festinger's cognitive dissonance theory applies here: That
parents whose children have been in the institution for longer periods of time—and we have already seen that Stayers are, in general, an older cohort—must ratify institutional care or experience the dissonance (guilt) of having placed their children where they did not belong. Mother's age was chosen over child's age because mothers are the informants and because child's age is highly correlated with mother's age ($r = .74; p < .001$).

**X9, Importance of Religion.** The greater the importance of religion, the more positive the placement outcomes. This variable is measured by parents' report of how important their faith is to them on a scale of 0 to 4 (where 0 = not important; 1 = slightly important; 2 = somewhat important; 3 = very important; and 4 = extremely important).

McCubbin, et al. (1982), Caplan (1976) and Fewell (1986) have shown that religion is a powerful social psychological resource which cushions the family's experience of adversity. The importance of religion may thus make for greater optimism with regard to the child's return to the community.

**X10, Attitudes toward DI Ideology.** The more positive the parents' attitudes toward DI ideology, the more positive the placement outcomes. This DI scale is described at length in Chapter 4. It measures the extent to which parents ratify the concepts of normalization, deinstitutionalization, least restrictive alternative (living arrangement), and the decision to discharge their child from LSS. It is reasoned that parents who are greatly in favor of these concepts, will be more likely to cooperate in making their child's placement a success and will be more likely to view their child's
return to the community as having a positive impact upon their family.

XII, Year of Community Placement. The later the year, the more successful the placement. Year of first placement was obtained from the LSS records and the service provider interviews. As we have seen in Chapter 4, the post-1978 cohort, those who benefitted from the enactment of P.L. 94-142, was generally happier about their children's return than the pre-1978 cohort. Not only can we surmise that normalization ideology has taken more of a hold the later the year, we may also expect that there may be more services available in the community, thus positively influencing success. This variable only appears in the Successful Placement (Y1) equation.

X12, Services in the Community. The more confident parents are that services are available in the community, the more likely they will regard their children's return to the community as having a positive impact upon the family. This is a measure of parents' subjective belief about availability of community services. This relationship was argued extensively in Chapter 4. This variable only appears in the equation predicting Impact (Y2).

Samples

The two equations are based on different sample sizes. Successful Placement is based only on data from Leavers (N=68). Since Success is measured by educational as well as residential outcomes, only those children eligible for educational services at the time of their leaving LSS (i.e., before the age of 21) could be included.
On the other hand, impact is based on data from parents of both Leavers and Stayers (N=93), because parents were only asked to react to the prospect of their child's return and not to the specific placement. In each equation, the total sample on which the regression analysis was based was reduced due to missing values and the constraints of the listwise criterion (Nie, et al. 1980:354). Thus, the Success equation was based on an N of 46, representing 68% of the sample of Leavers and the Impact equation was based on an N of 45, representing 48% of the sample of Leavers and Stayers.

Table 6.1 Correlates of Successful Placement of Persons Who Left LSS Before Their 21st Birthday

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>Regression Coefficients</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Standardized</td>
</tr>
<tr>
<td>Father's Education</td>
<td>.52**</td>
<td>.19</td>
</tr>
<tr>
<td>Father in the Home</td>
<td>-.36*</td>
<td>-.43</td>
</tr>
<tr>
<td>Mother's Current Age</td>
<td>.02</td>
<td>.002</td>
</tr>
<tr>
<td>Child's Diagnosis</td>
<td>-.02</td>
<td>-.10</td>
</tr>
<tr>
<td>Female Child</td>
<td>.07</td>
<td>.08</td>
</tr>
<tr>
<td>Importance of Religion</td>
<td>.04</td>
<td>.02</td>
</tr>
<tr>
<td>Kin Support</td>
<td>-.06</td>
<td>-.02</td>
</tr>
<tr>
<td>Family Size</td>
<td>-.15</td>
<td>-.03</td>
</tr>
<tr>
<td>Year of Placement</td>
<td>-.03</td>
<td>-.003</td>
</tr>
<tr>
<td>Parents' Attitudes toward DI Ideology</td>
<td>.39*</td>
<td>.36</td>
</tr>
<tr>
<td>Proportion of Sisters</td>
<td>-.01</td>
<td>-.01</td>
</tr>
</tbody>
</table>

Rsq= .44
Adj Rsq= .25
F= 2.37
N= 46

*p<.05  **p<.001
Results: Correlates of Successful Placement

Father's educational score and parents' positive attitudes toward DI ideology are highly correlated with the child's successful placement. Table 6.1 shows the values of the coefficients when all the independent variables are forced into the equation, yielding an Rsq of .44 and an adjusted Rsq of .25. Backward elimination was used to create a more parsimonious model by considering only those variables with coefficients significant at the .10 level, which yielded an adjusted Rsq of .36. Thus 36% of the variance of Successful Placement may be explained by father's education, his presence in the home, and parents' attitudes toward deinstitutionalization ideology.

The negative correlation of father's presence in the home with the child's placement seems a cryptic result. It may be that when both parents are together to face the difficulties of placement, they are less willing to compromise outcomes. It may be that fathers are less willing to cooperate with the service delivery system without questioning what is being offered. Interviews with fathers in this study have indicated that they are critical of the facilities, especially those in the community, and not easily swayed by service provider's endorsement of various options.

Though not significant, the family variables that were included in the equation, kin support, proportion of sisters, family size, all influenced placement slightly negatively. Again, this may mean that with greater family involvement, placement is subject to greater criticism. Though this may be seen by professionals as potential for
greater interference in their already difficult task of placing
disabled people in the community, in the long run, greater scrutiny by
consumers should improve the quality of care.

Another explanation may be that the relationship of these
variables to successful placement may not be linear. Extreme values
may have a negative effect but middle range values may have a positive
influence. A moderate amount of kin support, for example, may be a
positive influence upon success while too much or too little involve­
ment may be a negative influence. Or, as another example, very large
or very small families may not be able to lend support or be a posi­
tive influence because they may have too few resources to spare or be
highly protective of the resources they do have, respectively.

These results may also have to do with the way Successful
Placement was measured. Since it included objective measures of resi­
dential and educational outcomes, it may be that family variables are
not directly relevant, that their effect is upon some intervening
variable, such as parents' confidence in their ability to problem
solve. We have seen in Chapter 4 that availability of services is the
strongest determinant of placement success in the minds of parents.
Table 6.2 Correlates of Positive Impact of Children's Return to the Community

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>Regression Coefficients</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Standardized</td>
<td>Unstandardized</td>
</tr>
<tr>
<td>Attitudes Toward DI Ideology</td>
<td>.28*</td>
<td>.23</td>
</tr>
<tr>
<td>Father in the Home</td>
<td>.22</td>
<td>.38</td>
</tr>
<tr>
<td>Female Child</td>
<td>-.46**</td>
<td>-.57</td>
</tr>
<tr>
<td>Child Diagnosis</td>
<td>-.04</td>
<td>-.03</td>
</tr>
<tr>
<td>Father's Education</td>
<td>-.13</td>
<td>-.05</td>
</tr>
<tr>
<td>Mother's Current Age</td>
<td>.07</td>
<td>.01</td>
</tr>
<tr>
<td>Kin Support</td>
<td>.09</td>
<td>.04</td>
</tr>
<tr>
<td>Services in Community</td>
<td>.31+</td>
<td>.12</td>
</tr>
<tr>
<td>Importance of Religion</td>
<td>.02</td>
<td>.01</td>
</tr>
<tr>
<td>Proportion of Sisters</td>
<td>-.12</td>
<td>-.19</td>
</tr>
</tbody>
</table>

Rsq* = .44
Adj Rsq* = .28
F* = 2.70
N = 45

*p<.10  **p<.05  ***p<.01

Results: Correlates of Positive Impact of the Child's Return

Table 6.2 shows the predictors of positive impact on family routines when the child returns to the community. The resulting Rsq was .44 with an adjusted Rsq. of .28. Backward elimination yielded an adjusted Rsq .32. Thus 32% of the variance of Impact is explained by parents' score on the DI Scale, their belief in the availability of services in the community and the child's gender.

The key correlates of a positive impact are parents' ratification of DI ideology and their belief that services are available in
the community. When the sex of the child is female, however, the impact is less positive. Carson (1986) has suggested that perhaps because females are viewed as caregivers, a retarded girl's return to the community may be viewed with disappointment in the face of the knowledge that she cannot fulfill this role. Another plausible explanation is that retarded girls are vulnerable to sexual attack which families find worrisome (Trainor, 1986). Another, less dramatic, explanation is the fact that the impact scale measures change in family routines. For the most part, parents did not anticipate a great deal of change, either positive or negative except with respect to their children's own personal happiness and socialization. (See Table 4.3.) It may be that, since boys are more likely to be institutionalized, their return is greeted with an element of surprise at this achievement. A girl's return on the other hand may be seen as somewhat less of a change in routine since females tend to be more a part of the domestic scene.

Summary and Conclusions

The overarching hypothesis tested in this chapter is: The greater the kin support, the more likely placement outcomes will be successful and have a positive impact upon the family.

Contrary to our expectations, kin support was not significantly correlated with either Successful Placement or Impact, all other variables held constant. Before we speculate as to why this result was obtained, let us review the findings.

Two regression models of placement outcomes served to identify correlates of successful placement and positive impact of the child's return on the family.
Successful Placement was measured by a scale comprised of five variables including the length of stay in the community, not returning to LSS, attending and staying in an educational program, and a normalized residential setting. Successful Placement was found to be positively correlated with fathers' education and fathers' socioeconomic status, but negatively correlated with the presence of the father in the home. This latter finding suggests that, as a team, parents may be more skeptical of services available in the community. In order to fully understand this outcome and to verify it, it would be necessary to ask parents separately and jointly their opinions about placement. However, anecdotal evidence and other writers suggest that once parents have seen the results of good programming—that children do improve in skills—resistance to communitization melts. Our sample sizes were too small to examine regional differences in attitudes regarding services, but I would suspect that regions in which services are well developed and available would reveal populations of parents who showed confidence and optimism for placement outcomes.

Positive impact seems to be best predicted by parents' belief that services are available and parents' approbation of deinstitutionalization ideology. It was further concluded that boys' community placement has a greater positive impact upon parents than when a girl returns to the community. It was speculated that a boy's return might be seen as a greater achievement because boys are more likely to be institutionalized in the first place.

To return to the central focus of this chapter, kin support was not found to have any appreciable correlation with placement outcomes.
as tested in the regression models. This should not be interpreted to mean that kin support is irrelevant to successful programming. As emphasized in this report, extended families are being recruited to help in the process of early treatment and intervention (Sonnek, 1986; Vadasy and Fewell, 1986). The variables used to measure success do not "match" with the structure of extended kin. Successful placement outcomes were operationalized by objective measures of residential and educational placements. According to Litwak's typology, these are the spheres of large organizations, which provide services that kin do not provide in industrial society (i.e., education). These tasks are therefore unrelated to tasks that can be accomplished by family members. Hence, kin support was essentially uncorrelated with Success or Impact. We might expect that familial support, care and love are irreplaceable in contributing to one's sense of well-being. By this, I mean that substitutes are just that; they are not equivalents. It may well be that kin support has an indirect effect upon placement outcomes.

Other relevant criteria of success were not included. Recall that a key criterion that was missing was the disabled person's own evaluation of what is a desirable outcome. In future research, then, success should be operationalized not only in terms of programming and treatment, but also in terms of the reintegration of the role of the family. Litwak (1985) has identified such variables as the use of the telephone, periodic face-to-face contact with the family, afforded by proximity and/or material resources, as important in fulfilling the nurturing role of the family.
In the next two chapters, we will examine the correlates of kin support.

In the next chapter, we will examine the influences of kin support on the process of communitization. Since we did not see any correlation of kin support with community outcomes, it is necessary to look at how and when kin become involved with the handicapped family. To reiterate the rationale: If the goal is communitization and kin are the interface between the handicapped family and the community, then they are a most important target group for resources, shared responsibility and changing the attitudinal climate.

In Chapter 7 we will further ascertain the correlates of kin support and we will take a closer look at developmentally disabled children in the lives of three families.
CHAPTER 7

KIN SUPPORT AND COMMUNITY PLACEMENT: CASE STUDIES

Several issues involved in examining kin support are brought to light in the case material presented here. The role kin play in the care of handicapped children and their families can be examined using Litwak's principle of matching. Recall, this principle states that the structure of the task, in this case, the treatment and care of a disabled child, must be matched by the structure of the group providing the care in order for the task to be properly carried out. The essential point that Litwak makes is that these groups are not interchangeable with respect to their tasks.

The structures of the tasks of caring for handicapped children require a combination of interventions characterized by both professional expertise and long-term commitment. I will try to show that these characteristics serve to demarcate the roles of professional and non-professional caregivers, where they may overlap, and where they may be quite separate. The guiding questions are: Who are the key sources of support? What aspects of the family and its structure are likely to promote kin support? How is kin support related to the care of developmentally disabled people?

One important element in determining the potential availability of support from the kin group is the location in the developmental cycle of its members. If most relatives are involved in the care of their own young children, then there is less likely to be material or human resources leftover for the care of a child outside the nuclear family, especially a child with multiple handicaps. Another element
is the sheer number of women in the family network. At this writing, women still bear the most responsibility for the care of children, whether they provide that care directly to their own children or to others' children, or plan the use of daycare (Genovese, 1984). Whether a mother of a handicapped child has sisters and a mother still living, will greatly increase the likelihood of her receiving social support. Geographic proximity is also necessary for any provision of respite care, but not for social support (Litwak, 1985).

Data from the first interviews of all 93 families of both Leavers and Stayers were combed for volunteered comments regarding family support and will be presented first, followed by three case studies.

Table 7.1. Numbers of Families Reporting Kin Support*

<table>
<thead>
<tr>
<th></th>
<th>Leavers (n=19)</th>
<th>Stayers (n=20)</th>
<th>Totals (n=39)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>A. Extended Kin</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maternal Kin</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grandmothers</td>
<td>13</td>
<td>12</td>
<td>25</td>
</tr>
<tr>
<td>Grandfathers</td>
<td>4</td>
<td>7</td>
<td>11</td>
</tr>
<tr>
<td>Aunts</td>
<td>5</td>
<td>6</td>
<td>11</td>
</tr>
<tr>
<td>Uncles</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Cousins</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Paternal Kin</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grandmothers</td>
<td>6</td>
<td>13</td>
<td>19</td>
</tr>
<tr>
<td>Grandfathers</td>
<td>5</td>
<td>6</td>
<td>11</td>
</tr>
<tr>
<td>Aunts</td>
<td>3</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Uncles</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Cousins</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>B. Nuclear Family</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sisters</td>
<td>8</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>Brothers</td>
<td>5</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Fathers</td>
<td>4</td>
<td>0</td>
<td>4</td>
</tr>
</tbody>
</table>

*All kin are referenced to the child.
Families of 19 Leavers and 20 Stayers specified the kin who were supportive. Table 7.1 shows the number of instances certain kin were specified. Grandmothers were reported most often as the key figures in the support network. In no instance was a grandfather identified as supportive and not the grandmother, though, in one instance a paternal grandfather was reported as more supportive than the paternal grandmother. With regard to handicapped families, these findings are consistent with those of Farber (1960), Gath (1978), Nemzoff (1979), and Suelzle Keenan (1980).

Differences between Leavers and Stayers were shown in the level of involvement of paternal grandparents, brothers and sisters, and husbands. In the majority of the Stayers' families, paternal grandparents were just as supportive as maternal grandparents. By contrast, only a fifth of paternal grandparents were as involved in Leavers' families. Siblings and husbands were reported proportionally more often as sources of support in Leavers' families than in Stayers'.

In sum, families of Stayers tended to report equal involvement of maternal and paternal grandparents, whereas for Leavers, maternal kin in general were the more involved. Mothers' sisters were mentioned proportionally more often by Stayers' parents. In both groups, mothers' sisters were more likely to be supportive than husbands' sisters.

What these data suggest is that when support, in the form of goods and services, is required, mothers' greatest resources are among the women of her consanguine kin. This is not surprising since mothers of Leavers require more concrete help since their children are
home with the family. Generally, researchers have found that in intact marriages, women look to their own mothers and sisters for support and aid rather than their in-laws (Bott, 1957; Young and Willmott, 1957; Komarovsky, 1962; Yanagisako, 1977). By contrast, mothers of Stayers are most likely reporting support in the form of visits to the institution, small gifts, advice, etc. These expressions of support are more easily provided (requiring less time and effort) and so, perhaps, support can be divided more equally between both sets of kin in Stayers' families.

In the case studies that follow, we will look more closely at the processes involved in kin support. Unlike our overall survey where we looked at perceived kin support, in the studies that follow, we are interviewing the family members themselves and asking them directly about their involvement.

<table>
<thead>
<tr>
<th>Table 7.2. Persons Interviewed in the 3 Case Studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cheryl Bonaventure</td>
</tr>
<tr>
<td>Mother</td>
</tr>
<tr>
<td>Paternal Grandmother</td>
</tr>
<tr>
<td>Paternal Grandfather</td>
</tr>
<tr>
<td>Maternal Grandmother</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>
The Case Studies

The families appearing in this chapter were chosen for the case studies because they provided at least four family members and were the most willing to cooperate. Table 7.2 shows who was interviewed in each family. Each interview averaged about two hours. The interview schedule used appears in Appendix E.

More on Method: The Familygram

The main reasons for interviewing mothers and their relatives for the case studies was to discover what motivated and inhibited kin involvement in the care of the disabled child and kin's support of the mother. I was interested in identifying the resource pool, the kinds of help that were provided, by whom and in what time frame. Finally, I wanted to find out about relatives' attitudes toward deinstitutionalization and what influenced these attitudes.

In order to establish rapport quickly and simultaneously to map out the kin resource pool, the first part of the interview with each relative was devoted to the familygram, an evaluative tool used by and known to family therapists as the "genogram" (Hartman, 1976). The familygram focuses on the informant's nuclear family and branches outward from there to the descriptions of the informant's family of origin, her or his spouse's family of origin and sketches out the relevant collaterals (those siblings with whom they have contact). The resulting diagram (e.g., see Figure 7.1), becomes a point of reference to help the informant recall key individuals, occupations, as well as significant losses by death.

Guerin and Pendagast have adapted the anthropologist's diagrammatic representation of kin relations as an efficient means of
identifying family strengths and weaknesses in order to

spell out the physical and emotional boundaries, the
characteristics of membership, the nodal events [events
around which, e.g., family contact--either spontaneous or
routinized--is made], toxic issues, emotional cutoffs, the
general openness/closedness and the multiplicity or paucity

In this study, the use of the familygram is the same as when it
is used in therapy: to identify loci of support in the family net-
work. The major difference, however, is that while the therapist's
goal is to identify areas for potential restructuring of family rela-
tions at the group and individual levels, the research goal is simply
to describe how families support one another and to identify elements
in family structure which place mothers of handicapped children at
risk of a lack of family support.

I use the term "familygram" (Shapiro, 1983) to replace the term
"genogram" because I believe it is more descriptive of what is being
depicted and examined. Since the focus is biosocial and not genetic or
geneological (though these play a part), the prefix "geno-" can justi-
fiably be replaced by "family-", since the main interest is a diagram
of the family. Furthermore, this term seems more salient, readily
comprehensible and less clinical-sounding to the families being inter-
viewed. For the most part, however, the terms are synonymous and the
techniques I used followed similar lines of questioning.

The questions I used to accompany this diagram were: What are
the birthplaces and current residential locations? Occupations? Who
has died? When? How? What are the distances (in miles) from the
child, if people remain within the state? Who is divorced?
Remarried? All these questions serve to identify a person's location
in the developmental cycle, level of emotional maturity, affective
relationships, socioeconomic status and social involvement in the network. Whether or not the informant can answer certain questions or volunteer certain information also plays a part in indicating the extent of the person's involvement in his/her family.

In the case studies that follow, a number of key aspects of kin support are illustrated. These are the importance of the number of women in the kin network, especially in the mother's family of origin; the level of cooperation among kin; the developmental stages of the nuclear families, and the child's level of retardation. The studies illustrate the indirect and direct influences of kin support on the care, especially amount of services and level of involvement in the community, of the handicapped person.

The families illustrate the positive effects of strong kin support on the care of a handicapped child and how a lack of this support can indirectly reduce community care opportunities. The studies suggest that the indirect effects of this support manifest themselves in the coping skills of the parents to meet the challenges of obtaining education and treatment for their children. The direct effects are daily social support and the occasional respite they have provided throughout the years. The proximity of the grandparents, especially the maternal grandmother, serves to enable material goods and services to be exchanged. However, there are factors inhibiting these exchanges. These factors will be discussed near the end of the chapter. Although fathers are poorly represented in this study, as will be seen, their role, either by their way of handling the provider role or their absence, is not to be underestimated.
The names of all participants and the names of towns where they live, have been changed to conceal their identity. Most quotes are verbatim from tape recorded interviews, unless otherwise indicated.

CHERYL BONAVENTURE

The story of Cheryl Bonaventure is the story of a family's struggle for independence in the face of a great need for services. This case illustrates the strong indirect effect of kin support which appears to provide the moral strength for the mother's unflagging and effective efforts to obtain services for her child.

Mrs. Penny Bonaventure, a housewife with two children, lives with her husband, Jason, in a community near the State School. She presents many of the difficulties which parents face when they have a handicapped child. She has challenged the service delivery system by not accepting the status quo and by treating it as it's name implies, as a servant to the needs of her disabled daughter and her family. It might be said that Mrs. Bonaventure has single-handedly re-oriented professionals at Laconia State School from the role of dispensers of pearls of wisdom to the role of co-workers. Mrs. Bonaventure's orientation is one of shared responsibility with the social service delivery system. With full knowledge of her rights as a citizen and as a parent, she has not allowed State agencies, such as the State School or the public schools her daughter has attended, to take over her role as parent and guardian. Just as she would have, had Cheryl remained at home, Mrs. Bonaventure has taken part in all decisions concerning Cheryl's treatment and education. This mother describes what many parents face in obtaining services in the 1980s.
What I believe is suggested by this example, in addition, is that kin support has provided Mrs. Bonaventure with a foundation of moral strength which enables her to fight for services for Cheryl and which gives her a willingness to support other parents with developmentally disabled children. More formally stated, the hypothesis I am posing is: The stronger the kin support, the better able the mother of the handicapped child is to solve the problems of care and treatment. We will first look at how Mrs. Bonaventure has coped with Cheryl's programming difficulties and then look at the kind of support her family network has provided.

Early Support and Treatment

Mrs. Bonaventure has asserted her role as parental guardian of Cheryl, describing eloquently how she and her family have overcome the hurdles of obtaining appropriate treatment and education. Most of this story is told by Mrs. Bonaventure as we talked at her kitchen table on a winter afternoon while she was baking a birthday cake for Cheryl and her older daughter Dierdre, both born on the same day of the year.

Cheryl Bonaventure is seventeen. The State School records show a diagnosis of severe mental retardation and scoliosis. She wears glasses, hearing aids and speaks in complex sentences, though her mother adds, to understand Cheryl, great patience is required on the part of the listener. Cheryl was born to hard-working, practicing Catholics, when her mother was 23 and her father was 25. Her mother knew immediately there would be problems.

She had no fatty tissue on her body when she was born. It just...her flesh hung off her bones, so you knew—it was pretty obvious. They don't have a category for her... She had a protein deficiency. And she wasn't able to walk. She didn't know how to eat. But she was a good baby.
Like Featherstone (1980), Penny relied on professionals for understanding in the early years of Cheryl's treatment.

It was hard because I had no support. There wasn't anyone to talk to. No one except the pediatrician here. . . . Maybe some people might feel you want to be alone, even though you don't want to be. I often wonder if I could want to go charging in--offering whatever. Although, I probably would now that I know.

I remember once Cheryl had a teacher--she was really quite good when Cheryl was younger--I remember she came over one day and said, "I have two hours. I'll stay with Cheryl. Go do whatever you want for two hours." And I remember thinking, "God!" I was so thrilled, you know? But not too many people ever did that.

[Were you ever part of the Laconia State School Association for Retarded Citizens (LSSARC)?]

No . . . I never was really familiar with them. I don't know much about them . . . I guess I never really wanted to be a part of them 'cause I hated the fact that [Cheryl] had to stay there anyway. That's probably why. I was not interested in joining any parent support group at the State School 'cause I hated the institution anyway, so why became involved?

[I hated the institution] because I wanted her at home and I couldn't have her here and the only thing that they offered me was their--. . . I don't know what it is now but at that time [1976], they had a "respite program". . . . You could have 30 days a year but it was a one-shot deal. . . . Well, you just don't take a kid that lives at home and put 'em in an institution for 30 days! . . . I didn't need 30 days at one shot. Maybe I'd 'ave taken it had it been home . . . but not too many people are running up there for 30 days to dump a kid in an institution.

There are several types of support identified in these excerpts. There is professional advice and understanding; there is respite care; and there is emotional support from other parents whose children are in the institution. None were completely satisfactory and all contributed to a sense of isolation that this mother felt. Professionals were only available periodically and at scheduled times. Parents in the LSSARC were working to improve their children's situation within
the institution, thereby tacitly supporting the status quo. Though Mrs. Bonaventure says, "I had no support," we shall see that this seemingly contradictory statement has more to do with the distinctions among types of support. In an earlier interview, she rated her extended family as "somewhat supportive." We will see later that her family did provide a great deal of social and material support, though not in the amounts that Mrs. Bonaventure would have liked.

Prior to entering the State School, Cheryl had been receiving day care. Mrs. Bonaventure describes a turning point in Cheryl's treatment.

[Cheryl had] had the same therapist for a year and we'd work with her together and then I'd work with her at home. One day we were trying to get her to use little tiny crutches, little Canadian crutches, and she wouldn't use 'em. She'd sit there and throw 'em around the room. And they had decorated them with pink crepe paper . . . so she wouldn't be afraid of them and she'd throw 'em around the room and play, never use 'em. And then—we don't know why--[she crawled over to the wall and--hand over hand--she braced herself to an erect position.] She got up and walked and just kept on going! Started walking down the corridor and we were chasing her down the corridor! But, once she got going,' she was absolutely delighted and she wouldn't stop. She loved it!!

Cheryl has been in school ever since. She was in her second year of public school, when Cheryl's behavioral problems of aggression, hyperactivity and self-abuse became too difficult for her parents and teachers to handle. With no other resources in the community at the time, the family physician counselled the Bonaventures to send Cheryl to the State School. The first admission occurred in the Fall of 1975 when Cheryl was 7 years old. Ironically, with the
deinstitutionalization movement in full swing, the admission process was not easy. Her mother recalled:

[Laconia State School] didn't want Cheryl there any more than we did.... It was kind of a problem there for a while. I said I couldn't take care of her at home. Then I got the school district behind me because she was having so many problems in the classroom that they [the school district] backed me up at the time so that the State School took her, but let me tell you, I think she was the last one admitted. And then it would take an act of Congress to get a child in there.

Cheryl was admitted on two separate occasions. The first admission lasted for a year; the second occurred in the Spring of 1978 and continues at this writing. (That is to say, Cheryl has not been officially discharged.)

Programming has consisted of physical therapy, a total communications program, socialization, including behavior modification and activities of daily living. Cheryl has also continued to participate in a full program of physical fitness and swimming. Throughout her years at the State School, Cheryl received her education in a regular school in the community because her parents "insisted" that she do so.

Mrs. Bonaventure: You couldn't wait around to have her attend classes up there [LSS] because half the residents never did. They were overcrowded--lack of teachers. So, at least Cheryl spent her days in a classroom. That didn't change! .... She was only out of school six weeks and that was because they expelled her. That's against the law now [chuckles triumphantly]. But it wasn't then.

.... So she was never really out [of school] because we started working with the behavior program and so forth. .... If there'd been something out there she probably wouldn't have had to spend any time at Laconia State School. And that makes me angry because there wasn't!
Cheryl's Father

The Bonaventures are committed to Cheryl's continued progress. Jason Bonaventure works at a good job which is a three-hour commute from home. Though this means a fifteen-hour day for him, Jason has not been willing to move the family away from the services that are provided in their community that they fought so hard to obtain for Cheryl. This sacrifice has enabled Penny to closely oversee and be involved in the care and treatment of their daughter.

The Family and The State

Litwak (1985) has pointed out that large organizations are good at delivering advanced treatment because at their disposal are resources of equipment, facilities and trained personnel (though expertise at institutions has been historically uneven). Primary groups (Cooley 1929:23), on the other hand are able to provide the personal care and understanding which help to tailor the treatment to the individual, crossing barriers of language, culture and beliefs, and family times, not readily comprehended by professionals.

In the following excerpts, Mrs. Bonaventure illustrates how the concepts of the principle of matching and shared responsibility (see Chapter 1) between large organizations (the service delivery system) and primary groups, how professionals and parents, can work together in their complementary roles, where neither one replaces the other.

Mrs. Bonaventure: . . . [W]hen Cheryl was there [at LSS], we still stayed involved. . . . She had to be there because we couldn't take care of her at home, but we didn't put her there to "dump" her. And sometimes, sometimes it was hard for them [the staff at LSS] too, because they weren't used to having parents around to deal with them all the time, either. I was up there all the time. My husband kept saying to me, "It'd be easier if you got a job there!"
never did, but . . . (chuckles). . . I wanted to be informed. . .
If you developed a program, why did you develop it and did she
need it? And I had to approve it first. But that's the way
it should be with any child. . . . Dierdre [their older daughter]
was in the public school system, too, and she didn't enter
programs without my knowing about it. . . I didn't want it to
be any different with Cheryl. So if we developed a program,
I was usually in on it.

[I] mainly worked with [the staff], because we decided
that if we didn't work together, we were never going to get
anywhere, which is important. Which is why I think it's
very important . . . [that] all these different agencies [the
school district, community services, Laconia State School
and Training Center] had really better start working with
each other because it makes it a whole lot easier. If you
can work together.

Mrs. Bonaventure's observation about the need for the coordination
of services has been reiterated throughout the literature (Bruininks,
et. al., 1981; Fewell and Vadasy, 1986). The question remains is who
is the best person (or what is the best organizational structure) for
the task? In this particular instance, Mrs. Bonaventure herself has
acted as the most efficient coordinator of Cheryl's services.

The Bonaventures have been active all along in Cheryl's care
even when she lived at the State School. They continue to provide
Cheryl clothing and to do her laundry. All medical costs have been
paid by their family insurance plan. Cheryl now lives with Nancy, her
teacher aide. According to Mrs. Bonaventure, "She lives in a shared
home during the week and Jason and I usually take her home on
weekends. It's working out real well." Her parents will be the first
to admit that Cheryl drains their energy when she comes home on
weekends, "Unless she's asleep," Mrs. Bonaventure quips. There is,
however, no question in their minds that Cheryl is happiest in the
community.
Normalization in Real Life

A champion of community treatment, Mrs. Bonaventure describes its advantages and speculates as to why people resist it.

People really need to be educated about mentally retarded people. They're not going to harm you and they're not going to hurt you and their desires are the same as yours and mine. . . . That's the whole thing. . . . That's what it is. . . . They need to be educated.

[Interviewer: What would you want members of the community to know most of all?]

That if five mentally disabled people lived together in a house, they're not going to destroy the home. . . . I don't think that your property values will go down!

[Interviewer: Is there any advantage to having a group home in the neighborhood?]

I thought the advantage might be that people might be a little more understanding. . . . if you see that they enjoy the same things you and I enjoy. They like to go swimming. They like to have a picnic in the back yard or a barbecue. They keep their home clean.

They also have supervision. I found that a lot of the people in the neighborhood were afraid of a lack of supervision. That's terribly important to these people [neighbors]. And I'll admit some of 'em [developmentally disabled people] need it. Ah, Cheryl will never be able to live alone. She always will need some kind of supervision.

(That's a hard 24 hours-a-day if you're a parent. You don't have a shift. I never had anyone come in to relieve me every 8 hours ya know.) That's what people were concerned about; I think they were afraid they were going to run around and all be crazy.

[Interviewer: They kinda confuse it with mental illness.]

Amazingly enough the State of New Hampshire thinks we should put [mentally ill and mentally retarded people] together. . . . That's scary! [This refers to the proposal put forth by the Division of Mental Health and Developmental Services for a new hospital complex—a proposal now tabled.]
That's the most ridiculous thing I've ever heard of. You don't put mentally ill people... They're not retarded; they have mental problems, but you don't put the retarded with the mentally ill. You can't do that. Their problems are so different!

People say "You know what it costs to educate your retarded daughter, don't you?" Well the last I knew, it was $50,000 a year to maintain Cheryl at Laconia State School. I understand the figure has risen. You know what it costs to maintain her in a shared home? A quarter of that! I wish someone had given me $50,000 to keep her at home!

Mrs. Bonaventure is now part of a parents' support group—a group that is seeking to develop educational, recreational, and therapeutic services within the community for all handicapped children on the entire continuum of disability. Much to her amazement, not only parents, but grandparents and other relatives attend the meetings seeking to be better informed and to learn how they can help—something Mrs. Bonaventure wished were available to her and her relatives in those early years before Cheryl could walk. She further gives insight into the nature of support that is required from the community and from policymakers.

Mrs. Bonaventure: Interestingly enough, it's not just emotional support—everybody needs that and everybody has problems and everybody wants to talk. What we're trying to do is: This committee over here will try to educate people; this committee over here [will develop a summer program, etc.]

And another thing we've learned is: You can't separate the disabilities. We're not going to have, "Your daughter's learning disabled so you don't belong here." Because it's a lot easier to be in together because there's a lot more strength in numbers if you ever want to get anywhere—get anything, done. And when you have to talk to legislators, boy, you'd better know what you're talking about!

... If you want... laws changed, bills enacted, you sure better have a powerful lot behind you. You're dealing with the big guys then. That's not easy. But that's—hey, that's where it's all happening! If you want your kid in school, it's the laws that do it! The neighbors didn't do it. But
it was the people banding together. And . . . without that--
forget it! Never gonna happen.

[Interviewer: What a battle!]

It really is and it isn't over yet!

The Extended Family Interviews

Mrs. Bonaventure's wholehearted cooperation in this study was
just one more piece of evidence of her pioneer spirit. It was
apparent that she viewed her involvement in the study as part of the
necessity of using all avenues, including research, to further advance
the understanding of the needs of handicapped children and their
families.

In our interview, I explained how I would need to explore with
her which family members would be amenable to an interview. I
explained that in order to understand how her relatives view Cheryl's
situation, it would be important to talk to them directly and pri-
vately. It was decided that I would interview both of Cheryl's
grandmothers, who lived in the same town as the Bonaventures. Mrs.
Bonaventure acted as liaison, introducing the project to them in brief
terms and giving me a good recommendation with the result each home
welcomed me cordially.

In the survey, only a global measure of perceived kin support
was obtained. In the case studies, however, it was possible to
discover the processes governing the amount and type of support
extended kin provided the family. Cheryl's grandmothers illustrate
the differential involvement of mothers and mothers-in-law and how the
developmental stage of each family impacts upon the extent of
exchanges of services.
Figure 7.1 The Family Network of Cheryl Bonaventure (2/6/85)
The Maternal Grandmother

Mrs. Jean Schoffield, aged 59, is Cheryl's maternal grandmother who lives two houses down the street from the Bonaventures. Jean and her husband, Bud, a design engineer of large engines, have five children, three of whom live in the same town and two of whom live within 40 minutes' drive from them.

In a sense, Jean and Bud have had three families of two girls, an only son, and then a girl and a boy. Figure 7.1 shows Cheryl's familygram with her mother's family of origin on the right. Penny Bonaventure, Cheryl's mother, the firstborn and her sister Linda were born two years apart. Ten years later, John, the Schoffield's first son, was born. Jill, their third daughter, followed four years later and, finally, two years later, Peter was born.

There is a high degree of connectedness (to use Bott's term) among the members of this family. Jean told me she has the most contact with Penny, seeing her about two hours a day by visiting at each other's houses. Jean visits her daughter-in-law, Mary, John's wife, twice a week and travels out of town almost every week with Bud to have dinner with Jill and her husband ("he's awfully nice.") Their youngest child, Peter, aged 23, still lives at home while working full time in a construction firm.

When Cheryl was born, Diedre, her older sister, was 2 years old and Mrs. Schoffield's three younger children were 12, 6 and 4 years of age. When I asked Jean what kinds of help her daughter asked for, Jean told me she would babysit. "I would take them both." However, Jean remarked, the Bonaventures "never did go out very much." (Penny had told me that she and Jason didn't go out much because
finding a sitter who could understand Cheryl and handle unpredictable situations was just too difficult. They had to rely on family.) Jean quickly pointed out the fact that Diedre was only 2 1/2 years older than Peter. She therefore could offer no help with the shopping or housework, though, Penny recalled that her mother did, on occasion, help with the shopping. When Jim and Jill were teenagers, 17 and 13, respectively, they would provide respite by babysitting. Jean remembers Jim taking Cheryl for rides in his car and treating her to ice cream. Even when the children were small, though, the family rallied support when Cheryl was in the hospital for a long stay for surgical treatment of scoliosis. Jean would take the three children and visit three times a week. Truly, Mrs. Schoffield had her own family to look after. Hers and Penny's family were essentially at the same point in the family developmental cycle. The two main impediments to providing her daughter with a lot of help were her own duties to her young family and her arthritis, which made the lifting that Cheryl often required impossible.

Jean remembered some of the circumstances that led up to Cheryl's admission to LSS:

She was getting a little bit hard to handle between the two of them [Jason and Penny], as she got older and got bigger. She'd get awfully mad if the other kids were yelling. She'd throw herself on the floor. She couldn't stand to think anyone were getting hurt. It took a while to get her calmed down--she was dead weight when she was on the floor . . . . A lot of times Cheryl needed help getting up. My arthritis kept me from lifting Cheryl. . . . Bud was here a lot of the time . . . and Cheryl had braces. Penny and Jason were fantastic with her. She was about ten; she was getting hard to handle. Penny broke her toe and Cheryl broke her thigh when Penny was carrying Cheryl. She certainly has come a long way.
When I asked Mrs. Schoffield what she thought of Cheryl's living with Nancy, her teacher's aid, Jean told me: "I don't know where Nancy lives. I don't know Nancy very well--I've seen her just twice . . . . It's just the two of them. [Nancy] is really good for her . . . . I think Cheryl's doing great where she is." When I asked Jean her opinion about the level of skill of community workers, she expressed doubt. "I'm sure Nancy [knows what to do], but I'm not sure about [workers in general.]

The Paternal Grandmother

Cheryl's paternal grandparents, Edith and Marcel Bonaventure have three children (see the left side of Figure 7.1), spaced at least four years apart, of whom Jason, Cheryl's father, is the middle child. They told me they feel closest to their youngest son, Michael and his family, who live three miles away. Edith sees Michael very often and they call each other on the average of three times per week. Edith says, with a doting look, "We see Mike [a lot]. His children are young [ages eleven and eight]."

The senior Bonaventures live about 2 1/2 miles from their disabled granddaughter's family. Like the Schoффfields, the Bonaventures reported that they had more contact with Cheryl and her family before Cheryl went to the State School. Currently, Marcel and Edith see the Bonaventures about once a month. Though this might seem to be low in frequency, considering the fact that the paternal grandparents would want to see their son on such visits, it seems quite frequent, since Jason Bonaventure's workday is fifteen hours long, leaving little time for his own family except on weekends.
Interviewer: Did Cheryl's parents ask you for help?

Edith Bonaventure: Never—a few times. When Cheryl was seven years old, Cheryl would come over for the day or for an evening. Maybe a few times a year. We didn't know what Cheryl wanted. She'd scream and we wouldn't understand her.

[Penny and Jason] did it on their own. They're never the type to ask [for help]. At first you couldn't [help] anyhow. . . . Michael would go and babysit at Cheryl's home for a little while before she went to Laconia [State School]. . . . at night when Cheryl was in bed.

Interviewer: Did you offer any kind of help?

Edith Bonaventure: We took care of Diedre overnight—not too often. When Penny was in the hospital with Cheryl, we took care of Diedre. [This refers to a time when Cheryl was hospitalized for a week and, because the staff did not have experience with disabled children, Penny was required to sleep in Cheryl's hospital room and be available a tiring 24-hours a day.]

Mike babysat and Jill [Mrs. Schoffield's younger children] babysat. It was awfully hard for them [Jason and Penny], so you can imagine it would be hard for someone else.

When we began the interview at the kitchen table, Marcel was in the cellar doing chores but eventually joined us. He sat in a chair away from the table. Edith answered most of the questions but occasionally the two would consult together. Marcel enthusiastically described his own family of origin—his eight brothers and sisters, their whereabouts, his nieces and nephews. However, when I began to ask about Cheryl, in less than a minute, Marcel left the room. Edith indicated Marcel's pain at Cheryl's disabilities more by a wince than a word. I asked, "Did you offer any other kind of help?" Somehow, I found myself whispering the word "money." Edith made a 'hush' sound and whispered that they had "helped" Jason and Penny out on occasion. "All those operations and hospital bills!" The steely question, "How much?" was moot. By the whisper, it was clear I had already entered
the antechamber of a secret room, a privilege in itself. There was a sense that his monetary help compensated for their feeling so sad about Cheryl—a "doom and gloom" attitude that Penny found irksome.

Though Marcel and Edith Bonaventure have a comparatively small family of only three children, they themselves come from fairly large families by current standards, with many siblings, nieces and nephews. Edith comes from a family of five and Marcel from a family of nine children. It was clear these other kin absorbed quite a bit of their time and attention, in addition to six grandchildren (see Figure 7.1).

When I asked Edith what she thought of Cheryl's placement at LSS, she replied, "I knew it was the place for her. She wouldn't have learned a thing [otherwise]. Only after that [being placed at LSS] did she learn to go to the bathroom by herself and feed herself."

Though it is true that only after Cheryl began to walk was it possible for her to be toilet trained and that within two years of her walking, she had been admitted to LSS, Mrs. Schoffield gives her daughter the credit for Cheryl's progress in personal skills. However, Edith may not have been aware of the full extent of Penny's involvement in Cheryl's treatment program while at LSS.

With regard to Cheryl's current living situation with her teacher's aide, Edith expresses more skepticism than Mrs. Schoffield.

This is bound to come to an end. I wish it wouldn't end. Cheryl keeps talking about "Nancy." Jason and Penny are not too sure about it. She's grown by leaps and bounds since she's been there. Parents are apt to let her get away with things, but she's [Nancy's] not like that—she's firm and loving.

Interviewer: How much do you agree with this statement? "Persons who work in community living arrangements are skillful enough to handle situations that may arise with regard to Cheryl."
Edith: Nancy is, but I don't know how good the others are.

The grandmothers were not confident in the security of funds for services nor in the consistency of professionalism among personnel in the community. At this writing, the service delivery system is not well developed throughout the State of New Hampshire.

Now we turn to a case where there is a lack of kin network support. Aside from the psychological factors that may inhibit support in this case, we shall see that this lack of support is due to a paucity of female kin and a lack of family cohesion and connectedness. In turn, the resulting lack of support seems to inhibit or depress the mother's ability to seek out services for her developmentally disabled son.

LES DAWES

At the time of the interview, Les was 34 and lived at home with his mother and stepfather in a one-family house in a coastal community of New Hampshire. Les is tall, well-groomed, neatly and appropriately dressed for a man his age. Diagnosed severely retarded, he has no physical complications or sensory difficulties. His speech is difficult but not impossible to understand, though he tends toward echolalia. The day we met, Les came into the living room where his mother, Marian, and I were talking to show me his stuffed rabbit. It was clear that Les was making an eager attempt to socialize. His mother was a little embarrassed, and told Les to go to his room and listen to his records. "Maybe I baby him too much," she said apologetically.

Les was admitted to Laconia State School at the age of fourteen because, at the time, his mother was going through a bitter divorce.
The admission was at Marian's attorney's urging. However, by the time the admission was granted, Marian was already remarried. The reason for Les' discharge at age nineteen is rather vague. It seems to be a culmination of several factors: There was no particular plan for Les' future training; Marian missed her son and wanted his companionship; Marian thought her son would fare better at home.

Three years prior to entering LSS, Les had been involved in job training activities at Great Bay School and Training Center in Newington, New Hampshire, when Les was between the ages of 9 and 12. Marian explained that Les "couldn't cope with confusion and was kicked out for behavior problems." The incident sufficiently discouraged Marian so that she never again sought programming for her son. But why would such an incident completely discourage one mother, while another, like Mrs. Bonaventure, might meet the challenge and continue to press for services? I believe, apart from psychological variables, the answer lies in the amount of kin support a mother has behind her.

Despite the barriers a parent may encounter in the service delivery system, a parent who has a grounding in a supportive family, will be better able to engage in fruitful problem solving behavior. What I am suggesting coincides with the notion that social support has a counterbalancing rather than a buffering effect upon the person facing stressful life events (Thoits, 1984). This means that social support does not reduce the problems, as in buffering, but it reduces the felt stress of the problems (counterbalancing). This is not to say that actual material, or other instrumental support, does not have a buffering effect, in addition.
Figure 7.2 The Family Network of Les Dawes (3/85)
I began the interview with Marian with the question about helping. She quickly answered, "I never got any help! They're too busy with themselves!"

Figure 7.2 shows a familygram of Les' mother's family of origin representing all the people identified in my interviews with Marian and her two brothers Bob and Clay. The potential resource pool spans three generations to include Marian's mother and her father's brother, Les' great Uncle George and his wife Dotty, Les' uncles and aunts (by marriage), his cousins, and his estranged sister, Marcia. The dates at the stems of the diagram are the years of birth of each person. Note that Tom and his brother Bob share a common stem to indicate they are twins. The mileage given refers to the distance each person or family lives from Les' family.

When There is No Support

What is immediately obvious in the familygram is the greater proportion of males to females in Les' mother's network, the incidence of divorce (indicated by a double slash mark on the connecting lines between Craig and Marian, Bob and his wife, Ed and his second and third wife) and the spacing of Marian's siblings which all contribute to Marian's isolation from her family. Note too, that the maternal grandmother has lived in Florida for over ten years. In the interviews that follow, we will see how lack of family cohesion counteract the positive potential of kin proximity and indirectly relate to the complete lack of services for Les.

Interviewer: What was it like back then? What were the family's reactions to the birth of Les? Were they uncomfortable with him?
Marian: I don't know. They never said anything. ... I wonder if they were uncomfortable. They're wrapped up in themselves.

Interviewer: Being the eldest, you probably did a lot of the caretaking of the boys?

I raised the youngest one. ...

To give you an idea of how it is [i.e., what trying to get some help is like]: I was going to have surgery on my hand on a Thursday, so I called my [youngest] brother. He said he would ask his daughter, Susan. She would have to take two days off from school to watch Les. See my [second] husband worked during the day, so he would have to lose time from work to watch him.

So, things were set. I called my mother in Florida (my mother offered, but I thought she should stay in Florida with my father since he wasn't well) and she said that was ridiculous that Susan would have to travel down [30 miles] and lose schooltime when Mrs. Big Cheese [or words to that effect as Marian referred to her brother Clay, a police officer] lived only five miles away and could easily watch Les since she didn't work or anything!

[Clay and his wife] were over on Sunday from 4 to 9 for a visit. Just on the way out the door, my brother says, "Oh, don't worry about Les, we'll see that he's taken care of. He'll come over to our house." Well she was standing behind him while he was facing me, and she looked over his shoulder and shook her head "No" [Marian mimicked the gesture by sucking in air and tightening her lips] ... From then on, I never asked them for another favor! To this day, my brother doesn't know she did that!

On Wednesday—the day before I was scheduled for the operation—she called me and said her husband was involved with a big murder investigation. She didn't want to miss anything. [I asked: Did she say this?] No, I just read between the lines. See [their town] has two big police cheeses! She's Mrs. Police Cheese! She wouldn't be anything without him! So now I was in trouble. My [youngest] brother wasn't home. His daughter was in school ... so I called my good friend in [another nearby town] ... and she took care of Les. I was supposed to stay in the hospital overnight, but I asked if I could go home. As it was, I wished I'd stayed ... but it worked out okay.

Marian described an incident where Clay's wife did babysit when Les was about 13 or so, before he went to live at LSS. Briefly, Les couldn't stand to watch his aunt spank her younger son and so he ran
away. His aunt couldn't control him. Les showed up in his Aunt's
backyard a few hours later. That was the last time, Marian recalled
her sister-in-law volunteering to provide respite.

Interviewer: Besides your mother and your youngest brother,
did anyone ever offer you help?

Marian: No!

Interviewer: Why do you think that is?

Marian: They're too involved with their own families.
We've never been close, that's all.... Boys tend to lean on
the wife.... They don't reach out to me.... No [last
summer when they came over] they came over to see mother [who was
spending her first summer as a widow with her daughter.] If
she hadn't been here, they wouldn't have come. They don't
come to see me otherwise. They don't offer any help and I'm
stuck with Les. I'd like to get away sometimes.... My mother
has always been my supporter. Mom helped while she lived
here in town.

I asked Marian who influenced her decision to seek Les'
admission to LSS. Marian told me: "My attorney. I was alone. I
worked." I was at loose ends." Marian went on to describe how her
husband had left her to commit adultery with her friend who lives down
the street. "The whole town knew about it but me. I was the last to
know. He was a car salesman, and he'd have 'appointments' in the eve-
nings! You could see his car from the house, parked in her driveway!"

The Maternal Uncles

Tom and Carol Judson live about 23 miles from Les. Of all
their relatives, Tom and Carol say they feel closest to Tom's brother
Clay and Carol's sister, Kitty. They see Clay and his wife Audrey
four or five times a year including Christmas, and Kitty very often.
Kitty lived with their family for a year after Kitty's "difficult
divorce." Now Carol visits Kitty each year in Florida, sometimes
accompanied by Tom. Like Clay and Audrey, Tom and Carol are involved in several activities that have brought them into close companionship with friends rather than relatives. Tom has golf cronies and Carol has her church friends and church-related activities. Tom explained, "I don't really know any of my brothers that well; there's five years difference between all of us, except for my twin brother. . . . When Mom comes home [up from Florida], the kids and their families will go out together. . . ."

When I asked whether Marian did much of the caretaking (in order to test the notion of the overburdened older sister), Tom said emphatically: "No! My Mom never had to work, so the only thing . . . Marian only . . . well, she babysat of course, if they went out in the evening, but my Mom was more of a housewife. She stayed home all the time." Carol remarked, "She's a good mom that way. Not a 'huggy' mom, not that kind of a person, but a good housewife." Carol explained at length that Tom's family was like an iceberg in comparison to her own family. Mealtimes at the Judsons' were solemn and quiet with the business of nourishment an efficient affair. Carol's family, in contrast, enjoyed a family forum at mealtimes, with much laughter and news passed round with the garden peas.

The nature and kind of contact they had with Marian and Les was described in the following way.

Tom: [Reaction to the birth of Les:] We didn't have a reaction really. We didn't know he was a problem 'til we were overseas. . . . I was in the service then; I was away then when he was born. Then we went to England.

Carol: Before I went to England, I lived in [a nearby town within five miles distance]. I used to take care of Les and I taught Marian how to drive. I was over there a couple of times a week. We lived at the base. . . . She didn't like our children. . . .
Carol babysat both Marian's children before Marian knew that Les was developmentally impaired. "He was such a precious baby. . . . She asked me to babysit when we lived at the base." Carol recalled an incident which seemed to curtail further exchange between the two sisters-in-law. Carol referred to herself in the third person,

Les got very upset when his Aunt Carol spanked one of her son's for disobeying her. 'You spank Bruce?' he cried.

After that incident, Marian never asked me again. The same thing happened to Audrey [Clay's wife]. Les took off when she spanked one of her own kids.

Other help this couple knew of came in the form of some money that the elder Judsons gave to Marian's first husband. It wasn't clear whether this was for support of the family or not. Tom remembered that his father's brother once helped. "The year my father died, Marian went down to visit in Florida. Marian left Les with Uncle George and Aunt Lucy (see upper left-hand corner of Figure 7.2), but something happened and Marian had to cut her vacation short."

Carol indicated that Les was used to his mother's assistance in personal hygiene even though he was a grown man and fully capable, in the family's estimation, of grooming himself. Aunt Lucy found the chore repugnant.

This is an example of the structure of the task not matching the structure of the group. The task was too intimate. Litwak has not categorized such tasks specifically, though he does have a "marital" category of household chores, such as laundry. Since this would not be an appropriate term, I offer the term "intimate familial tasks" of which this is an instance.

Whether a family was supportive or not, the relatives I interviewed supplied explanations for the limitations of their involvement.
The Judsons gave an interpretation in keeping with the theory of the Circumplex Model of Olson and McCubbin (Olson, et. al., 1979; Olson and McCubbin, 1982), which states that rigidly disengaged family systems make for poor problem solving.

Tom: You get tired of visiting when all she does is put down other people.

Carol: That's all she does.

Tom: I think it was our upbringing. My parents were very much disciplinary. None of us kids are open to each other or to my mother or to my father. We all are what we are by the way we're brought up. . . . Our deep roots are in our childhood.

Carol: [recalling her visits to Tom's family and the atmosphere at the dinner table]: Rigid. It was so rigid.

Tom: Oh, yeah, it seemed rigid to me. Sterile. [pointing to an object on the coffee table] If that was black and my father said it was white, you said, "Yes, it's white." Oh yeah, I've seen his mistakes and he wouldn't admit they were mistakes. . . . He mellowed a lot when he got older, but I'm talkin' about when we were teenagers. He had a father that was even stricter than he was. . . . Oh, he had a father that if you came through that door five minutes late you got a razor strap.

The couple gave another reason why Marian did not have help. Like brother Clay, this couple was critical of Marian's refusal to use her ex-husband as a resource for help and respite. Tom said, "Through the years she's never asked her ex-husband--you know, the boy's father. He'd be glad to take him. She's so bitter."

Carol admits she doesn't think she and Tom were very supportive of Marian and her situation, but "it wasn't as if we didn't want to be." They referred again to Marian's difficult personality. Tom gave an example: "She absolutely put her foot down that [her second husband] could not go to his father's funeral!!!
A question that I asked all the relatives was: What do you think the disabled person should be doing now? The aim of this question was to discover relatives' views of the disabled person's situation and the kind of current support he/she receives from them. Relatives occupy a midway position between stranger and intimate wherein they are distant enough to objectively identify problems but close enough to evaluate which solutions are most plausible given their understanding of the family's current situation.

Tom: At present, he's fine where he is. He dresses himself, feeds himself and plays by himself. He has duties at home. He knows what to do. They don't have to tell him. When the wood box is empty, he fills it. He brings in all the wood. When the pile [in the cellar] starts gettin' low, Les knows where to bring the wood and he enjoys doing it.

Carol: I would say, the only thing about his being home—it would be nice if he could get with and do things with other people who are like him. I've seen him play basketball. . . . I'm sure he has some kind of dexterity that he could be shown how to use and I think he would probably enjoy it. I think it'd be fun for him to shoot baskets with other people who are like him. Maybe, in his capacity, he doesn't care, but I think it would be fun for him—even just if it were a couple of days a week.

Tom and Carol spoke with obvious admiration of Les' ability to play the organ. I asked them how he came to learn how to play. As if the question had never occurred to them, they chimed together: "Marian, I guess."

As an observer, it seemed to me that the family needed mending. Marian's barbed personality had made even positive recognition of Marian's accomplishments with her disabled son unspoken. It was clear, too, from my further probing, that this couple had thought about the needs of their developmentally disabled nephew, but had decided to steer clear of any action.
Uncle Clay

I interviewed Clay in his office at the police station where he had an important position on the force. This interview was not taped and much of the interview had to be committed to memory because Clay was not comfortable with my taking notes verbatim. He indicated that, as a public figure, he was very sensitive to being quoted.

His view of his sister Marian was one mixed with humor and consternation. Though he and his wife, Audrey, lived only 2 1/2 miles away from Les and his mother, Clay's contacts with his sister and nephew were limited to family gatherings around their mother's visits from Florida.

He recalled the incident when his wife Audrey had babysat Les before Les went to the State School. Les got very upset when he saw Audrey spank their younger son and ran away. The search took all afternoon until Les showed up in the backyard. Marian was unsympathetic to Audrey's situation and further exchanges were brought to a halt.

Clay conveyed the opinion that Marian was an unreasonable woman, jealous, and bitter. Friendly with Marian's ex-husband and his current wife, he could not understand why Marian did not allow Les to visit with his father, which was a normal way to handle relationships among children and their divorced parents. Clay shared Tom's opinion that perhaps Marian was frightened that her ex-husband would alienate Les' affection for her. I did get the sense that Clay had more sympathy for Marian's first husband leaving her for her best friend, than for Marian's being hurt by this man's adultery.
I asked Clay if he had any thoughts about Les' current situation. From his rapid response, it was clear he had thought about this very issue.

If you or I don't send our children to school, the truant officer would be out after them and us! It should be the same with those kids! He should be in school! He could really learn to do so much for himself. I have a friend, whose son, Stan, is at a workshop. His brother, Rocky [also developmentally disabled] works at the ... shipyard. ... Les is like Stan. He could handle a job of some kind. But [Marian] won't let him.

Ironically, Clay is actively involved with the yearly Special Olympics that are held in New Hampshire. "I guess Les has something to do with that. Having him in the family made me see [that mental retardation] can happen to anybody and they should get a chance." I asked if he'd ever invited Les to participate. "Oh, Marian wouldn't let him." Again the reluctance.

**Factors Inhibiting Kin Support**

There are a number of explanations we might consider for the lack of kin support in this family. We could take the theoretical tack of Marian's brother, Tom, and delve into Marian's psychological makeup. However, such complex psychoanalysis should not supercede the taking into account of simpler and more blatant social factors that are operating here.

First, what Tom says about his family does suggest that there were rigid lines of communication which precluded closeness and cooperation. The work of Olson and McCubbin and their colleagues on the Circumflex Model (1979) and the Double ABCX Model (1982), respectively, would certainly illuminate the coping processes here.
Though I have not examined the family to place them in a category to apply these models exactly, the simple self-report that Marian's family of origin was a "rigid" system would be associated in this model with poor problem solving. Second, the fact that Marian names her mother as most supportive is certainly the most frequent response that mothers in general give to a question about who helped them. Third, Marian is the firstborn of five children. Firstborn children tend to act as surrogate parents in large families. The fourth point is that the siblings in this family, with the exception of the twins, are spaced about five years apart. Therapists (e.g., Minuchin, 1974) have reported that when children are spaced four or more years apart, it is as if there are different families consisting of two parents and a single child. This means that each child had a rather separate relationship with his or her parents and a less intimate relationship with siblings, which may have contributed to the failure of the brothers' families to provide a great deal of support to Marian in the way of goods and services.

A fifth factor operating in the case of Marian, is that, not only was the spacing wide between her and her siblings, but these siblings are all brothers. Marian herself offered two explanations inhibiting kin support of her situation. She says, "Boys tend to lean on the wife." Aside from the element of condescension in calling her brothers "boys," there is an element of truth in what Marian says. Men in working class families or men in traditionally structured families, do tend to leave domestic matters to their wives (Komarovsky, 1962; Rubin, 1976; Farber, 1981). A second reason Marian gives is that only when their mother comes up from Florida, do the siblings get
together. The tie between mother and child is the strongest (Fox, 1967). It has already been widely observed that women are still the chief domestic caretakers in American society. Thus it is not surprising that Marian's brothers were not particularly solicitous of their sister. Having to support their own families, they are not in the position to offer respite care themselves, nor can they easily volunteer their wives' support. Litwak has pointed out that in order for women to provide caretaking services outside the nuclear family home, husbands must give their consenting support (1985:162). It may be that when one spouse wants to provide help, the other must give at least tacit agreement, regardless of whether that spouse is husband or wife. Certainly, the requirement of matching task to group structure is not met in Marian's case. At the time Marian needed respite, Marian's brothers' families had similar needs, each family having preschoolers in the home.

There were additional negative forces operating. Chief among them was the stress of a failed marriage. It appears that the relationship was not a good one from the beginning. Both Gath (1978) and Farber (1959) have noted that unstable marriages do not fare well with the introduction of a mentally retarded child. Gath (1978) studied the effects of having a Downs' Syndrome child on the marriages of a matched sample of thirty families. She found that the child was likely to precipitate marital separation among partners whose marriages were already frail. Among strong marriages, the special child served to bring the partners even closer.
In sum, Les' situation illustrates some of the factors which inhibit kin support: 1) paucity of female kin; 2) poor family cohesion in the family of origin; 3) marital instability; and 4) similar developmental stages among families of kin, leaving no kin free to provide material goods and services.

In the next case study, we will look at some of the limitations of the service delivery system. The purpose, in this next section, is to demonstrate, using the principle of matching, how certain types of care can only be met by caring members of the family who are irreplaceable by agency (large organizational) personnel.

GG LAWSON

GG Lawson, age 31, works at a prep school in New Hampshire, about 25 miles from her parents and about an hours' drive from each of two of her sisters. She lives on campus in staff housing which consists of a small dormitory room with space enough for a bed, a dresser, a desk and a chair. There are kitchen facilities and a living room for the common use of resident staff, but these are seldom used. Since there are so few who currently live in the dorm, GG prefers to take her meals in the kitchen, off the main student dining room, among her fellow workers on the kitchen maintenance crew.

At the time of the interview, GG had only been at the prep school two or three weeks after a two-year hiatus of unemployment. She had been living with her parents and her younger brother, Kevin, aged thirteen, with whom she was at odds. Kevin was embarrassed by his obese sister and would tease her about her "slowness." "I know I'm slow," GG explained, "but that's no reason to tease me." She was
clearly still frustrated at the thought of her brother's insensitivity.

GG had other regrets too. Near the end of her ten-year employment at the nursing home, some two years prior to our interview, GG had had a child. She looked down at her fidgeting hands in her lap.

My parents said it would be better to give her up...where she'd have a good home. I couldn't take care of her...I have a boyfriend now. He wants to get married, but I'm taking my time. He was my first friend when I came here. He showed me around so I didn't feel lonely. [At the change of subject, GG perked up.] The kids really like me. I went to one of their dances. Sometimes I go to their basketball games. They always say "Hi GG! Howya doin'?"

Having worked 13 out of the 15 years since being graduated from the vocational program at Crotched Mountain, a residential school in New Hampshire, where she learned housekeeping skills, GG clearly enjoys her independence.

Upon arriving at the prep school, I was impressed with the respect for privacy offered GG. The kitchen supervisor made no inquiry as to my identity. It was sufficient that I had an appointment with GG. The supervisor told GG we could use one of the offices to have our meeting where we "would not be disturbed."

The coded data from the LSS clinical records is bland and imprecise in comparison to a face-to-face interview with GG, who converses with animation and enthusiasm for meeting new people and making friends. She is an affable woman who embraces the truth about herself, her limitations and her accomplishments. Her history reveals how she attained this level of independence and her family's commentary gives us insight into what needs are still to be met.
GG's Background

Geraldine and Dwayne Lawson were 23 and 26, respectively, when their third child, GG was born. GG would be one of six children, four girls and two boys. After GG, there is a five-year gap before the last girl was born, then two years later, a boy and then ten years later, Kevin.

Mrs. Lawson told me when GG was five years old: "In 1958, we took her for a hearing test because she wasn't talking. Mental retardation wasn't even mentioned. . . . In 1960, the teachers said she was 'slow.'" There were many conferences between the parents and the teachers. Though GG had been promoted every year, by the time she had finished the fourth grade, she was "unhappy and lonely." The "social promotions" were not a substitute for the appropriate education GG's parents sought for their daughter.

A doctor, and friend of the family at New Hampshire Hospital, suggested GG be tested. The evaluation at the Child Guidance Clinic resulted in the diagnosis of moderate retardation. Mrs. Lawson recalled in the interview: "'She cannot learn,' they said. 'She is trainable but not educable.'" The advice was to send GG to Laconia State School for training.

GG was almost twelve years old when her father and mother brought her to the administration building of Laconia State School for the first time. Admission was upon the recommendation of the clinic, the school, and as routinely done, ordered by the probate court. Mrs. Lawson told her other children, when they had returned home, that their father had cried in the car on the way home, even though he strongly believed that Laconia was the best place for GG's training.
After several weeks of separation, required by the school, for the purpose of acclimating new residents, the family would come up to visit. GG's eldest sister described GG's program and the family's involvement at the time.

She was moved into this cottage program, which, at the time, was this fantastic program. It was like a home situation. They had nice rooms and they had a dining room like at home and they had house parents and the kids were--it was so different than an institution. It was really a nice set-up and we'd go and visit her on weekends. . . .

When we saw how happy she was--that she was beginning to blossom out there and come into her own, we really felt better about it. You know, I think that was important, that part. And we all went. That was a big thing, to go to Laconia. We'd go up and visit GG. We were very interested in her progress, in how she was doing. . . . Sometimes my Dad wouldn't be able to go because he was working, but my Mom would go and all of us kids that were home. There were six of us and we were all like this [clasps hands together tightly]. Lots of times my grandmother would go. And we'd take a picnic lunch and we'd go up, pick up GG, and go out for the day. Or we'd bring her home. She got to the point she could come home on weekends.

I'd say [we went up] at least 2 or 3 weekends a month. We went up quite frequently in the beginning 'cause she really needed that; she really needed family contact.

After five years at Laconia, when GG was almost seventeen, arrangements were made for GG to participate in a residential vocational program in housekeeping skills at Crotched Mountain. The program would not start until the fall of 1971, so for the summer months, GG spent a vacation at home, her first community placement from the institution. The two sisters whom I interviewed remembered enjoying GG when she was home. Her being home was not treated as anything unusual. GG was home from school "just like the rest of the kids."

Mrs. Lawson was very pleased with the training her daughter received at Crotched Mountain--excellent personal attention, guidance
**Figure 7.3 The Family Network of GG Lawson (2/6/85)**
and training which launched GG into an independent life where she was self-supporting. The culmination of the program was a job placement. GG only waited home a month before she was placed at the Clover Nursing Home where she lived and worked for ten years. Her mother commented with pride on GG's industriousness, "She's a good worker. She'll do things that a lot of people won't do."

[As an incidental, after GG had already been working for several months, she was officially discharged from LSS on January 10th, 1973. It was the usual procedure in those days to keep a slot open.]

GG's Grandmothers

During the two-year gap between the nursing home position and her current employment at the prep school, GG played a key role in her family. When her paternal grandmother ("Granny," in Figure 7.3) became ill and housebound, GG became the mainstay. She took care of her grandmother, making sure she took her medicine at the appointed times, prepared meals, did laundry and kept her company in the last months of her life. GG's mother and sisters told me about GG's relationships with her grandmothers and remembered GG's courage and fortitude with a deep sense of gratitude and pride.

Valerie is GG's eldest sister and the firstborn of six children. I asked Valerie in several instances throughout our interview, to talk about how members of the family viewed and treated GG in order to discern how supportive this family was toward GG herself and toward her parents. Valerie recalled:
Oh, I could always remember from the time [GG] was a little girl... she was always special to [paternal] Grandma. Granny just always seemed to be very protective of her... [S]he just had this special thing about GG and encouraged her to act like anyone else. She always made her feel like she could do anything she wanted to, that she was good at a lot of things, and never really treated her like she was different, like she was retarded... [S]he wanted her to be herself and to be happy.

Interviewer: Do you think that your grandmother's attitude toward GG had any influence upon anybody else in the family?

Valerie: Oh, yes. Maybe not consciously, but I think we all--I think a lot of it has to do with my parents, though, too. GG was always included in everything... from the time we were little kids... I think the first time I really realized that she was different was when she had to go to Laconia for training... I thought more about... how difficult it was for my mother. 'Cause it was a terrible time for my mother and father, when she was committed to Laconia... They just didn't want to leave her there. I remember them coming home. We didn't go with them. When they came home, my father and mother were very, very upset. My mother said that Daddy cried in the car on the way home...

Interviewer: Let's see now, who were the relatives that gave help at that time?

Valerie: I would say my parents were pretty much on their own. Of course, my [paternal] grandmother [who lived next door] and Don [unmarried brother of GG's father]--they had GG visit a lot and they were very interested in how she was doing and would write to her [at Laconia and at Crotched Mountain]... Of course, my mother's mother was alive then... and my grandfather. They... were very interested in how things were going.

[I asked whether Valerie, as the oldest sibling, was burdened with the care of her retarded sister.]

Valerie: Well, I was the oldest so I got stuck babysitting anyways when there was any babysitting. But, say, to stay home for GG, that wasn't it, no. When they were young enough to be babysat and I was old enough to do it then I was the one elected to do it... Being the oldest is just a fact of life. [chuckles.]

Sisters

Though my questions were directed toward information about the kinds of support the family received with regard to their "disabled"
daughter, much of what I was told was about the kinds of support GG herself was able to give to her family. I asked Valerie to tell me who were the main supports currently and she told me the following:

Well . . . she's pretty self-sufficient at this point . . . . It still is always my parents [who have taken care of her] financially. . . . My husband and I bought her a pair of glasses one time but that was because she was here and had helped me out and needed a hundred dollars for glasses . . . . She was here, oh, a good three months . . . . I was in the hospital for 3 1/2 weeks [with back problems]. And then I was home and couldn't do any housework. She was here. She was out of work and came down and took right over. My husband and her get along fine. So she did okay.

[I asked about GG's effects upon friends and visitors.]

I always thought she was an indication of boyfriends—you know, my husband—the way they acted with GG. All of us girls have always thought that. . . . That was the kind of tipoff, if they were of good character—if they took to GG right away—you know, gave her a hug and acted like she was just like anybody else.

[Interviewer: If they were kind to her, then you knew?] Right, then we knew they were okay and that's true 'cause both our—all of the in-laws are the same way. They all love GG and are good to her.

The Family and the State

The question I am raising in this section is: How well equipped is the State (i.e., the service delivery system) to deal with the kinds of problems that arise in the daily life of a mildly retarded person, such as GG? If normalization goals are to be met, problems, like the ones to be described here, will indeed arise. I am suggesting that the difficulties and subtleties of maintaining a balance between freedom and discipline cannot be as easily accomplished by State personnel as by members of a person's family. In sum, I am saying that the goals of normalization can best be met by
a great deal of family involvement and I am asking the reader to consider whether this is true in light of the case presented here.

Though GG is self-sufficient and described as "fiercely independent," there remains considerable concern among family members for GG's need for continued guidance and socialization.

Adulthood carries with it outward trappings that are mistakenly equated with maturity which are often embraced by the naive and untutored. Anxious to "pass," GG has been vulnerable to people who would take advantage of her. "She fell into the wrong crowd," her sisters told me. GG's younger sister, Corey, recalled with good humor, an incident which brings to light GG's ever-present need for guidance.

Having relocated to a higher managerial position in Manchester, and having been recently divorced, Corey Lawson became GG's roommate at the nursing home, where GG lived and worked. Corey was then able to observe more closely the complications of GG's friendships. Arriving home before GG one day, Corey noticed a bill from Visa/Mastercard addressed to her sister.

Corey: I found a Mastercard bill in the mail addressed to her and I opened it which I normally would not have done, except that I knew that this was serious business. . . . She had $800 worth of bills racked up on it! . . . And I said, "How did you get this card?" She said, "I went down and they gave it to me." Because in her mind, that's how easy it was. And after talking with the bank, it was just about that easy!

I explained to the credit manager, "I don't know how she got this card. The only thing that's her writing on this application is her signature." And he said, "Well, a lot of people don't write that well and they have the girls make them out. . . ." I [asked], "What did you use for credit references?" And they had used a corner market that she had used to charge stuff at. And I just looked at him and said, "That's all it takes?" And he said, "Well, she's been at her job for
seven years."

... I said "That's enough?... [Y]ou work at a job where... you probably make just the cost of living increase every year for a pay raise and you have [credit at] a corner market that probably keeps their accounts on the back of a brown paper bag and you take that as... someone who is good to dish out a credit card to... I'll be in touch with you. In the meantime, don't give her a loan or anything."

Corey concluded that GG's "friends" had "helped" GG enjoy her Mastercard privileges because most of the bills were from restaurants and bars. The Lawsons' major criticism of the service delivery system could be summarized as "a lack of follow-up care." Mrs. Lawson complained, "the case management system dropped her at age 18. She had a lot of social problems that she needed guidance on. She received no aid from anybody after she left LSS."

The Deinstitutionalization-Communitization Gap

It is generally acknowledged that deinstitutionalization has been successful in reducing the populations of large institutions (e.g., Conroy, 1985). The problem lies in the fact that only half the battle is won. One cannot simply have a goal of getting away from a noxious situation; one must also have a goal toward a more favorable situation. In this case, the twofold goal is to leave behind the isolated life in a total institution and move toward a life in the community. Often to reach this goal, intermediate steps of training and supervision are required to make the smooth transition. The chief complaint of GG's family was that there was, and continues to be, a gap between deinstitutionalization and communitization.

In hindsight, after the traumatic events of GG's pregnancy and the resulting adoption and subsequent sterilization to which GG agreed, Mrs. Lawson "went to every agency. I'm so disgusted with our region."
They are worthless. They need more half-way houses where they have someone they can turn to." GG's mother was referring to her own tireless efforts to find GG another job where she would be safe as well as self-supporting and productive. She found the prep school through her own research.

The family is delighted with GG's new job at the prep school. Knowing that the schoolmaster has hired other ex-residents of Laconia State School, assures the Lawsons that GG will be given patient understanding. However, there are still major concerns that seem to be neglected by the service delivery system.

Mr. and Mrs. Lawson have had to bear all GG's expenses when GG left the nursing home. During that time, they picked up her medical treatments, dental bills, glasses and insurance, and fought the bank over the credit card incident. They do not believe case workers are competent, nor are the Lawsons optimistic with regard to the funding of community programs. They complain that there is no group home in the town where they live, so when GG left the nursing home, she had to return home rather than live semi-independently while between jobs.

As demonstrated in Chapter 4, among all the families of dependent adult children, there is a concern for their welfare once the parents die. The Lawsons are no exception.

Valerie: My mother and I talk about GG a lot, because my mother worries about when they die what's going to happen to GG. 'Course I have reassured her that I would be here to oversee her, help her out. But I think that . . . we feel that there's been some regression on GG's part because of different events in her life and stuff.

Valerie had already described what she meant by "stuff," when she told me about some particular difficulties GG still has, areas
requiring further socialization, that the family seems to have some reluctance in addressing.

Her hygiene was one thing she had trouble with; she had to be reminded of that. . . . You had to make sure that she was safe. . . . Now I notice as she gets older it's more noticeable now--to me it is. She regresses more.

Interviewer: You think it's because you're still maturing and she's not, maybe?

Valerie: That could be. You begin to see that you have your own life and your children and she still is kinda where she was. . . . That may be part of it. . . . She wants to be her own person. But at the same time she can do things that can really be upsetting to you. For one thing she distorts the truth terribly. . . . And another thing is that she is very nosey. She's right there all the time. . . .

When she was staying here, she was coming down in the morning and telling John [husband] that she knew that we had . . . you know . . . . Oh, well [smiles] you know and make a little comment. And my husband would get beet red. It's the kind of thing she picks right up on, but she says it right out, ya know? So you're embarrassed and you say, "Now GG" and you kinda kid it off but if you live with it long enough like that--

This family's chief complaint is that currently, GG has no person in the service delivery system who is overseeing GG's situation. They complain that 1) GG received no follow-up care from the institution. At the time GG left LSS, there was a program nominally set up to take care of follow-up, but this family reports they were not helped by this "supposed" program. They further complained: 2) The case management system was not able to help find employment for GG, the way Crotched Mountain did; and 3) that there is no group home available for GG with a houseparent who can make sure GG keeps track of her paychecks and makes friends appropriately.
GG's sister, Corey, summarized the family's assessment of GG's current needs this way:

The ultimate, deluxe situation would be that she could live alone or . . . with . . . other individuals a lot like herself and have someone that . . . that could check in on her periodically. Somebody that she would trust to talk to . . . somebody that would make sure that she was getting along well financially. See, the thing is with GG is that--that sounds like it's . . . it's . . . in some ways, it might sound like it's a shuckoff to somebody else--let somebody else worry about [her]--but GG, I think, gets resentful with us as a family because she thinks we're interfering . . . so if she had an impartial type of person . . . a mature person . . .

Here we see a dilemma. The principle of matching states that tasks that require long-term commitment are idiosyncratic and are best handled by primary groups. The question that this situation presents is: Would a practitioner, generally trained to be non-judgmental, exercise the kind of authority that Corey assumes? In the next breath, Corey demonstrates her unique position as a family member to deal with her sister's situation.

She might say that when she was [living in the other town, in the nursing home] running with a loose crowd, that she was happy, but she wasn't. You know, I could tell that. There was something in her voice, in the way she acted. She just wasn't happy. And now she is. She's got a life. She's got something she can talk about. She's saving money. She just feels a lot better about herself and that's really important. And I don't think she should be shunted away to some corner of the world where you put these people together.

Corey states, "I could tell . . . there was something in her voice, in the way she acted." It is this kind of data which comes from a long-term relationship and which cannot easily be comprehended by professional intervention; this kind of intervention also cannot be easily routinized.
The principle of normalization wears thin at the point where personal moral decisions need to be made. Since the State is not in the business of legislating morality, it is difficult to formulate policy in which service providers can make choices for their clients with regard to their friends and companions, even if they have strong personal opinions. For example, would a service provider have the right to dictate to GG with whom she should spend her time? Corey made a controlling move that was tactically expedient and efficient. As Caplan (1976) has pointed out, families are judgmental and thereby exercise social control. However, GG's family is ambivalent about their role with regard to GG's sexual activity. Should they try to influence GG with regard to further sex education or is there some professional who can take over for them? Though gradually schools are taking over this function (for good or ill is an empirical question), parents are still the role models for their children. This is a gray area and the problem of sexuality among developmentally disabled people is unresolved. This is only an example of the larger problem of definition of what large organizations are equipped to handle.

Both families and professionals need to know the limits of the service delivery system in order to better define their respective roles toward each other and with regard to dependent persons. The understanding of the principle of matching will contribute greatly to the development of shared responsibility.

Discussion

All the case studies presented in this chapter illustrate the various types of relationships handicapped families can have with the State. The Bonaventures illustrate how shared responsibility can work.
Les’ family illustrates how a lack of case finding on the part of the community service delivery system and the lack of follow-up from the institution, in interaction with a lack of kin support, result in no involvement on the part of the State. GG’s family illustrates the need to better define what the State can handle, what it cannot handle, and what is best left to families.

These case studies illustrate the several characteristics and processes which determine the amount and type of kin involvement in the care of developmentally disabled children: The role of women, the developmental stages of nuclear families in the network, Litwak’s principle of matching, and how families and professionals can potentially enhance one another’s roles. These issues will be discussed in relation to various relatives who are potential helpers in the network.

Grandmothers

Anthropologists have observed that the mother-child dyad is the fundamental unit of culture (Fox, 1967). That there is a "matrilateral bias" (Yanagisako, 1977) among kin in American industrial society, there is no doubt (Komarovsky, 1962, Rubin, 1976; Litwak, 1985). Not only does this bias apply to women, but it applies to their husbands as well. Husbands are more likely to spend time with their in-laws, fathers- and brothers-in-law, than their own fathers and brothers.

Yanagisako (1977) has made some interesting arguments as to why this is so. She gives four reasons: 1) there is a decline of family-based entrepreneurial enterprises; 2) families live in nuclear units and neolocally; 3) men, in this nuclear arrangement, are inhibited
from building ties because the new norms dictate that they must now be independent of their families of origin in order to demonstrate their ability to function in the breadwinner role; and 4) women are (sic) left to maintain the family connections.

Komarovsky points out that there is a stated cultural belief that ties are bilateral, but families also hold a norm of matrilateral bias that is practiced. Husbands, in her study, stated it was "natural to go with the wife's family" (1962:246). However, this bias has its limits. Bott, in her review of her work (1971), notes Bell's finding that financial aid flows from fathers-in-law and fathers to sons and sons-in-law. Bott suggests that, "Perhaps women arrange the visits and certain minor types of mutual aid, but when large sums of money are involved, the men take over" (1971:261). She further observes that "gifts are asked for and given, however, with great subtlety so as not to infringe upon the ideology of independence for each elementary family" (Ibid.). In this present study, we observed this phenomenon in the Bonaventure family. The paternal grandmother whispered that she and her husband provided money to their son for their granddaughter's surgery. The whisper was evidence of the need to preserve the ideology of independence.

In this study we find that grandmothers stated that their involvement tended to be most active in the child's early years. These findings corroborate those of Komarovsky (1962) and, more currently, the findings of Sonnek (1986). Generally, grandmothers are more likely to have reached the stage in the developmental cycle where their own children are independent, yet they are young enough to enjoy their grandchildren. However, we see that when they still have their
own young children to care for, their involvement will be attenuated.

When it comes to actual exchange of goods and services, we can expect that maternal grandmothers are more likely to provide assistance than paternal grandmothers. At the outset, we saw that among Stayers' families paternal grandparents were about as equally cited as supportive as maternal grandparents. There are a couple of explanations that may be tenable. First, because most of the Stayers were still in the institution at the time of the interview, it may be that the mothers were referring to social support in the main. Second, as we learned in Chapter 3 these families were generally of a higher socioeconomic status. Where social mobility is highly valued, there is a greater concern for the other siblings' career development, not to mention that of the father. Where there is greater expectation for the father to succeed, his parents may have more contact with his family (Kennedy and Stokes, 1982).

Aunts and Uncles

Aunts and uncles may be able to provide occasional respite, as we saw in the case of Cheryl, mainly because they were teenagers at the time babysitting was needed. More usually, however, they are founding their own families and so are less able to assist. In Les' family, the two uncles interviewed were viewed as "making things worse" by Les' mother. Since caregiving is a female role, for sisters-in-law to provide respite or other helps, a good relationship with one's brother would be necessary but not sufficient. The one brother whom Marian felt she could draw upon would have provided caretaking through his daughter. This is not to say that brothers are not able to be social
supports. It is a matter of empirical investigation to discover when brothers do become involved, since generally their provider role in their own nuclear families would conflict with giving direct services, but not monetary aid or support through their wives. We saw, in Les’ case, that there were too many factors working against his uncles’ support. In Bott’s terms, there was a lack of connectedness among kin (i.e., communication among the rest of the network and not just with the focal family). Visits were relegated to a few occasions in the year and centered around the maternal grandmother.

Sisters

Sisters, especially older sisters, are most easily co-opted into the surrogate parent role on a routine basis since they live in the household and because they are in training for the caretaker role. There is some evidence that eldest sisters are at risk for poor psychological adjustment if overburdened by the caretaker role (Featherstone, 1980; Mori, 1983). In one family I interviewed at length, an eldest sister of six children, the last two of whom are severely retarded, described her life fraught with great concern for her siblings, their placement and treatment. This woman was in great turmoil because she was not able to develop her own career. Every crisis having to do with her handicapped sisters dictated her turning away from her own developmental issues.

GG’s family is an illustration of how positive support from grandparents, siblings, and good services during her early years, as well as an optimistic definition of the situation, provided a healthy atmosphere in which family members shared responsibility for GG, so
that the eldest sister was not overburdened. The eldest sister learned early in life to appreciate the uniqueness of her special sister and took in stride the fact that, as the eldest, she would be the babysitter. The younger sister, too, though quite busy with her career, and her own personal difficulties, was able to provide guidance when GG needed it most. Of course it will be remembered that GG's disabilities are mild. Turnbull, et. al., (1985) have strongly advised that differences between levels of retardation must not be overlooked. Each level brings with it unique challenges and difficulties and the degree of the disability calls for different sets and amounts of resources. These differences, however, should not overshadow the fact that similarities outweigh the differences.

Fathers

The role of fathers may be typified by GG's sister Valerie's observation:

My mother's really been the one who's handled all this, too. My Dad's not really a big support system in that he never has been with GG. He's a good man and I know he loves her. He's a provider, but he's never been one to help my mother get through all of this, and do all this. He's not that type of person.

Nevertheless, the provider role cannot be underestimated. Penny Bonaventure's description of her husband Jason's 15-hour day was given with a great deal of respect for her husband's sacrifice. Recall that it was the mothers of Leavers who voluntarily praised their husbands' support while none of the mothers of Stayers voluntarily mentioned their husbands. This suggests that children are more likely to receive services in the community if fathers are supportive and involved in making plans for their children. In Nemzoff's study
five of the ten fathers had a regularly scheduled time of "babysitting" with their special children; the rest "babysat" sporadically. The main roles these fathers played were in taking the children on outings and in the financial and educational planning for their children's futures, the traditional role of the provider.

**Support from Other Primary Groups**

In a pilot study of ten mothers of mentally retarded children, Nemzoff (1979) found that of all the primary groups, female relatives, chiefly grandmothers, provided respite care (no distinction was made between whether the grandmothers were paternal or maternal). In only one instance did a mother receive respite care from a neighbor or a friend. In the main, non-relatives provided occasional supervision of the child. The mothers in Nemzoff's sample expressed concern that respite care, for the most part, was an imposition upon neighbors and friends, i.e., these primary groups were not matched to the task. In the case of Les' mother, we saw how Marian only called her friend as a last resort and curtailed her time of recuperation from the operation on her hand to an afternoon rather than 24 hours because she too did not want to impose on her friend. This finding is consistent with those of Litwak and Szelenyi (1968), that only when relatives are unavailable are friends and neighbors called upon; this was especially true of their rural sample.

**Summary**

In this chapter, we examined the processes that guide and inhibit kin involvement in the lives of handicapped children and their
families. We saw that, where there was a great deal of kin support, the handicapped persons, regardless of their level of retardation, were well on their way toward integration into the community. One person has begun living in a shared home and another is living and working at a prep school. We saw, too, that a family where the mother received minimal support, the handicapped person lived an isolated life at home.

Using the principle of matching in conjunction with the principle of normalization, I tried to show the limitations of the service delivery system. In the next and final chapter, I will discuss how knowledge and understanding of these limitations can serve to define a relationship of shared responsibility between the family and the State and the resulting policy and programming implications.
Initially, in this research, I set out to discover the influence of kin involvement in the care and treatment outcomes of a New Hampshire sample of handicapped children selected for their eligibility for educational services as a result of P.L.94-142. As do many research novitiates of sociology, I learned that the question I was asking was embedded in a history influenced by social movements, progressing for more than a century, influenced by personages and personalities, and that the original scope had to be broadened to encompass the context. What has emerged, therefore, is a three-pronged approach to the problem of communitization, namely, historical changes in attitudes toward deinstitutionalization and current correlates of successful placement, and kin support.

An Hypothetical Model of Communitization

Figure 8.1 illustrates how the variables we have been considering in this study may interact and influence communitization. What makes the future testing of this model challenging is that we must take into account macro and micro variables simultaneously in order to predict successful communitization. This is realistic because this is precisely the task of families, practitioners, and policymakers alike. This figure represents only one of the myriad permutations of this constellation of variables and is presented here in order to summarize the implications of this study.
Figure 8.1 Hypothetical Model of Communitization
Communitization is a unifying concept representing a large number of processes that must take place for handicapped people to truly participate in community life. I have stated that communitization is the logical next step beyond deinstitutionalization. It is more than that. Deinstitutionalization really only affects 5% of the 3% of the United States population who are handicapped. Communitization affects every one of the 3%! Just because a handicapped child lives in the community and has never lived in an institution does not necessarily mean she/he is fully a part of the community. This is why we must continue to strive for more adequate models of communitization.

If we think of the model as a system, it can be seen that when one element fails, or is less than optimal, other elements must compensate. This is basically the notion of shared responsibility. The large question mark in Figure 8.1 represents the intermediate variable(s) that are directly effected by Kin Support and DI Attitudes. The relationships among these variables and others implicit in the model, will be discussed further in subsequent sections. The implications of the findings of this study will also be discussed along the way, followed by the conclusion.

Attitudes

Attitudes toward deinstitutionalization have changed over the years. These changes have been brought about by professionals and parents who have had the courage to fight the many battles in their communities and in the courts. We have seen how a change in policy can dramatically influence people's points of view with regard to community placement. This is why Social Policy appears antecedent to
Attitudes Toward Deinstitutionalization in the model (see figure), even though the relationship is clearly bidirectional over historical time. To repeat, these attitudes are strongly influenced by practical considerations. Philosophy is not a substitute for services in the community. Skepticism remains well-founded. Though policy is in place, implementation remains incomplete. Parents of more severely handicapped children are worried about services. This is especially true when intensive one-to-one care is required. This concern also continues to be the major barrier to closing large state institutions such as Laconia State School and Training Center in New Hampshire. Parents expressed concern about sustained community support and continuity of care over the lifetime of their children. At least to some extent, this is more a matter of staff ratios and professional expertise and not a matter of geographic location nor size of the building. However, we must remain cognizant of the limitations of substitutive care.

Correlates of Successful Community Placement and Kin Support

When it comes to successful placement, there are those who fare better than others. It was found that the characteristic of families' socioeconomic status seemed to help. On the other hand, fathers' presence in the home at the time of placement seemed to have a conservative influence upon placement outcomes suggesting that fathers are likely to be more critical of their childrens' situations. I see this influence as a necessary check on the service delivery system. Every public agency should be, and must be, subject to the scrutiny of the public it is intended to serve.
Successful placement is also positively correlated with a rati-
ification of deinstitutionalization/normalization philosophy, hence the
indication of a direct effect in Figure 8.1. This ideological
adherence is, in turn, was highly correlated with confidence that the
needed services are available in the community.

A serendipitous finding, for the benefit of practitioners,
should be mentioned because it has significance for the continuance of
these needed services. If service providers feel unappreciated, it
may be because they do not ask the recipients of their services for
feedback often enough. Good services and training are appreciated.
When parents were asked what contributed to their children's progress,
most often trainers, therapists, and teachers were cited as playing a
major role in the children's growth and development. The dedication
of these people who do make a difference should be rewarded—not only
with a "decent" salary, often too low—but with on-the-job recogni-
tion, and tools to continue upgrading their performance, skills and
knowledge. The goal is to reduce staff turnover. These are community
variables, which are also candidates for the box marked with a
question mark having a direct influence upon communitization success.

Recall that successful placement was operationally defined by
five criteria based on the principle of normalization: staying in the
community; not returning to the institution; living in a residence
with only a few other people (4 or 5 being optimal); attending and
remaining in an educational program. It was pointed out that a
serious deficit in this definition was the lack of a measure of the
disabled person's own satisfaction with the community placement. With
new methods being developed to better communicate with and learn the
desires of mentally retarded people (Sigelman, et al., 1983), this variable can and should be included in future research and policy-making.

Successful placement was not significantly influenced by kin support in the regression models. It was concluded that, since success was operationalized in terms of large organizational variables, there was a "mismatch" between kin support and the measures of the child's care. In this light, it was not surprising that the most significant variables influencing outcomes were ones that had to do with parents' belief in normalization principles and their confidence that community services are secure, permanent, professional and available for their children. However, there may be indirect effects of kin support upon parents' problem solving and coping skills which were not measured.

The families in this study showed that, even though the child's diagnosis varied, successful placement had more to do with mother's motivation and persistent pursuit of services, whether within the service delivery system or in the community at large. Case material suggested that kin support has an indirect influence upon placement outcomes. The two families (the Bonaventures and the Lawsons) who did manifest a high degree of cohesion and involvement did seem to provide the means of motivating the handicapped family, especially the mother, to obtain services.

The box with the question mark in Figure 8.1 may also represent the array of variables which are directly influenced by kin support. Possible candidates are mother's or family's confidence in her ability to problem solve and develop coping strategies, the family's sense of
isolation or connectedness with the community at-large, or courage to face one's neighbors and encourage their acceptance of one's child.

**Kin Support, Its Nature and Correlates**

The fact that families of Leavers reported that their immediate families (i.e., nuclear) were most helpful, even though a majority did say that their extended kin were extremely supportive, suggests that key elements in the nature of support must be measured in order to better define the process of support. For example a particularly important variable made plain in the case studies, is proximity. In order for kin to provide respite care, close proximity is essential. This variable can easily be included in large surveys in future research and is also a simple device for practitioners to assess the potential resources of their clients.

Another measure of kin support which needs to be considered in future research is the nature of the support supplied, whether it is in the form of goods and services, telephone calls, letters, money, etc.

**Child's Characteristics.** There are seeming inconsistencies in the results of this study. As pointed out above, the regression model suggests that kin support does not influence residential and educational outcomes of disabled persons. On the other hand, we see that the majority of parents reported that kin were very supportive and helpful with regard to their handicapped children. However, the regression model also suggested that the greater the child's impairment, as indicated by diagnosis, the less kin support. Does this mean that kin tend to abandon the families with the greatest hardship as one would abandon a sinking ship.
With greater medical and behavioral problems, kin, as a primary group, may be less able to cope with the child. Litwak has shown, in studying the elderly, that, when there are more medical problems, proximity becomes increasingly important if involvement is to be sustained by kin. Since proximity was not a control variable in this present study, it is not possible to tease out exactly why severity of diagnosis does affect kin support. It could be that, with the greater need for professional intervention, kin recede into the background. It was suggested, in light of the findings of Emerson (1966), that, in extreme conditions, people tend to remain hopeful of reaching their goals if the outcome remains uncertain. In other words, if there remains a possibility that one's actions will make a positive difference toward reaching a desired goal, one will likely continue to problem solve.

Several parents stated that their relatives simply did not understand the needs of their children. They suggested that if their relatives had more information about the disability and about their children's medical and behavioral difficulties, they would not feel so helpless. This should further encourage practitioners to include extended family members in their orientation groups for parents, in order to develop resource networks that parents can rely on to give them help along the way.

If kin are educated about how their support can make a difference, even when the child is very retarded, their involvement may be maintained. It is perhaps when kin believe there is no hope, that they withdraw from helping. The basis of this hope is a fundamental question and requisite to our complete understanding of kin support.
For example, in the case of profound retardation, the family's definition of personhood is more greatly put to the test. There are families who have been able to demonstrate the intrinsic value of a human being above and beyond intelligence or the ability to make an economic contribution. The Rossows have been recognized as exemplary in this regard and have received national commendation (see, e.g., Caldwell, 1985).

**Gender.** Analysis of the effect of gender on kin support revealed an interaction effect of fathers and handicapped sons which dampened kin involvement. It was speculated that this outcome had to do with sons' inability to meet fathers' expectations with regard to the masculine role. This possible disappointment may, in turn, have affected kin attitudes and involvement. Recalling our discussion in Chapter 5, we know that when men define their roles more broadly—i.e., serving varying levels of both instrumental and affective functions—their place in the family is more secure and viable.

Possible interventions in families with handicapped boys, then, might include helping fathers to expand their definitions of the masculine role that their sons might play. Programming for handicapped males should not therefore, have a unitary vocational focus, but include avocational foci, such as art, music, animal care, domestic arts (e.g., cooking), team and individual sports and hobbies, in order to discover and develop boy's talents and abilities. I do not advocate here the usual routinized program of activities and therapies which, all too often, decay into meaningless busywork or glorified babysitting, but I advocate a means of exploring what may become interests which a particular man will actively pursue for himself.
Though I have argued that women are the main caregivers, there is evidence that men supply other forms of support. In other words, men and women provide different types of support. Another word with regard to fathers is thus in order. Though fathers have a conservative influence, it must be reiterated that mothers of Leavers voluntarily praised their husbands for their support whereas none of the Stayers' mothers indicated such satisfaction. The in-depth interviews suggest that children are more likely to receive services in the community if fathers are supportive and involved in planning for their children's future. Recall the instance of Cheryl's father who travelled long distances to work rather than move his daughter out of a community that was superior in its service delivery system--one that his wife is working to improve. Men's support, thus, tends to be indirect, financial and advisory. Men are "silent partners" in this enterprise of support. There is also some evidence in this study that fathers tend to show greater resistance to deinstitutionalization, not because they are opposed to it, but because they require convincing evidence that services are available in the community. Women's support tends to be in the form of direct care. This should not be taken to mean the support can be measured by an objective yardstick, scale, or clock. An essential feature of support is the family's perception and knowledge that it is there.

Developmental Cycle and Family Values. The case studies showed that a number of factors are salient in the process of kin support: the number of females in the kin pool; the stability of marriage; family values of helping which contribute to family cohesion and
connectedness. It became apparent in these studies that the developmental cycle of the families in the network was important in releasing women for additional caregiving to the family. That female relatives are the greatest source of help has been shown by other researchers (Suelzle and Keenan, Gath, Farber, Nemzoff, Litwak, Sonnek) and is confirmed here. It was found that grandmothers were especially prominent in giving assistance. It was argued that grandmothers are also the most likely candidates because they are at a point in their family developmental cycle where they are freed from their own caregiving responsibilities in their own nuclear families.

The family values of cooperation and affection served to provide an emotional cushion for mothers caring for their handicapped children. These values flourish in this particular sample in which Franco-Americans are highly represented and where the values of church and family are emphasized. We saw, too, that these families tend to live near each other, having relatives within the bounds of New Hampshire. Thus kin support, for this small sample reflected ethnic, religious, class and rural ways of life which tend to promote mutual caring and accountability. New Hampshire especially is comparatively rural with respect to Boston or New York and thus there is still the effect of small town life—being one "brother's keeper." We saw too, how a lack of social support, in the face of kin proximity, to the point of social derision, in the case of Less's mother, served to further isolate this mother and son.

Year of Placement. The historical context of any study should be taken into account. It was found that the later the year of placement, the more support. (Year of Placement could be represented by
Social Policy in Figure 8.1, e.g., the enactment of P.L. 94-142). All the relatives who were interviewed ratified the concepts of normalization. Even though some did not immediately recognize the terms, once defined, relatives were in favor of such concepts as the least restrictive alternative, normalization, and deinstitutionalization. This was true of grandparents, uncles and sisters—in other words, three generations of persons showed awareness and support of these ideas.

In sum, exchanges of social support and material support are influenced by proximity, the size of the resource pool (relatives, friends and neighbors), the socioeconomic status of kin, family values, the number of women in the extended family (especially whether grandmothers are alive and willing to help) and finally the types of services available in the community.

Handicapped Families and the State:
Implications for Social Policy

The tasks of handicapped families are not fundamentally different from those of other families. All families are responsible for the intellectual, spiritual, and healthful growth of their members, adults as well as children. The major difference is not, then, of kind, but of quantity. The tasks extend over longer time periods because of developmental lags due to the children's impairments.

It should be pointed out that not all impairments lead to disability. The purpose of treatment is to reduce the impact of impairments so that potential disabilities may be curtailed to handicaps and handicaps may be circumvented wherever possible. Thus, there is a continuum from impairment to disability that is often overlooked and
the terms are mistakenly used interchangeably by the lay public. Impairment refers to the actual, physical, chemical, and/or emotional aberration which is measured by diagnostic procedures. The American Association on Mental Deficiency (AAMD) has developed diagnostic categories intended to cover the entire continuum of developmental impairments. Disability is the term applied to the resultant dysfunction from the impairment, whereby the individual is unable to perform certain tasks due to impairment. For example, without training, a person who is born blind is unable to walk safely down a city street. However, with training the individual can manage to navigate, though not as well as sighted persons. In this latter instance, the person is said to be handicapped, but not disabled. The purpose of education and training is to reduce the probability of disability and to minimize the impact of an impairment to a manageable handicap, tightening the boundaries of the handicapping condition, so that the individual is liberated to independent functioning as much as possible.

This discussion is based on the premise that persons at the extremes of the normal curve of human growth and development are on the same continuum as those in the middle and should be viewed as such as far as social and family policy are concerned.

As I have tried to show in the outline of the history of the deinstitutionalization movement (Chapters 1 and 4), policy toward disabled persons has gradually shifted toward a view that people with impairments should have increased chances for improvement with increased opportunities to develop in normal environments. Underlying this principle of normalization, is the notion that emphasizing similarities of disabled persons to non-disabled persons is a more
fruitful approach to the reduction of disability than emphasizing differences. Furthermore, treatment approaches are gradually shifting from a focus on the disabled individual to the individual in the family context. This present study goes a step further in providing evidence for the inclusion of the extended kin network to widen the scope of resources for the family in need of services. I believe that the case material, presented in Chapter 7, shows that the network is the interface between the family and the public and that it provides a transitional structure for smoothing the path for the integration of the disabled person into the community.

What I believe the present study shows is that there is a necessity to move beyond the concept of normalization, which provides for the equal opportunity of all persons regardless of impairment, handicap or disability (and the value of individual uniqueness above and beyond the stigma of the outward signs of impairment, yet without ignoring special needs due to that impairment) and move to the concept of communitization which focuses on equality of outcomes. If we view persons with impairments as persons so different from the rest of society, then they are isolated from that society. If we view them as similar to the rest of society, we will develop compensatory schemes in order for them to remain and take part in the community. Paradoxically, such compensation, by its very nature, requires the recognition of differences. The approach should be intelligent and devoid of sentimentality.

Communitization

In this section, we will deal with many of the variables in our model appearing in Figure 8.1. The relationships among these
variables are assumed to be multi-directional. For purposes of discussion, we might reduce the model to an equation:

\[
\text{FAMILY} + \text{STATE} \rightarrow \text{COMMUNITIZATION}
\]

(Kin, parent, children, attitudes, values, resources, SES) + (Community Services, funding, stability) \rightarrow (Familial, social, political, integration)

With this equation in mind, let us reconsider the relationship between the family and the State in light of the insights provided by the 93 families who participated in this study.

The introduction of a handicapped child into the kin network would seem to present a steady stream of tasks calling for greater kin involvement. However, a special child also requires special knowledge and treatment. All extended family resources may be called into play to support the family. What also must be called upon, however, are the available resources of large organizations, such as the medical industry and social services. A key point of Litwak's study on helping the elderly, is that kin and professionals provide different, but compatible, kinds of help and that the two must be regarded as separate entities "... in that each is capable of performing functions not easily performed by the other."

To reiterate, the principal of matching is both descriptive and prescriptive of the relationship between the family and the State. The example of the deinstitutionalization movement is a case in point. The large institution is notorious for the depersonalization of its residents. For purposes of the punishment of prisoners, this may be deemed appropriate, but as a means of rehabilitation, it is no longer considered tenable. A major deficit in institutional life is the lack
of privacy, of personal space and personal possessions which are the material, outward expression of individual differences. Large organizations are not good at keeping track of the poetry of the soul nor the vicissitudes of a person's idiosyncracies. Primary groups are.

In the daily domestic care of all persons in the family, there is no state agency that can substitute for kin. Certain tasks of a personal nature are best handled by persons with an ongoing relationship with the disabled person, out of obligation or love.

Large organizations, on the other hand, are good at applying principles of health and disease and state-of-the-art technology and knowledge to individual instances of disability and impairment. Primary groups are not so equipped, though they are good at providing observations about changes in their relative/patient that may go undetected by organizational personnel and they are useful in seeing to it that he/she follows prescribed methods of recovery (Cobb, 1976).

The prescriptive aspect of the principle of matching has to do with the nature of the relationship between the family and the State. Moroney (1976) classifies two main types of relationships possible. In one, the State replaces the family in the care of dependents, and in the other, the State acts cooperatively with the family. He further cites points at which the State can become involved: At the point when the family has depleted its resources and is in crisis, in which case the State is said to have a "residual involvement." Or, it can become involved at some earlier phase, when the family still is equipped to choose the kinds of support it needs to function. This latter type of State involvement Moroney terms "shared responsibility."
Litwak's principle of matching serves to identify when each of these types of involvement is appropriate. By identifying the tasks that the families and other primary groups are able to perform, service providers, and policymakers will be able to assess how the State's involvement can best serve families and their disabled members. When should the State replace family functions? When should it share these functions? The principle of matching brings to light certain functions large organizations (whether in the community or not) are equipped to perform and which they are not.

Often there is an emphasis upon the family's dependence on the State. Moroney (1976, 1986) flips the coin and argues that there are still many caretaking functions that the family fulfills which obviate State expenditure. It is, therefore, in the best interest of the State to develop family policy that strengthens families. This means that it should not discourage or reduce the family caring function by creating expectations that the State will take on these responsibilities. Indeed, I argue the matching principle dictates that it cannot! However, the State must make services available that enhance but do not presume to replace this caring function. Regardless of the task, however, both the State and the families need to more clearly define and demarcate their respective areas of responsibility and expertise.

As an example, the recent work of case management in the State of New Hampshire toward development of respite care is a means of providing parents with in-home, secure special child care for short periods (such as an afternoon or a weekend) so that parents are better able to continue caring for their children. This system provides parents with a less extreme choice of either home or institution.
Community-based arrangements are still institutional because they replace family functions. What is called for are substitutive services for disabled persons without family resources and supportive services for those with family resources. As long as the determination of need is based on a focus on the individual, however, the former will take precedence over the latter and these distinctions will be ignored. To quote Likwak, "what is required now is the provision of services that ease the management task of the family" (1985: 124, emphasis mine).

Focussing on the individual makes the task of dispersing services easier for large organizations. However, a shared responsibility focus is not incompatible with an understanding that the individual is embedded in a network of friends, neighbors and relatives who can offer the supports complementing and helping to realize the stated (task appropriate) goals of the large organization and vice versa.

As stated earlier, a major impetus of the deinstitutionalization movement has been the response to the lack of individualized care of persons in large institutions. Size alone, nor low staff-client ratios, however, will not remedy the lack of personal attention. Small group homes where staff rotate in shifts (for the purpose of so-called "continuity of care") and where staff turnover is high, will do little to reduce the problem of providing personal care which comes only from long-standing relationships.

In other words, we should be aware of the limits of the role of the State when it replaces or substitutes for family functions. This was illustrated by the case of GG Lawson. Can her family's desire for
GG's moral supervision be met by a service agent whose requisite professional stance is to be non-judgmental? Litwak has already made it clear in his work of the last twenty years that, even among primary groups, there are distinctions so that not even they are equivalent. Certain family functions cannot be replaced and will simply be lost!

This is not a criticism of professional care; it is merely a statement of the facts of the matter. Both Moroney and Litwak have pointed out that shared responsibility between the State and the family is a more difficult goal to reach because it requires a more flexible policy, including the development of a greater variety of subroutines. With this greater flexibility also comes greater difficulty for the family in choosing which services they require. This is why it becomes imperative for service providers and families alike to understand and acknowledge the limitations, as well as the provisions, of service alternatives. If they realize that certain family functions cannot be replaced and are lost, they will be better able to decide on the best alternatives for their children and clients.

Thus, when it comes to successful communitization, there is no substitute for professional expertise and intervention, but there is also no substitute for kin involvement either. What is needed is a social policy that recognizes this and incorporates the special knowledge of each.

Parents' Recommendations

In 1985, the director of the New Hampshire Division of Mental Health and Developmental Services, Mr. Don Shumway stated that
Laconia State School would remain open and part of the continuum of services available to developmentally disabled people in New Hampshire. Since this research could not have been carried out without the cooperation of the 93 families who comprise the sample, it is imperative that this final chapter should make plain their thoughts and desires. It therefore makes sense to take into account the recommendations participating parents have made in our interviews to improve the service delivery system as a whole, whether their children (who are not children any longer, for the most part) reside in the institution, in community living arrangements or at home.

Here is a list of some of the suggestions and goals proposed by parents.

1. Education in Home Towns.
   Children should be able to go to school in their own town. One mother complained "Barbara has always been bused out of town to school."

2. Continue School Age to 21.
   Currently there is talk of New Hampshire lowering the school age limit to 18 for handicapped children. One can see the misuse of the concept of normalization to suit the political ends of persons faced with a tight budget which always impinges upon education.

3. Continued Training.
   One relative told us "Since those kids are slower than the normal kids, why should their education stop at 21? Eric is 17, but he could still learn more."

4. Home-Based Services.
   Mothers often expressed the need for assistance in managing their children at home. They believe that if they had had the skills and professional support at the time, they would not have had to place their children in LSS.

5. Respite Care.
   Whole chapters could be written about the importance of respite care. A common cry among parents was: "If I'd have had respite care--a week here, a weekend there--I could've avoided sending him/her to Laconia altogether."
6. Community-Based Homes.
In the state of New Hampshire where many of the local services are dependent upon local budgets, quality of care and availability of group homes is greater in the more populace regions. Unless distribution of funds is altered, we will continue to hear "The only thing that's heartbreaking is that there's no place (like the group home in Nashua) here in Dover. It's an hour and a half trip, every time we go to see her." This situation does not foster closer family contact if every visitation becomes a major journey.

7. Recreation
More programs are needed. Recreation programs in the community are important for developmentally disabled children especially because they tend to lose what they learn in school without the stimulation of other children and teachers. Parents suggested programs were needed: a) after school; b) weekends; c) summer vacations.

8. Programs for Adolescents.
There are programs for children and programs for adults, but, in this age of "normalization," there is still a paucity of programs geared to the needs of adolescents. E.g., one father suggested returning to a curriculum that once again included farming and raising animals and a greater variety of choices besides the sheltered workshop.

Parents and service providers alike expressed the need for greater coordination among agencies to insure continuity of care and elimination of duplicity as well as the omission of services.

10. More contact between service providers and members of the community and vice versa.

11. Quality control should be revised so that it does not interfere with service delivery. House parents and foster parents complained of "too much paper work," which included daily logs on each person regarding ADL skills, behavior, medicine, expenses so that "home" had become "more like an institution." Ironically the paper work interfered with direct care of residents.

12. Case finding remains a problem.
One mother pointed to the need for a much stronger system to find and help all those people who have "fallen through the cracks." She was indignant that "LSS clients are getting priority in services over community clients whose families struggled to maintain their children at home.... With all the services we claim to have, we are
still fighting to support them [i.e., these parents and their children] and we shouldn't have to." Another mother adamantly stated, "Unless people have strong advocates, they don't get served. It shouldn't be that way, but it still is!"

In looking at the testimonies of opponents of deinstitutionalization, the question arose: What is it about the institution that parents trust? In order to shed light on what goals communities should attempt to reach, here are some of the parents' expressed concerns.

1. A Safe Place.
   Parents want their children to have "lots of room to roam" in safety.

2. Protection from Criminal Acts.
   Liaison with police, community leaders, and neighbors are needed to reduce the sense of isolation and to prevent group homes from being mini-institutions that are removed from the mainstream of life. Often there is a confounding of the notion of isolation with safety. This latter problem requires community education.

3. Continuity of Care.
   Parents who are not keen on communityization, lack confidence in group home staff. Aside from the explicit request often made that group home staff should consist of married couples, the need for low turnover certainly should be addressed. This has to do with underlying issues of staff morale, good supervision and training, opportunities for staff's personal growth and advancement, salaries, benefits, and budgets for good programming.

Conclusion

Kin support may have an indirect influence on the care of developmentally disabled people, as a motivating force in parents' seeking of professional services and as a source of social support and occasionally a source of goods and services. It is hoped that this study has demonstrated the need to encourage the involvement of whole networks of families in the care of disabled people, not only because
they are a repository of human resources but because such involvement may expedite the advance and success of communitization.

In sum, the study highlighted the positive impact on the deinstitutionalization movement and normalization ideology. We saw how most of the parents, whether their children left the State School before (the Leavers) or after their 21st birthday (the Stayers), generally favored these concepts. Parents whose children had returned to the community reported that they were happier because they saw their children were happier, as a result (at least in part) of their improved relationships with others. We saw that the groups differed, however, in their readiness to believe that the community was equipped economically, and in the amount of professional expertise to take care of their children. Parents of the younger cohort, especially those who left after 1978 (when P.L. 94-142 secured handicapped children's right to an education) were more enthusiastic about their children's community placement. Parents of older more severely involved children, were fearful of the threat of closing LSS without proper services in the community already in place. A third concern lay in the political arena: Would the State of New Hampshire maintain continuous and consistent support of community programs? The State's history of conservatism in spending gave reasonable cause for doubt. Thus, it would appear in my reading of the data, the parents are willing to do as much as they are able for their children, in guiding them in a life plan that gives them as much autonomy as possible, but with as much community support as necessary. At one end of the continuum of shared responsibility, we find, families like the Lawsons, where periodic counseling and help with financial management is all
that is required. In this instance the State's involvement is minimal but would act as a resource for the family. The handicapped person would be on the rolls as eligible for case management and would be periodically contacted to insure that the person was receiving needed services and generally functioning well. Toward the other end of the continuum, the State substitutes its own continuity of care for the family's caring function. In this instance, family financial obligations would continue in some attenuated form, pro-rated according to ability.

When the State substitutes for the family, however, another institution takes over. As Moroney and others point out, institutional care is not defined by location or the size of the facility but by the organization. The actual physical preservation of a large edifice such as LSS has become unnecessary and a thing to be phased out as soon as possible. This is not as alarming a proposal as it might seem to some. The major concerns voiced by parents in New Hampshire--those in our study and in the survey conducted by the Watsons (see Chapter 4)--were that the community offer: 1) proper facilities; 2) professional care; and 3) that their children's primary relationships be preserved. Litwak (1985) has already observed that the first two items are fairly well handled by large institutions, while the third is not. In this latter instance, the State cannot readily act as the substitute because of its present bureaucratic structure. (Handicapped persons are shunted from LSS to communities "where there is a bed" rather than where their friends and family are.) If parents and professionals can be educated to understand this latter point, they and their kin and neighbors, may be more willing to
take political action to develop community services (such as more extensive home visitation). In a small state such as New Hampshire, preserving the Gemeinschaft of the remaining LSS residents requires effort and planning but it is not impossible.

If there were to be only one thought that I should want the reader to remember from this study, it is this: When it comes to the preservation of individual welfare—with all that these two words imply—there is no substitute for the healthy functioning family.

Persons involved in formulating policy and who have taken a special interest in the analysis of its impact upon families, have pointedly observed that the family is a great resource of government: The family has been identified as both a cause and a solution to social ills (Dempsey, 1981; Kamerman and Kahn, 1978; Moroney, 1986). A healthy family is a preventive of delinquency, economic dependence, mental illness, etc. More specifically, with regard to developmentally disabled people, Bruininks, et al. (1981) have argued that community care within the natural home—even with all the available services supplied as support—is probably the least expensive alternative to institutional (albeit community) care. For example, in a study involving a small sample conducted in the State of New York, Willer, Intagliata, and Wicks (1981:215) reported that the recidivism rate for persons who had been placed with their natural families was significantly lower than among persons placed in foster care or group homes.
One may interpret the lack of family policy in the United States to mean a tendency toward a hands-off approach or a high regard for privacy. If we are particularly uncomfortable with dictating normalcy and morality in our society, then we should be willing to provide greater supportive (and affordable) services to families, for it is they who make the moral decisions which are part of daily problem solving.
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APPENDIX A: CLINICAL RECORDS SURVEY

NAME ___________________________________________________________________________


LSS RECORDS
DATA PROFILE SHEET

5. Today's date / / / / / / / 6. Sex 0 = male; 1 = female
               Yr Mo Day

7. Date of birth / / / / / / /  
                Yr Mo Day

8a. Case manager ___________________ 8b. / / / / / / /
                name Yr Mo Day

9. Region of case manager (based on 1983 map; 01 to 12)

Admission: is a stay of 21 days or more

10. Region of child this admission (Based on 1983 map, upon / / /
    address of person with whom child lives at time of admission)

11. Date of this admission to LSS  12. Date of discharge from LSS
               / / / / / / /  
                Yr Mo Day

13. With whom was child living at time of this admission to LSS? / / 
    Enter one digit selected from the following:
    0 natural parent(s)  4 Division of Welfare
    1 foster parent(s)  5 attorney
    2 adoptive parent(s)  6 other (specify)
    3 non-parent relative  Specify ____________________
    4 other (specify) (recode) / //
    9 not specified in records

14. Who has legal responsibility for the child at time of this
    admission? Place a "1" in all boxes that apply; "0" in boxes that
    do not apply. If no information code, code "9s" in all the boxes.
    0 natural parent(s)  4 Division of Welfare
    1 foster parent(s)  5 attorney
    2 adoptive parent(s)  6 other (specify)
    3 non-parent relative  Specify ____________________

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15. Person(s) who initiated/requested this admission
Place a "1" in all numbered boxes that apply; "0" in boxes that
do not apply. If no information, code "9s" in all the boxes.

0 natural parent(s)  
1 foster parent(s)  
2 adoptive parent(s)  
3 non-parent relative  
4 Division of Welfare/Social Worker  
5 Court  
6 mental health worker  
7 psychologist  
8 LSS staff  
9 Other (specify)  

(Recode)

16. Reasons for this admission: Place a "1" next to as many as apply;
"0" in others. If no reason given (can't tell from records),
place a "9" in each box.

1 parent(s) or guardian request institutionalization  
2 placement recommended by child's physician  
3 placement recommended by child's teacher  
4 placement recommended by community mental health worker  
5 placement recommended by psychologist  
6 placement recommended by welfare worker/social worker  
7 child has behavioral problems  
8 child has medical problems  
9 child had contact with law enforcement agency  
10 placement recommended by IEP team at LEA  
11 out-of-home residential arrangements not available  
12 local educational services not available  
13 child judged to be dangerous to self or others  
14 family unable to support child financially  
15 LSS staff recommends admission  
16 Other (Specify) _________________________________(Record)

AAMD DIAGNOSIS (LSS)

In chronological order, fill in the diagnoses and dates the diagnoses
were made, combing the entire record. Enter numbers as indicated on
Certification Committee's letter. If no diagnosis is given, review
medical records and enter level of severity at time of admission in
the 3 boxes, using the code list. Write in the blank space all
diagnoses (include numbers, e.g., AAMD secondary diagnoses when
possible) given at the corresponding date.

001 no retardation present  
002 borderline (IQ 70-85)  
003 mild (IQ 55-69)  
004 moderate (IQ 36-54)  
005 severe (IQ 20-35)  
006 profound (IQ less than 20)  
007 unspecified degree of severity  
008 retardation suspected but
not yet diagnosed

41. a) Date of first diagnosis _/__/__/_/__/__/_/

b) Diagnosis: _/__/__/_/__/__/_/

Yr Mo Day

c) Other ____________________________
42. a) Date of diagnosis (AT 1ST PLACEMENT or AGE 21) /__/__/__/__/__Yr Mo Day/
   b) Diagnosis: __/__/__/__/__/__/__/__//
   c) Other: _____________________________________________________________

Medical and Behavioral Description

For each admission, please answer the following questions, using information from the LSS records dated closest to the FIRST community placement.

Ambulation:  
1 Walks with no difficulty /__/\ 
2 Walks with difficulty 
3 Walks only with help 
4 Unable to walk 
9 Can't tell from records

Level of Cerebral Palsy /__/\
0 Does not have cerebral palsy
1 Mild: does not have limiting effects on daily activities and functions.
2 Moderate: limits ability to carry out daily activities and functions but does not preclude them.
3 Severe: severely impairs or precludes daily activities and functions.
4 Cerebral Palsy is suspected but not diagnosed.
5 Has Cerebral Palsy, level unknown.

Seizures: Client  
0 Does not have seizures /__/\ 
1 Has occasional seizures 
2 Has frequent seizures 
9 Can't tell from records

What is the impact of seizures on client's ability to function? /__/\
1 Mild: does not significantly affect client's ability to function.
2 Moderate: condition significantly affects client's ability to function, but does not completely prevent functioning.
3 Severe: condition impairs or completely prevents the client's ability to function.
4 Condition suspected, not diagnosed.
5 Condition diagnosed, impact undetermined.
8 Not applicable 
9 Can't tell from records
(Medical and Behavioral Description - continued)

Hearing: 
0 No hearing loss
1 Mild to moderate hearing loss (hard of hearing)
2 Severe hearing loss (conversation must be very loud or shouted to be heard)
3 Profound hearing loss (does not rely on hearing as a primary channel of communication, although may hear some loud sounds)
4 Hearing loss suspected, not diagnosed
5 Hearing loss diagnosed, severity undetermined
9 Can't tell from records

Hearing Correction: 
0 Not required
1 Hearing corrected with hearing aid
2 Not correct
9 Can't tell if corrected or not

Vision: 
0 Normal vision
1 Near normal vision (causes no serious problem)
2 Moderate vision loss (glasses usually provide adequate vision)
3 Near blindness (vision unreliable, except under ideal circumstances. Must rely on nonvisual aids)
4 Total blindness (no light perception)
9 Can't tell from records

Vision Corrected: 
0 Not required
1 Corrected with glasses
2 Not corrected (does not have glasses)
9 Can't tell if corrected or not

Speech: 
1 Speech is easily understood
2 Speech is somewhat difficult to understand
3 Speech very difficult to understand
4 Makes sounds
5 Makes no sounds
9 Can't tell from records

Physical Aids:
1 Has no need
2 Needs, has, and uses
3 Needs and has, but does not or cannot use
4 Needs, but does not have
9 Can't tell from records

Glasses
Hearing aid
Special Eating Utensils
Communication Aid
Wheelchair

Walker
Braces
Cane
Helmet
Other (SPECIFY)
Other Major Medical Condition(s)—Recorded closest to date of FIRST CP.

This section is a rating of major medical problems other than developmental disabilities such as diabetes, severe asthma, heart condition, endocrine disorders, Prater Willi, drug regimens requiring professional administration and monitoring of effects of drugs, etc.

Condition Type: On the space provided specify the type of problem, leaving the boxes blank. If there are no other major medical conditions, code box with an 0.

Condition Impact: Select from the codes below the appropriate entry for impact of the specified medical condition upon current client functioning.

Impact Codes: 0 - No major medical problem(s)
1 - Major medical problem(s) do not affect functioning (maintains normal level of work, communication, activity)
2 - Major medical problem(s) have minimal effect on functioning (slight decrease in performance level)
3 - Major medical problem(s) substantially affect functioning (limits work, communication, activity level)
4 - Major medical problem(s) (work, communication, interaction and daily activities)

Condition Type(s) Leave boxes Condition (Use Impact Code)
Specify type(s) on line(s) below blank) Impact
a. specify diagnosis /__/
b. /__/

Medical Information

In general, how urgent is this person's need for medical care?
4 Generally has no serious medical needs /__/
3 Needs visiting nurse and/or regular visits to the doctor
2 Has life-threatening conditions that requires very rapid access to medical care
1 Would not survive without 24 hr. medical personnel
9 Can't tell from records

If this person has a life-threatening medical condition, name it:

R ecode: /__/


SELF-CARE AND SOCIABILITY

Toileting:
1 Goes to toilet by self, completes by self
2 Goes to toilet by self, needs assistance to complete
3 Indicates need and/or must be placed on toilet or bedpan
4 Not toilet trained
9 No information

Dressing:  
1 Dresses self without help
2 Dresses self with help
3 Does not dress self
9 No information

Feeding:  
1 Feeds self totally independently, uses utensils
2 Feeds self, using fingers
3 Feeds self with help
4 Does not feed self
9 No information

From the records, it seems this person:
1 Generally has an even disposition/is pleasant/likable
2 Generally has an uneven disposition, fluctuates between being pleasant and difficult to get along with
3 Is generally difficult to get along with
9 Can't tell from records

Interaction:
When it comes to interacting with others, this person
1 Actively seeks to interact with others
2 Will interact with encouragement/help/given the opportunity
3 Actively avoids interaction with others
4 Does not interact with others
9 Can't tell from records

Writing
1 Has general writing skills (can write words and sentences)
2 Some writing skills (writes name and/or single words)
3 Does not write
9 Can't tell from records

Reading
1 Has general reading skills (reads stories, books, etc.)
2 Some reading skills (reads single words only)
3 Does not read
9 Can't tell from records
MALADAPTIVE BEHAVIOR—described at or near the FIRST CP

1 Never or rarely observed or described in records or reported not to occur
2 Occasionally observed, described or reported to be occasional
3 Described or reported to be frequent or usual behavior

Threatens or does physical violence to others
Damages own or other's property
Disrupts other's activities
Uses profane or hostile language
Smears feces
Is rebellious, e.g., ignores regulations, resists following instructions
Runs away or attempts to run away
Is untrustworthy, e.g., takes other's property, lies or cheats
Displays stereotyped behavior, e.g., rocks body back and forth, non-purposive hand motion
Removes or tears off own clothing
Does physical violence to self
Is hyperactive, e.g., will not sit still for any length of time
Displays sexual behavior (heterosexual or homosexual) that is socially unacceptable, e.g., forcible advances, public masturbation, public exposure, etc.
Requires restraint or time-out
Causes problems with neighbors in surrounding community, e.g., fighting, loud arguments, stealing, property damage, etc.
Any kind of problems with police
Is withdrawn, e.g., extreme inactivity, extreme shyness; extreme unresponsiveness
Abuse or over-use of drugs or alcohol-interferes with daily functioning

DOES THE CLIENT'S PROGRAM INCLUDE ANY OF THE FOLLOWING?
0 = No 1 = Yes 9 = Can't tell from records

Mechanical/Physical restraints / / 
Psychotropic Medication / /

Name of Drug(s) Recode Daily Dosage Recode
______________________________________________________________/ / / 
______________________________________________________________/ / /

TIME OUT / / 
AVERSIVE PUNISHMENT / /

Does this client's program include any reinforcers? (e.g., Candy, social praise, money, holding, trips, etc.) Describe.
APPENDIX B: SERVICE PROVIDER INTERVIEW QUESTIONS

| Name | ID# / / / / / X/ | Rater / / |

CASE MANAGER AND SERVICE PROVIDER INTERVIEW SCHEDULE

1. TODAY'S DATE / / / / / / / PLEASE INDICATE THE NAMES, SEX TITLES OF OTHER INFORMANTS

<table>
<thead>
<tr>
<th>Informant</th>
<th>INFORMANT</th>
</tr>
</thead>
</table>

2. Title ____________________________________________

   Address ____________________________________________

   Work Telephone ______________________________________

3. Sex of informant 0=male 1=female

4. Location of Interview ____________________________________________

5a. Where is client living now? ____________________________ 5b. Date began (address and name)

   [use town code] ______________________________________

   Name of Contact Person ______________________________________

   Telephone ______________________________________

6. At PRESENT, is your client attending school? 0=NO 1=YES

7. School ____________________________________________ 7a. Date began

   Address ____________________________________________

   Contact Person ______________________________________

8. Does [client] have a CASE MANAGER? 0=NO 1=YES

9a. Case manager ______________________________________ 9b. / / / / / / / Yr Mo Day

   name recode / / / / / / / |

9c. Region of Case manager (based on 1983 map; 01 to 12) / / / |

10. When did you first become involved with this client? / / / / / / / Yr Mo Day
11. How often do you contact [your client]?
1. 3 times or less per year
2. 4 to 6 times per year
3. Once a month
4. Every other week
5. Once a week
6. Two times or more a week

If you were to break your CONTACT TIME with this client into the nearest 25% what would it be?

For example:
Would you say your contact time is 100% face-to-face? Or none of the time is spent face-to-face, but you contact him/her by telephone 50% of the time and write letters 50% of the time?

12. Is your contact:
   a. in person? None 25% 50% 75% 100%
   b. by telephone? 0 1 2 3 4
   c. by mail? ______ ______ ______ ______ ______
   d. by other means? ______ ______ ______ ______ ______
   e. other? ______ ______ ______ ______ ______

Specify (e.g., through another person who acts as messenger such as mother?)

13. THIS CLIENT LIVES IN:
    (circle number) 1 natural parents' home
                    2 adoptive parents' home
                    3 foster parents' home (or shared home)
                    4 group home
                    5 residential facility
                    6 other (specify) _________________________

14. Does [client] have a legal guardian 0=NO 1=YES

14a. If YES, who has legal responsibility (CIRCLE ALL THAT APPLY)
    a. natural parent(s) ______
    b. foster parent(s) ______
    c. adoptive parent(s) ______
    d. non-parent relative ______
    e. Division of Welfare ______
    f. attorney ______
    g. other (specify) _________________________
IF CLIENT DOES NOT LIVE AT HOME:

15a. How interested would you say [your client's] family is in his/her well being?
   0 Not interested at all
   1 Slightly interested
   2 Somewhat interested
   3 Very interested
   9 Don't know

15b. How often does your client see his/her family?
   0 Never
   1 Once or twice a year
   2 3 or 4 times a year
   3 Once or twice a month
   4 Weekly
   9 Don't know

16. Who comes to visit? (CIRCLE ALL THAT APPLY)
   a. Mother
   b. Father
   c. Brother(s)
   d. Sister(s)
   e. Other (Specify)

   RECODE / / / / / / /

FINANCIAL AID

17. At present, how does your client support her/himself? CIRCLE ALL THAT APPLY)
   a. Works for pay
   b. AFDC
   c. APTD
   d. SSA
   e. SSD
   i. Parent support
   j. Other (Specify)

   RECODE: / / / / / / /

18. In order to meet medical expenses: (CIRCLE ALL THAT APPLY)
   a. Client pays his/her own bills
   b. Client's parents pay bills
   c. Medicaid pays bills
   d. Medicare pays bills
   e. Client's insurance pays bills
   f. Client's parents' insurance pays bills
   g. Other (Specify)

   RECODE: / / / / / / /

NOW I WOULD LIKE YOU TO TRACE, TO THE BEST OF YOUR KNOWLEDGE, THE PLACES YOUR CLIENT LIVED RIGHT AFTER LEAVING LSS. PLEASE USE YOUR RECORDS IF YOU NEED TO. LET ME START BY ASKING: WHERE DID YOUR CLIENT GO WHEN S/HE FIRST LEFT LSS?

1a. Name and address of Residential Placement
   Contact Person (relation to client)

   / / / / / / / Id. School?
   / / Yes
   / / No

   Tel#

   Dates of residence: From lb / / / / / / / / / / to lc / / / / / / / / / /

WHERE DID YOUR CLIENT LIVE NEXT?
[The above information is obtained for each residence?]
WRITE THE NUMBER OF THE CHOICE IN EACH BOX FOR EACH CP

<table>
<thead>
<tr>
<th>Client's Residences After LSS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
</tr>
</tbody>
</table>

5. How many TIMES did your client VISIT this particular RESIDENCE BEFORE being placed there (9 Don't know)
   - / / / / / / / / / /

6. Residential placement is:
   - / / / / / / / / / / 1 Public 2 Private 3 family home 9 Don't know

7. Placement is:
   - / / / / / / / / / / 1 Non-ICF/MR 2 ICF/MR 8 NA 9 Don't know

8. With regard to the AGES of clients in EACH residential placement, residents are:
   - / / / / / / / / / / 1 Under 21 2 Are mixed, some children, some aged 21 or older 3 All are adults (21 or older) 8 Not applicable 9 Don't know

9. The size of this residential placement (number in household if foster or natural parents' home)
   - / / / / / / / / / / 1 1 to 3 residents 2 4 to 6 residents 3 7 to 10 residents 4 11 to 15 residents 5 15 residents or more 9 Don't know

10. What is actual number
    - / / / / / / / / / /
SCHOOLS ATTENDED

PLEASE TELL ME THE NAMES AND ADDRESSES OF THE SCHOOLS YOUR CLIENT ATTENDED ASSOCIATED WITH EACH RESIDENCE.

<table>
<thead>
<tr>
<th>District</th>
<th>School Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>In Out</td>
<td></td>
</tr>
</tbody>
</table>

12a. / / / / Name ________________________ 12c. / / / /
Address ________________________
Contact Person ________________________

Dates in SCHOOL: From 12d / / / / / / / / to 12e / / / / / / / /

Yr Mo Day Yr Mo Day

Reason for change 12f ________________________

DID YOUR CLIENT GO TO ANOTHER SCHOOL?
[The above information is obtained for all subsequent schools.]

SCHOOL Codes
00 No school assigned
01 full-time regular class with no related or support services
02 full-time regular class with related or support services
03 part-time regular and resource room (less than 50% resource room)
04 part-time resource room and regular class (less than 50% regular class)
05 full-time resource or self-contained class in regular school building
06 part-time regular school and special school (dual placement)
07 full-time special school (non-residential, public or private)
08 full-time special school - LSS used as a day school
09 homebound instruction
10 full-time special residential school (no adults served)
11 full-time residential institution (children and adults, non-psychiatric)
12 full-time residential psychiatric institution (children and adults)
13 other (specify)
99 missing data
APPENDIX C: PARENT INTERVIEW QUESTIONS

Name of Ex-Resident __________________________ Name of Informant __________________________

ID# / / / / / / Card# / / / / Rater / / / /

PARENT COMMUNITY INTERVIEW SCHEDULE

Section A

1. Today's Date / / / / / / Yr / Mo / Day

2. Ex-Resident's Date of Birth / / / / / / Yr / Mo / Day

3. Sex of Informant
0 = male 1 = female

Informant __________________________
Address __________________________

4. Relation to Client
1 Father 2 Mother 3 Other (specify) ______

Telephone __________________________
Work Telephone __________________________

5. Location of Interview ____________________________________________

6a. Where is client living now? ____________________________
(address and name) ____________________________
[use town code] ____________________________

Name of Contact Person __________________________
Telephone __________________________

6b. Date Began ______

7a. School __________________________
Address __________________________

Contact Person __________________________ TEL: __________________________

7b. Date Began ______

8. Does your relative have a case manager 1 / / YES: 0 / / NO

9a. Case manager __________________________ as of 9b. / / / / / / / /
name recode / / / /

9b. Date Began ______

9c. Region of case manager (based on 1983 map; 01 to 12) / / / /
NOW I AM GOING TO ASK YOU SOME QUESTIONS ABOUT THE TIME YOUR RELATIVE WAS ADMITTED TO LACONIA STATE SCHOOL.

10. Immediately prior to being admitted to LSS, where was [your relative] living? /_/  
   0 natural parent(s)  
   1 foster parent(s)  
   2 adoptive parent(s)  
   3 non-parent relative  
   4 other (specify)  
   9 Don't know  
   Specify ___________________________________________ Recode /_/ _/

BEFORE ENTERING LSS, DID YOUR RELATIVE PARTICIPATE IN ANY OF THE FOLLOWING? (PLEASE CIRCLE THE NUMBER OF ALL THAT APPLY)

<table>
<thead>
<tr>
<th>A</th>
<th>HOW MANY YEARS?</th>
<th>B</th>
</tr>
</thead>
<tbody>
<tr>
<td>/_/ 11. Preschool or nursery</td>
<td>/___/</td>
<td>/_/ 11. Preschool or nursery</td>
</tr>
<tr>
<td>/_/ 14. Special needs preschool</td>
<td>/___/</td>
<td>/_/ 14. Special needs preschool</td>
</tr>
<tr>
<td>/_/ 15. Day Care</td>
<td>/___/</td>
<td>/_/ 15. Day Care</td>
</tr>
<tr>
<td>/_/ 17. Public school education</td>
<td>/___/</td>
<td>/_/ 17. Public school education</td>
</tr>
<tr>
<td>/_/ 18. Private school education</td>
<td>/___/</td>
<td>/_/ 18. Private school education</td>
</tr>
<tr>
<td>/_/ 19. Job Training activities (for example, vocational training, sheltered workshop employment)</td>
<td>/___/</td>
<td>/_/ 19. Job Training activities (for example, vocational training, sheltered workshop employment)</td>
</tr>
</tbody>
</table>

If [your relative] attended school BEFORE being admitted to LSS; what was the school? 

20. Name__________________________________________________
   Address________________________________________________
   Contact Person__________________________________________
   Give the dates a. From /_/_/_/_/_/_/ b. To /_/_/_/_/_/_/ of attendance 
   Yr Mo Day Yr Mo Day

21. What kinds of instruction did [your relative] receive? 
   Recode:
DURING THE COURSE OF [your relative's] STAY AT LSS, HOW OFTEN DID YOU OR MEMBERS OF THE FAMILY VISIT [your relative]?

We are interested in visits you made TO LSS.

25. On the average, for each year, would you say you visited:

0 Never
1 Less than once a year
2 visited once or twice a year
3 visited three or four times a year
4 visited once a month
5 twice a month
6 once a week
9 don't know/don't recall

26. How often did [your relative] return home for a visit from

0 Never
1 Less than once a year
2 visited once or twice a year
3 visited three or four times per year
4 visited once a month
5 twice a month
6 once a week
9 don't know/don't recall

About how many times did [your relative] attend "summer camp" while at LSS?

27. How old was [your relative] when s/he left LSS? ________years

28. Was there a second admission to LSS? Yes / / No / /

29a. If yes, DATE / / / / / / /
Yr Mo Day

29b. Date of discharge / / / / / / /
Yr Mo Day
NOW I WOULD LIKE TO ASK YOU SOME QUESTIONS ABOUT YOUR FAMILY.

1. What was father's occupation at time of [child's name] admission (e.g., truck driver, nurse, store owner, manager, secretary, etc.). Please give the type of work done rather than the place of work.

2. What was mother's occupation at time of child's admission? (Type not place)

3. Is mother now employed for pay? 0 NO 1 YES

4. What was mother's occupation before marriage?

5. What was the kind of work mother did when last employed?

6. Father's occupation at first CP

7. Mother's occupation at first CP

Marital Status of Parents (Choose one number for each question.)

1  Married to client's mother/father
2  Married to other
3  Divorced, not remarried
4  Widowed
5  Separated

8a. Mother's marital status at time of admission.
8b. Father's marital status at time of admission.

9a. Mother's marital status when Client left LSS.
9b. Father's marital status when Client left LSS.

10a. Date of birth of mother

b. Date of death of mother

11a. Date of birth of father

b. Date of death of father
EDUCATION (re: parents mentioned in question#)

12. What is the highest level of education completed by child's father at time of admission?
   1  some grade school (K-8)
   2  completed grade school
   3  some high school (9-12)
   4  completed high school
   5  some college (INCLUDE POST H.S. TRAINING)
   6  completed college
   7  some graduate training
   8  graduate degree
   9  don't know

13. What is the highest level of education completed by child's mother at time of admission?
   1  some grade school (K-8)
   2  completed grade school
   3  some high school (9-12)
   4  completed high school
   5  some college (INCLUDE POST H.S. TRAINING)
   6  completed college
   7  some graduate training
   8  graduate degree
   9  don't know

14. Was there a change in educational level of parents by the time child was discharged (or final CP) from LSS?
   1  = father    2  = mother    3  = both    4  = neither

15. If yes, what is the new level? (Use choices above)
   a. father /___/
   b. mother /___/

INCOME
   00 = no income in 12 months prior to admission
   01 = less than $4,999
   02 = $5,000 to 7,999
   03 = $8,000 to 10,999
   04 = $11,000 to 13,999
   05 = $14,000 to 15,999
   06 = $16,000 to 17,999
   07 = $18,000 to $19,999
   08 = $20,000 to $24,999
   09 = $25,000 to $29,999
   10 = $30,000 to $39,999
   11 = $40,000 to $49,999
   12 = $50,000 and above
   99 = don't know

16a. What is family's income at time of child's Admission to LSS? /___/___/

b. What is family's income at time of child's Leaving LSS? /___/___/
17a. How many people living in the household at time of Admission to LSS?

b. Who lived at home at the time?

18a. How many people living in the household at time of
FIRST CP?

b. Who lived at home at the time?

Which of the following situations applies to your relative's current situation?

Which of the following situations would you prefer for him/her?
(CHECK ONE FOR A AND ONE FOR B)

<table>
<thead>
<tr>
<th></th>
<th>CURRENT</th>
<th>PREFER</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Live at LSS</td>
<td>/___/</td>
</tr>
<tr>
<td>2</td>
<td>Live with persons who function at a similar level and have similar handicaps</td>
<td>/___/</td>
</tr>
<tr>
<td>3</td>
<td>Live with persons who function at a higher level and/or have no handicaps at all</td>
<td>/___/</td>
</tr>
<tr>
<td>4</td>
<td>Live with persons who function at a lower level with somewhat more severe handicaps</td>
<td>/___/</td>
</tr>
<tr>
<td>5</td>
<td>Live with a mixed group of persons, some of whom have more severe handicaps and some of whom have less severe handicaps</td>
<td>/___/</td>
</tr>
<tr>
<td>6</td>
<td>Live at home with us</td>
<td>/___/</td>
</tr>
<tr>
<td>7</td>
<td>Live with a family like ours</td>
<td>/___/</td>
</tr>
<tr>
<td>9</td>
<td>Don’t know</td>
<td>/___/</td>
</tr>
</tbody>
</table>
NOW WE WOULD LIKE TO KNOW WHICH, IF ANY, OF THE FOLLOWING PEOPLE HAVE PROVIDED YOU WITH INFORMATION, ADVICE OR OTHER TYPES OF ASSISTANCE (FOR EXAMPLE, BABYSITTING, TRANSPORTATION, ETC.) WITH REGARD TO YOU MENTALLY RETARDED RELATIVE. (CIRCLE ONE NUMBER ON EACH LINE BELOW)

26. FREQUENCY OF ASSISTANCE

<table>
<thead>
<tr>
<th>NO ASSISTANCE</th>
<th>YEARLY</th>
<th>MONTHLY</th>
<th>WEEKLY</th>
<th>DAILY</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Family</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>b. Friends</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>c. Neighbors</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>d. Co-workers</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>e. Other parents</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>f. Priest, minister or rabbi</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>g. Doctors</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>h. Other</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(Please specify)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

OF ALL THE PEOPLE JUST MENTIONED WHICH HAVE BEEN MOST HELPFUL AND SUPPORTIVE? Read the List of people to the respondent again.

Recode:

27. Would you say that the support you have received from Extended Family Members as it relates to your mentally retarded relative has been:
   1 extremely supportive—that is, you could not have done without it,
   2 somewhat supportive,
   3 mildly supportive,
   4 not supportive at all, or
   5 it made things worse?

NOW I WOULD LIKE TO ASK YOU A FEW QUESTIONS ABOUT YOURSELF (CIRCLE NUMBERS)

28. Your religious affiliation is: 29. How important is your Religion to you?

| 1 Roman Catholic       | 0 Not important |
| 2 Eastern Orthodox    | 1 Slightly important |
| 3 Congregational      | 2 Somewhat important |
| 4 Methodist           | 3 Very important |
| 5 Baptist             | 4 Extremely important |
| 6 Jewish              |                   |
| 7 Other               |                   |
| Specify               |                   |
30. How frequently do you attend religious services?
   0 Never
   1 A few times a year or less
   2 Once a month
   3 Two to three times a month
   4 Once a week
   5 Two or more times a week

31. What is your racial or national background?
   1 White, not of Hispanic origin
   2 French Canadian
   3 French
   4 American Indian or Alaskan native
   5 Hispanic
   6 Asian or Pacific Islander
   7 Black, not of Hispanic origin
   8 Other

32. At home what language do you speak?
   1 English
   2 French
   3 Spanish
   4 Other
   Specify ______

WE WOULD LIKE TO KNOW HOW MANY OTHER CHILDREN YOU HAVE, THEIR SEX, THEIR BIRTH DATE, AND WHETHER OR NOT THEY ARE DEVELOPMENTALLY DISABLED.

<table>
<thead>
<tr>
<th>a. BIRTH DATE</th>
<th>b. SEX</th>
<th>c. MENTALLY RETARDED?</th>
<th>d. ADMITTED TO LSS?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yr/Mo/Day</td>
<td>(0=M 1=F)</td>
<td>1 Yes 0 No</td>
<td>1 Yes 0 No</td>
</tr>
<tr>
<td>33. _________</td>
<td>______</td>
<td>1 Yes 0 No</td>
<td>1 Yes 0 No</td>
</tr>
<tr>
<td>34. _________</td>
<td>______</td>
<td>1 Yes 0 No</td>
<td>1 Yes 0 No</td>
</tr>
<tr>
<td>35. _________</td>
<td>______</td>
<td>1 Yes 0 No</td>
<td>1 Yes 0 No</td>
</tr>
<tr>
<td>36. _________</td>
<td>______</td>
<td>1 Yes 0 No</td>
<td>1 Yes 0 No</td>
</tr>
<tr>
<td>37. _________</td>
<td>______</td>
<td>1 Yes 0 No</td>
<td>1 Yes 0 No</td>
</tr>
<tr>
<td>38. _________</td>
<td>______</td>
<td>1 Yes 0 No</td>
<td>1 Yes 0 No</td>
</tr>
</tbody>
</table>

(IF MORE SPACE IS NEEDED, PLEASE WRITE AT THE BOTTOM OF THIS PAGE)
This is a study of the extended family of developmentally disabled people who have been at Laconia State School. The purpose is to understand points of view of kin about having a handicapped child in the family, and to ask you what you think about the new trends and policies about handicapped children.

Be assured that you are free to answer or not answer any questions I ask you. I only request that you tell me if you don't like a question that you tell me what about the question you don't like.

Feel free to ask me any questions you like during the interview.

Familygram: [On a separate piece of paper, the researcher asks the parent to map out her family. The researcher introduces this procedure by saying something like the following: "In order to get a better picture of who's who in your family let's map out your family with a "family gram." We'll start out with your family--you, your husband and the children and we'll branch out from there. The researcher then asks about birth dates, dates of marriage, divorce, death, geographic location of the relatives, occupations, etc.]

1. WHAT WAS IT LIKE THEN? WHAT WERE THE FAMILY'S REACTIONS TO THE BIRTH OF ____________?
2. WHO HELPED YOU TO DECIDE TO PUT ____________ IN LSS?
3. DID THE FAMILY EVER HELP YOU? WHO HELPED YOU?
4. WHY DO YOU THINK THE FAMILY DIDN'T HELP YOU?
5. WHICH MEMBERS DO YOU THINK SHOULD HAVE HELPED YOU BUT DIDN'T? WHY DO YOU THINK THIS?
6. WHICH MEMBERS WERE LEAST HELPFUL?
7. IS THERE ANYTHING YOU WISH TO SAY THAT I HAVE NOT ASKED YOU ABOUT?
8. DO YOU HAVE ANY QUESTIONS YOU WOULD LIKE TO ASK ME?
### APPENDIX E: KIN NETWORK INTERVIEW SCHEDULE

<table>
<thead>
<tr>
<th>Ex-Resident</th>
<th>ID #</th>
<th>Name of Informant</th>
<th>________________________________</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Today's Date</th>
<th>____________________</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Informant</th>
<th>____________________</th>
<th>Relation to Client</th>
<th>____________________</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Address</th>
<th>____________________</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Telephone</th>
<th>____________________</th>
<th>Work Telephone</th>
<th>____________________</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Location of Interview</th>
<th>____________________</th>
</tr>
</thead>
</table>

**Familygram:** [On a separate piece of paper, the researcher asks the parent to map out her family. The researcher introduces this procedure by saying something like the following: "In order to get a better picture of who's who in your family let's map out your family with a "family gram." We'll start out with your family—you, your husband and the children and we'll branch out from there. The researcher then asks about birth dates, dates of marriage, divorce, death, geographic location of the relatives, occupations, etc.]

Immediately prior to being admitted to LSS, where was [your relative] living?

0 natural parent(s)
1 foster parent(s)
2 adoptive parent(s)
3 non-parent relative
4 other (specify)
9 Don't know
Specify ________________________________

Recode: ________________________________

How old was [your relative] WHEN SHE/HE WAS ADMITTED TO LSS? /__/__/

Who initiated/requested the admission to LSS?
(CIRCLE LETTER OF ALL THAT APPLY)

- a. natural parent(s)
- b. foster parent(s)
- c. adoptive parent(s)
- d. non-parent relative
- e. Division of Welfare/Social Worker
- f. Court
- g. mental health worker
- h. psychologist
- i. LSS staff
- j. Other (Specify) ________________________________
DURING THE COURSE OF [your relative's] STAY AT LSS, HOW OFTEN DID YOU OR MEMBERS OF THE FAMILY VISIT [your relative]?

We are interested in visits you made TO LSS.

On the average, for each year, would you say you visited:

0 Never
1 Less than once a year
2 visited once or twice a year
3 visited three or four times a year
5 twice a month
6 once a week
9 don't know/don't recall

How often did [your relative] RETURN HOME for a visit from LSS?

0 Never
1 Less than once a year
2 visited once or twice a year
3 visited three or four times per year
4 visited once a month
5 twice a month
6 once a week
9 don't know/don't recall

What were the reasons and circumstances that led to [your relative's] admission to LSS?

NOW I WOULD LIKE TO ASK YOU SOME QUESTIONS ABOUT YOUR FAMILY.

What was your occupation at time of [child's name] admission (e.g., truck driver, nurse, store owner, manager, secretary, etc.). Please give the type of work done rather than the place of work.

What was your Spouse's occupation at time of child's admission? (Type not place)

Is female head now employed for pay, check here: 0=NO 1=YES

What was female head's occupation before marriage?

What kind of work did she do when last employed?

Spouse's occupation at first CP

Informant's occupation at first CP
Marital Status of Kin (Choose one number for each question.)
1. Married to client's ______________________(state relation)
2. Married to other
3. Divorced, not remarried
4. Widowed
5. Single, never married
6. Don't know

a. Informant's marital status at time of admission /__/__/
b. Spouse's marital status at time of admission /__/__/
d. Spouse's marital status when Client left LSS /__/__/

Date of birth of informant /__/__/__/__/__/__/ Yr Mo Day
Date of birth of spouse /__/__/__/__/__/__/ Yr Mo Day
Date of death of spouse /__/__/__/__/__/__/ Yr Mo Day

EDUCATION (re: parents mentioned in question#)

What is the highest level of education YOU have completed?
1. some grade school (K-8)
2. completed grade school
3. some high school (9-12)
4. completed high school
5. some college (INCLUDE POST H.S. TRAINING)
6. completed college
7. some graduate training
8. graduate degree /__/__/
9. don't know

What is the highest level of education completed by YOUR SPOUSE?
(USE ABOVE KEY) /___/

NOW I WOULD LIKE TO ASK YOU FOR A FEW QUESTIONS ABOUT YOURSELF.

YOUR RELIGIOUS AFFILIATION IS: HOW IMPORTANT IS YOUR RELIGION TO YOU?
1. Roman Catholic 0 Not important
2. Eastern Orthodox 1 Slightly important
3. Congregational 2 Somewhat important
4. Methodist 3 Very important
5. Baptist 4 Extremely important
6. Jewish
7. Other (Specify) ____________________________
RELIGIOUS AFFILIATION continued

How frequently do you attend religious services?
- 0 Never
- 1 A few times a year or less
- 2 Once a month
- 3 Two to three times a month
- 4 Once a week
- 5 Two or more times a week

What is your racial or national background?
- 1 White, not of Hispanic origin
- 2 French Canadian
- 3 French
- 4 American Indian or Alaskan native
- 5 Hispanic
- 6 Asian or Pacific Islander
- 7 Black, not of Hispanic origin
- 8 Other

At home what language do you speak?
- 1 English
- 2 French
- 3 Spanish
- 4 Other

Specify

WHAT CLUBS OR ORGANIZATIONS DO YOU BELONG TO? HOW ACTIVE ARE YOU?

WE WOULD LIKE TO KNOW HOW MANY OTHER CHILDREN YOU HAVE, THEIR SEX, THEIR BIRTH DATE, AND WHETHER OR NOT THEY ARE DEVELOPMENTALLY DISABLED. (IF MORE SPACE IS NEEDED, PLEASE WRITE AT THE BOTTOM OF THIS PAGE)

<table>
<thead>
<tr>
<th>BIRTH DATE</th>
<th>SEX</th>
<th>MENTALLY RETARDED?</th>
<th>ADMITTED TO LSS?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Yr/Mo/Day</td>
<td>O=M I=F</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>1</td>
<td>0</td>
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<td>0</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

How many people living in the household in 19__ [give year of ADMISSION]?
How many people living in the household in 19__ [of FIRST CP]?

Who lived at home at the time?
NOW we would like to know which, if any, of the following people have provided you with information, advice or other types of assistance (for example, babysitting, transportation, etc.) with regard to your mentally retarded relative. (Circle one number on each line below)

<table>
<thead>
<tr>
<th>NO ASSISTANCE</th>
<th>YEARLY</th>
<th>MONTHLY</th>
<th>WEEKLY</th>
<th>DAILY</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Family</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>b. Friends</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>c. Neighbors</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>d. Co-workers</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>e. Other parents</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>f. Priest, minister or rabbi</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>g. Doctors</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>h. Other</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

(Please specify)

Of all the people just mentioned which have been most helpful and supportive? Read the list of people to the respondent again.

Would you say that the support the parents of your disabled relative have received from family members as it relates to your disabled relative has been: (Check one)

1 extremely supportive—that is, you could not have done without it,
2 somewhat supportive,
3 mildly supportive,
4 not supportive at all, or
5 it made things worse?

We would like you to trace the diagnoses applied to your relative's handicapping condition. Please tell me the diagnoses your child was given at the time of admission to LSS; at the time of first CP and now.

<table>
<thead>
<tr>
<th>At time of ADMISSION</th>
<th>PROFOUNDED</th>
<th>SEVERE</th>
<th>MODERATE</th>
<th>MILD</th>
<th>NOT RETARDED</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>/\</td>
<td>/\</td>
<td>/\</td>
<td>/\</td>
<td>/\</td>
</tr>
<tr>
<td>At time of FIRST CP</td>
<td>/\</td>
<td>/\</td>
<td>/\</td>
<td>/\</td>
<td>/\</td>
</tr>
<tr>
<td>NOW</td>
<td>/\</td>
<td>/\</td>
<td>/\</td>
<td>/\</td>
<td>/\</td>
</tr>
</tbody>
</table>
HOW WOULD YOU DESCRIBE YOUR RELATIVE'S DISABILITY WITH REGARD TO THE FOLLOWING:

SELF-CARE and SOCIABILITY

Toileting
1 Goes to toilet by self, completes by self
2 Goes to toilet by self, needs assistance to complete
3 Indicates need and/or must be placed on toilet or bedpan
4 Not toilet trained
   9 Don't know

Dressing
1 Completely dresses self
2 Completely dresses self with verbal prompting only
3 Dresses self by pulling or putting on all clothes with verbal prompting and by fastening (zipping, buttoning, snapping) them with help
4 Dresses self with help in pulling or putting on most clothes and fastening them
5 Cooperates when dressed by extending arms and legs
6 Must be dressed completely
   9 Don't know

Feeding
1 Uses knife and fork correctly and neatly
2 Uses table knife for cutting or spreading
3 Feeds self with spoon and fork - neatly
4 Feeds self with spoon and fork - considerable spilling
5 Feeds self with spoon - neatly
6 Feeds self with spoon - considerable spilling
7 Feeds self with fingers or must be fed
   9 Don't know

It seems this person
1 Generally has an even disposition/is pleasant/likable
2 Generally has an uneven disposition; fluctuates between being pleasant and difficult to get along with
3 Is generally difficult to get along with
   9 Don't know

Interaction
1 Does not enter into interaction
2 Enters into interaction only when others initiate
3 Initiates interactions in familiar or previously successful situations or settings
4 Initiates interaction in both familiar and unfamiliar situations or settings
   9 Don't know
WHICH OF THE FOLLOWING SITUATIONS would you PREFER for him/her?  
(CHECK ONE)

<table>
<thead>
<tr>
<th></th>
<th>CURRENT</th>
<th>PREFER</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Live at LSS</td>
<td>/___/</td>
</tr>
<tr>
<td>1</td>
<td>Live with persons who function at a similar level and have similar handicaps</td>
<td>/___/</td>
</tr>
<tr>
<td>2</td>
<td>Live with persons who function at a higher level and/or have no handicaps at all</td>
<td>/___/</td>
</tr>
<tr>
<td>3</td>
<td>Live with persons who function at a lower level with somewhat more severe handicaps</td>
<td>/___/</td>
</tr>
<tr>
<td>4</td>
<td>Live with a mixed group of persons, some of whom have more severe handicaps and some of whom have less severe handicaps</td>
<td>/___/</td>
</tr>
<tr>
<td>5</td>
<td>Live at home with us</td>
<td>/___/</td>
</tr>
<tr>
<td>6</td>
<td>Live with a family like ours</td>
<td>/___/</td>
</tr>
<tr>
<td>7</td>
<td>Other (specify)</td>
<td>/___/</td>
</tr>
<tr>
<td></td>
<td>-999 Don't know</td>
<td>/___/</td>
</tr>
</tbody>
</table>

ATTITUDE SURVEY  
[See Questions in Table 4.4, page 78.]

IMPORTANT

Throughout the interview, the informant may have indicated s/he wished to express some ideas, opinions, or ask you some questions about this survey. NOW is the time to ask:

IS THERE ANYTHING YOU WISH TO SAY THAT I HAVE NOT ASKED YOU ABOUT? DO YOU HAVE ANY QUESTIONS YOU WOULD LIKE TO ASK ME?
APPENDIX F: INFORMED CONSENT FORM

Informed Consent for ____________________________

1. Purpose

The purposes of this project are:

1. To find out what kinds of living arrangements and educational programs children receive after they leave Laconia State School.

2. To compare services children receive at the State School with services they receive in the community.

3. To find out how community services for handicapped children could be improved.

II. Procedures

To carry out this project, we will:

1. Read the clinical records located at Laconia State School and community programs.

2. Assign a code number to each child in the study so we can record information without using anyone's actual name.

3. Keep all identifying information in a locked file, and not let anyone outside the project see that file.

4. Use this information only for this project, and not share it with anyone else without your permission.

5. Interview you and others in the community over the telephone and in person to learn of your experiences in caring for a handicapped child. Our questions will focus on such issues as living arrangements, educational services, social services, etc. These interviews will be done at or near the ex-resident's home and will be scheduled at the convenience of those whom we are interviewing.

6. Spend some time with each person who left the school to find out how he/she likes living in the community, what problems have come up, how they were solved, etc.
III. Tour Consent

The next section lists the possible risks and benefits of this study. Your permission to include the person you have responsibility for indicates that you understand and agree to these conditions.

1. I understand that this project will not ask anybody to do anything they wouldn't normally do.

2. I understand that all information obtained in this study will be kept confidential. No actual names of ex-residents, parents, guardians, or service providers will be used when the study's results are published.

3. I understand that the only possible risks involved are 1) drawing some attention to the ex-resident because of the project staff's presence in the community, or 2) making someone feel a bit uncomfortable because of sensitive questions about family stress, financial problems, difficulties in caring for a disabled person, etc.

4. I understand that the University of New Hampshire is not liable for health or other services related to participation in this project.

5. I understand that the project staff will not try to change, embarrass, or criticize anyone involved in the study.

6. I understand that no one's disability will be pointed out unnecessarily.

7. I understand that the project staff will be as unobtrusive as possible, and will not inconvenience anyone.

8. I understand that the project will not try to change the services being received by anyone, and will not interfere with those services in any way.

9. I understand that I will have the right to refuse further participation in this project at any time either for myself or for the person I represent. The decision not to participate now or in the future will in no way affect the services I and the ex-resident receive.

10. I understand that my decision to grant permission on behalf of the person I am responsible for is entirely voluntary.

11. I understand that there are several possible benefits which could result from this study. These include a better understanding of the process and results of deinstitutionalization; more informed teachers, administrators, and legislators who plan and carry out community-based services; improved services at the State School and in the community for handicapped children based on the project's recommendations; and improved policies in New Hampshire and other states so that disabled children and their families/guardians can enjoy an improved quality of life.

12. I understand that this project will be directed by Dr. Bruce Mallory, who is a faculty member in the Education Department at UNH. If I have any questions now or in the future, I can contact him at (603) 862-2312.

13. I understand that the Laconia State School administration has approved the plans for this study and is providing its full support to the project. Dr. Frank Hackloon (524-5373, ext. 358) is available at the State School to answer any questions about the project. In addition, the case managers and community service providers in New Hampshire will be informed of the project once it gets under way, and will work with the project staff to obtain the necessary information.

Now that you know the purposes, procedures, risks, and benefits of the project, please sign underneath one of the following statements:

I grant permission for ___________________________ to participate in the study described above. I understand the purposes, procedures, risks, and benefits of this study.

[Date] [Signature of Parent/Guardian] [Phone #]

I do not grant permission for ___________________________ to participate in this study.

[Date] [Signature of Parent/Guardian] [Phone #]

Please place one copy of this form in the stamped, self-addressed envelope that is included with this letter, and mail it back to us as soon as possible. There is an extra copy of the form included for you to keep for future reference. Thank you for your help! Please call if you have any questions or concerns (603-862-2312).
Dear [Parent’s Name],

The purpose of this letter and the enclosed form is to ask your permission to include [Child’s Name] in a project called Project SID. A brief description also accompanies this letter. The purpose of the project is to find out what happens to people when they leave Laconia State School and Training Center before their twenty-first (21) birthday and enter the community. We will also need to get to know the circumstances of the people who stayed at Laconia past their twenty-first birthday. Because you are the parent or legal guardian of [Child’s Name], we need your permission to include [Child’s Name] in this study.

Please read the enclosed form carefully. It explains the purpose of the study, how it will be carried out, and what the possible risks and benefits will be for those who participate. We hope to include all of the children who have either remained or left the State School between 1970 and the present. This will give us the most complete picture of what happens when children return to their families or go to live in foster or group homes.

After reading the form, please sign it to indicate whether or not you will allow us to include [Child’s Name] in this project. Then place the form in the enclosed envelope and mail it back to me as soon as possible. If you have any questions about the form or the project, please feel free to call me at Laconia State School, 524-5373, Extension 358.

Sincerely,

[Signature]

FRANK W. MCALOON, Ph.D.
Director, Quality Assurance
Laconia State School & Training Center