The Effects of Participation in the Family Support Program on the Adaptive and Maladaptive Behaviors of Developmentally Disabled Individuals

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THE EFFECTS OF PARTICIPATION IN THE FAMILY SUPPORT PROGRAM
ON THE ADAPTIVE AND MALADAPTIVE BEHAVIORS OF
DEVELOPMENTALLY DISABLED INDIVIDUALS

by

Patricia L. McDonald

A Dissertation
Submitted to the
Faculty of The Graduate College
in partial fulfillment of the
requirements for the
Degree of Doctor of Education
Department of Educational Leadership

Western Michigan University
Kalamazoo, Michigan
April 1983

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THE EFFECTS OF PARTICIPATION IN THE FAMILY SUPPORT PROGRAM
ON THE ADAPTIVE AND MALADAPTIVE BEHAVIORS OF
DEVELOPMENTALLY DISABLED INDIVIDUALS

Patricia L. McDonald, Ed.D.
Western Michigan University, 1983

The purpose of this study was to investigate the differences in adaptive as well as maladaptive behaviors of those developmentally disabled persons who have participated in a Family Support Program and those who have not participated in such a program.

The study focused on the adaptive and maladaptive behaviors of 10 developmentally disabled persons for the time period from November 1980 to April 1982. These subjects for the study were between the ages of 4 and 20, residents of Macomb County, and actively serviced by the Macomb County Life Consultation Center. Data used in the study were generated through the use of the American Association of Mental Deficiency Adaptive Behavior Scale.

The developmentally disabled persons who participated in the Macomb County Family Support Program made greater changes in a positive direction on the adaptive as well as maladaptive behaviors than those individuals who did not participate in this program.
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Patricia L. McDonald
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CHAPTER I

INTRODUCTION

Statement of the Problem

The purpose of this study is to investigate whether or not developmentally disabled persons will demonstrate increased adaptive behavior and decreased maladaptive behavior as a result of receiving in-home support services such as those provided by the Macomb County Family Support Program compared to those developmentally disabled individuals who do not receive the same services.

Families with a developmentally disabled member face enormous problems. Developmental disabilities cover many aspects of an individual's growth and development. Specifically, a development disability can be attributed to one of the following criteria as outlined by Michigan's Mental Health Code (1977):

A developmental disability is a severe, chronic disability of a person which:

1. is attributable to a mental or physical impairment or combination of mental and physical impairments;
2. is manifest before age 22;
3. is likely to continue indefinitely;
4. results in substantial functional limitations in three or more of the following areas of major life activity:
   A. self-care,
   B. receptive and expressive language,
C. learning,
D. mobility,
E. self-direction,
F. capacity for independent living, or
G. economic self-sufficiency; and

5. reflects the need for a combination and sequence of special, inter-disciplinary or generic care, in a significant reduction of demand for residential services which are: (a) of lifelong or extended duration, and (b) individually planned and coordinated.

For decades, a developmentally disabled individual was, upon its birth, placed in a large, institutional setting which would be called "home" for the duration of that person's life. The child never experienced the environment of the parental home, and the natural aspects of sibling interactions was not part of the process of the growth and development of that child.

Very little time, effort, and money has been expended in viewing the natural families of developmentally disabled persons, and strategizing as to how assistance can be provided to them. The trauma, psychological stress and tension, and the emotional anxiety which parents face as a result of the birth of their developmentally disabled child is enormous.

Problem Related Issues

Throughout the duration of the innovation and creation of new settings, the natural home as an alternative location was very often overlooked or discounted (Perske, 1973). For some reason, those
individuals allocating resources gave minimal consideration to natural families who wanted to retain their child in the natural home, but needed assistance. Requests by the natural family for financial assistance were invariably ignored. It appears that those requests could prove a viable alternative to institutionalized care.

Conroy, Efthimious, and Lemanowica (1982) observed that developmentally disabled individuals can learn to function more independently if provided with adequate environments. The primary purpose of such services is, according to these experts, to foster such developmental growth. They further point out that in an era of ideological commitment to deinstitutionalization, a question of central concern is whether relocation of clients from large segregated institutions into small community-based facilities actually enhances developmental growth.

Group homes, foster-care homes, and nursing homes provide staff which are trained, licensed (in some cases), and monitored by the mental health networks. Positive aspects of growth and development are taking place. However, in viewing the array of services which do exist, the natural family has historically been left out of the network of services.

Significance of the Study

The relocation of mentally retarded persons from institutions to community settings and the development of residential alternatives to institutions has been the dominant thrust in the field of mental retardation for the past decade. In viewing the data
available on learning potential for those who spend years in institutional settings, O'Connor and Tizard (1956) observed that many institutions in the late 1800's and the early 1900's had an educational aim, but (as Binet had shown in France at the Bicetre and other hospitals) this training was largely ineffective in turning out socially competent citizens. Fewer than 15% of the patients discharged from the Royal Earlswood Asylum between 1893 and 1908 were socially useful in any sense and only 3.25% were earning wages.

Perske (1973) suggested that an individual progresses less in an institution than in a balanced home environment. Sustaining the retarded individual in the environment of the natural family presents a long-term burden of care problems for the family, particularly on the female head of the household. Willer, Intagliata, and Wicks (1980) avowed that the primary difficulties for the women who cared for the retarded individual in the home relate to the retarded person's need for supervision and the mother's inability to get relief, even for brief periods.

Overview

This study investigated the effects of the Macomb County Family Support Program on the adaptive and maladaptive behavior of developmentally disabled persons. The intent was to determine if behaviors of developmentally disabled individuals would change as the result of being provided with in-home support. Chapter I presents an introduction to the problem.
Chapter II contains a review of related literature, while Chapter III outlines the research design. Chapter IV provides an interpretation of the research results. Observations, conclusions, and recommendations, as a result of the analysis, appear in Chapter V.
CHAPTER II

REVIEW OF THE RELATED LITERATURE

The purpose of this chapter is to review the selected literature relative to the historical and contemporary care of the developmentally disabled in the United States. The review of literature is divided into four sections. The first section discusses the means by which the developmentally disabled have historically been cared for. The second section reviews the plight of the developmentally disabled in our society today. Section three attempts to discuss the resource allocation process as it relates to our developmentally disabled population. Section four reviews the related literature regarding the Family Support Program and presents two hypotheses which were developed as a result of both the literature search and this researcher's personal experiences and observations.

Historical Perspective

The concept of childhood as a stage of development different from adulthood, and having peculiar needs requiring different approaches by the society, did not arise in Eastern thought until 200 years ago (Shore, 1979).

For too many years, as soon as newborn children were diagnosed as developmentally disabled, an image of death overshadowed their future. Very little hope was given for future possible learning opportunities. The only options parents had were to take the child
home and be faced with lifelong dependent care, or consent to place their child into an institutional facility under the auspices of the Department of Mental Health. No other form of support service was extended by the community to the natural family. Minimal consideration was given to the developmentally disabled person, and maximum consideration was given to institutionalizing that person. In the middle part of this century, the reason for the large size of mental-deficiency hospitals was partly historical and partly economic. Buildings were built for the era, and the facilities presently standing reflect the influence of the past (Illich, 1976).

O'Connor and Tizard (1956) observed that ineducable children were referred by educational authorities to local health authorities which had the responsibility for (a) providing suitable supervision for such defectives and, if this proved to be insufficient protection, taking steps to secure that they were sent to institutions or placed under guardianship; (b) providing appropriate training or occupation for developmentally disabled under supervision or guardianship; and (c) making provision for the guardianship of defectives placed under guardianship by orders of the court.

As society, technology, and interaction moved into the era of the industrial revolution, a new phenomenon known as specialization emerged. Specialization provided minimal opportunity for persons who had minimal skills. A developmentally disabled person had, of course, not even minimally marketable skills and was, therefore, viewed as someone with nothing to offer (Traverso, 1964).
Plight of the Developmentally Disabled

The United States of America, as a progressive nation, has to own up to the fact that many of its efforts have been channeled into helping those who could help themselves. Of the conditions which have decayed American life, two of the most perplexing have been poverty and mental retardation. The existence of mental retardation has generally been blamed on heredity or simply labeled an act of God. Contemporary attitudes towards retardation are characterized not only by adherence to long-standing prejudices, but also by an appalling degree of ignorance. Of 100 men and women interviewed in a Minnesota study, only one in 10 demonstrated specialized information about retardation. One-fifth of the people interviewed confused retardation with other physical and mental disorders (Hurley, 1968).

Individuals who are developmentally disabled have little opportunity for specialized programming for growth and development. The mentally handicapped do not make a very powerful political lobby, in that they do not write letters to their congressmen. Therefore, it is quite likely that more dramatic and well-organized claims will take priority and will attract both funds and votes (Hannam, 1975).

According to Fein, Davies, and Knight (1979), approximately 220,000 to 350,000 children are in foster care in the United States. Many spend their entire childhood in foster care. Others move into foster care, back to natural parents, and back into foster placements a number of times during their young lives. Still other
developmentally disabled persons move from foster home to foster home within the system. The resulting damage to a developmentally disabled person's sense of belonging, permanency, and stability is incalculable.

Until the 1970's, parents who wanted to keep their disabled child at home often found themselves under great pressure to do otherwise. They were often made to feel that somehow they were neglecting their child by not providing the opportunities that supposedly would be available in an institution. Such pressures may have originated with schools and school counselors who decided that the child's problems centered around parents who did not understand or who did not want to cooperate. At times there almost seemed to exist the feeling that the child was unfortunate to have had parents (Leland & Smith, 1974).

Savino, Sterns, Merwin, and Kennedy (1973) noted that literature consistently stresses the need to look for new alternatives in the delivery of services to developmentally disabled persons. Traditional concepts of delivering service may no longer be appropriate, adequate, or functional. Nevertheless, innovative methods receive only reluctant acknowledgment from many. Excluded from the planning and decision-making process are those segments of the population with the highest incidence of need.

A retrospective study of the treatment of the developmentally disabled population provides little evidence of innovation and creativity. The purpose of any program designated to assist the retarded should be to help each person realize the fullest development
of his or her capacities. These include capacities for work, for play, and for all of the many ways in which any person finds fulfillment (Wolfensberger, 1972).

The needs and concerns of developmentally disabled persons along with their parents and siblings are constantly changing. Nearly every human service program—health care, counseling, income maintenance, education, legal assistance, housing, self-help groups, mental health, employment, and vocational training—will have an impact on their lives. Building linkages between all these systems are monumental tasks. Even more challenging is the fact that conditions of being a developmentally disabled person is a lifelong one ((Horejsi, 1979).

Families of Developmentally Disabled Individuals

According to Opirhory and Peters (1982), when a less than perfect infant is born, its parents experience unexpected and unprepared for reactions. Unfortunately, the parents frequently suffer because their own psychological and emotional needs are unmet and unresolved. Early intervention with both the family and the infant is a key concept in successfully counseling the family with the less than perfect newborn.

Leland and Smith (1974) postulated that in actuality the family can be a major resource for work with their disabled member. It can help keep the person out of an institution, it can develop skills or talents within the person in conjunction with other programs, and it
can function as a part of any treatment and training program necessary. Instead of the family being the first resource used, it has historically been ignored.

**Alternative Support Systems**

Horejsi (1979) observed that the social work profession has provided some hopeful aspects for improving the lives of developmentally disabled persons. Since the social work profession became directly involved in the field of the developmentally disabled, much attention has focused on the parents and siblings of developmentally disabled persons. Today, family considerations have taken on a new importance. Whereas the concerns used to be about the psychosocial reactions of family members, there has been a recent realization that parents and siblings can be powerful resources in rehabilitations.

As noted by Hurley (1968), many natural parents are pleased with having their developmentally disabled son or daughter placed in a foster home. They know their child is being taken care of, and they can have occasional interaction with their child. When faced with foster care of limited duration and the choice of either taking the individual home or having it adopted, most parents will consent to having the child return home.

According to Panzer, Wiesner, and Dickson (1978), single parents of disabled children are often overburdened by striving to meet basic survival needs. They are frequently physically and psychologically unable to provide much of the attention, guidance, and
stimulation their children need. As a result, their children are unable to realize their fullest potential, and the parents experience guilt and frustration due to not being able to assist them.

According to Willer et al. (1980), whenever there is discussion of developmentally disabled people exiting institutions to live in alternate settings, there frequently is little or no mention of returning them to their natural families. Institutionalization in the past was frequently recommended because of the expected benefits to the family.

Ehlers (1966) suggested that many families have requested some form of assistance in maintaining their developmentally disabled child in their home, but services have not been extended to them. Society has recognized the need to institutionalize individuals who require regular 24-hour supervision. For those who do not need intensive residential care, however, it is more appropriate to provide support which can be available from time to time as required, rather than the expensive process of 24-hour-a-day institutionalization. It is predominantly the mothers of developmentally disabled children who, in the final analysis, bear the brunt of the burden for their care and training. Until recently, however, little research has been undertaken concerning the type of help which mothers most need in acquiring more competence and security in the day-to-day care of their developmentally disabled children.

Gitterman (1979) noted parents of developmentally disabled persons want to be involved in their lives. They noted that their participation in their children's development needs to be maximized.
Not to do so tends to leave them feeling isolated and lacking in knowledge about their children. In recent years some inroads have been made in assisting parents by community mental health boards. As the deinstitutionalization process began to occur in the late 1960's, better use was made of the natural family and of the contribution they could make to the normalization process. Mental health professionals began to recognize the contribution the natural families of developmentally disabled persons could afford in providing emotional and psychological support (Perske, 1973).

Wolfensberger (1972) postulated that when group homes were established, foster care homes were licensed, and nursing homes were built, they had to meet strict criteria for operation and maintenance standards. To this end the policies and procedural guidelines of the Department of Social Services for the Department of Mental Health were utilized. In and through all of these creations, very little thought was given to using the natural family as an alternative.

Institutionalized persons have experienced innovative changes within the last decade. Treatment of developmentally disabled persons began, during this period, to focus on individualized program concepts (Perske, 1973).

All persons, according to O'Connor and Tizard (1956), are entitled to live in the most desirable of environments. That is, environments that provide and afford the least restrictive atmosphere and the most normalized setting.
Deinstitutionalization and the Normalization Process

In looking at the laws of the 1970's which proposed to impact on the advancement of the developmentally disabled person, one can note the growth in individualized concepts to enhance normalization principles (Perske, 1973). According to Perske (1973), normalization is defined as emphasizing the value of helping developmentally disabled persons to live as much like the rest of society as possible. Willer and Intagliata (1982) noted that with the normalization movement, there has been an implicit assumption in several court decisions, that the less restricted environment of the community setting is more consistent with the rights of developmentally disabled persons.

The guiding principle behind deinstitutionalization has been normalization because developmentally disabled persons should enjoy the same rights as nondisabled persons. The developmentally disabled person should be encouraged to respond in a normal, age-appropriate fashion. The manner in which this is achieved is by placement in a normalized setting which provides access to generic services and appropriate freedom to take advantage of such access. The normalization approach centers on the concept of mothering and on every human being's need to feel a sense of being worthy and cared about in a consistent, meaningful way (Wolfensberger, 1972).
Resource Allocation for the Developmentally Disabled

According to Leonards (1982), in the continuous effort to increase efficiency and bolster productivity, management frequently fails to recognize that organizations exist for the benefit of people. To their detriment, administrative policies are quite likely to reflect exactly the converse that people exist for the organization. This researcher correlates this concept in terms of housing the handicapped and retarded population during the course of the last 100 years. Institutions were built and they had to be used. As a result, the developmentally disabled person, once diagnosed, was earmarked for long-term residential placement. In actuality, there were no alternative locations.

According to Perella (1974), only in recent years has the social work profession demonstrated any direct concern for the field of mental retardation and developmental disabilities. Two basic groups of poor exist in America. The first is the working poor and their families which, given the proper resources and opportunities, can fend for themselves. They comprise approximately 45% of America's poor. The second group is the dependent poor, defined as female heads of families, the elderly, disabled, and poor children. This group comprises approximately 55% of the poor in the United States.

Roos, McCann, and Addison (1980) observed that parents have long requested assistance from governmental agencies for the care of their developmentally disabled children. Their pleas and requests
have often been ignored. Financial constraints appear to be the greatest obstacle in providing on-going care within the natural home. Leland and Smith (1974) suggested that financial difficulties invariably become a matter of concern to parents of developmentally disabled children. Such children often require special medical care, drugs, diets, and/or prosthetic devices. Care of the additional illnesses to which such children have a predisposition can result in catastrophic expenses.

Gitterman (1979) suggested help for learning disabled children requires a multidisciplined effort and may include the use of medication for hyperkinesis, education remediation, and service to individuals and families to interpret specific evaluations, and to provide consultation or counseling. Social group work services, too, have a unique potential for helping learning disabled children and their families.

As noted by Savino et al. (1973), professionals in the field are short on responding to the needs of the disabled. The limitations on resources from official funds often results in competition between programs. Programs for the developmentally disabled normally fare poorly when compared to the resources allocated to other areas.

Hull and Thompson (1981) suggested that the development of adequate and appropriate services in a community does not always keep pace with the growing numbers of deinstitutionalized persons. As a result, the life style of these individuals suffers.

The funding of community-based residential services for developmentally disabled persons is a relatively recent phenomenon. Leland
and Smith (1974), while lauding this development, pointed out that it has diverted funds that otherwise would go to the parents of developmentally disabled children, to reimburse them for medically related expenses.

As noted by Willer and Intagliata (1982), although cost alone should not be the primary factor determining the design of a system of community care, it appears inevitable that cost effectiveness will become an increasingly important consideration shaping the delivery of all human services in the 1980's.

Family Support Program

One resource that has historically been overlooked in planning for the deinstitutionalization of developmentally disabled individuals has been the natural family. The lack of a family support system represents a serious gap in the continuum of services to developmentally disabled citizens and their families. It was because of the lack of a family support system that the Macomb (Michigan) County Community Mental Health and the Macomb-Oakland (Michigan) Regional Center (MORC) was awarded a $100,000 grant for a family support services project, in March of 1980, by the Michigan Department of Mental Health, from funds appropriated by the Michigan Legislature (Terrone, 1980).

The parents of 229 institutionalized developmentally disabled individuals were interviewed in an attempt to determine how many families would be willing to have their institutionalized family member returned home if specialized services were provided to them.
Because none of the families interviewed were willing to have their institutionalized member returned home under any circumstances, it was ultimately determined to be appropriate to extend specialized services to five noninstitutionalized developmentally disabled individuals. A comparison was then made of the impact of full services on adaptive and maladaptive behavior of a control group of five different noninstitutionalized developmentally disabled individuals who received only routine services from Macomb County Community Mental Health (Terrone, 1980).

Life Consultation Center (LCC), an agency of the Macomb County Community Mental Health, was the primary provider of services, with the Macomb-Oakland Regional Center providing back-up support and resources as needed. The project funded case management, in-home intervention, and specialized financial assistance. Families who were involved in the project had sons and daughters who were severely or profoundly retarded or who had other multiple handicapping physical or emotional impairments which placed heavy demands on the family unit.

The idea behind the project was that support services for those families involved would improve their ability to maintain their children at home, increase their ability to cope and care for the needs of life, better utilize generic services, and decrease the dependency of clients and their families on the family support program over time.

The amount paid to each family was based on the needs of the family and programming done by the family, as it is with foster
parents. These funds enabled families to purchase respite care, sitter services, special therapeutic services, special equipment, transportation, and other special needs.

Each parent in the project was required to go through a 40-hour training program provided by MORC. To supplement this initial training, a staff person went into the home to provide demonstration and practical application of the course material.

Each client had an individual program plan of specific goals and objectives designed by the case manager in conjunction with a team of professionals. Parents were trained in helping their sons and daughters reach these goals. Consultants were available through MORC and LCC in a variety of disciplines, including psychology, psychiatry, medical, speech, occupational and physical therapy, education and vocational, nursing, and recreation.

This researcher has worked on a full-time basis for over 6 years in the field of mental health as both a teacher and a therapist. During this time it has been observed that 85% of those cases presented to the Department of Mental Health for institutionalization are families who have socioeconomic hardships. Examples of such hardships are broken homes, unemployment, and escalating costs of living requiring two working parents. It is this writer's opinion that given the chance, these families would have accepted financial support rather than seeking placement. Prior to the advent of the Family Support Program there existed no community generated services which provided financial assistance to the families of developmentally disabled individuals.
The review of literature clearly points to the need for and the lack of financial assistance to the families of developmentally disabled individuals. This review, combined with this researcher's personal observations and involvement with the Family Support Program results in the following hypotheses:

**Hypothesis 1**—There is a greater improvement in the adaptive behavior scores for developmentally disabled persons who participate in the Family Support Program compared to those developmentally disabled persons who do not participate in the Family Support Program.

**Hypothesis 2**—There is a greater improvement in the maladaptive behavior scores for developmentally disabled persons who participate in the Family Support Program compared to those developmentally disabled persons who did not participate in the Family Support Program.

**Summary**

In summary, the preceding review of literature was divided into four sections. Section one provided a historical review of the means by which the American people have historically dealt with the issue of developmentally disabled persons. Section two reviewed the plight of these same individuals in our contemporary society. This section reviewed: (a) the problems faced by families of developmentally disabled individuals, (b) alternate support systems available to the developmentally disabled, and (c) the impact and importance of deinstitutionalization and the normalization process to the disabled. Section three reviewed both the historical and current problems in allocating resources to assist the developmentally
disabled. There followed, in Section four, a review of the Family Support Program. The review of literature led to the presentation of two hypotheses regarding the impact of the Family Support Program on the mean adaptive and maladaptive behavior scores of developmentally disabled persons.
CHAPTER III

DESIGN AND METHODOLOGY

This chapter is a presentation of the research design and methodology used in the study. Contained within is a discussion of the population that will be studied, a description of the instrument selected for data gathering, and a discussion of the procedures used in the study.

Population of the Study

Macomb County is located in southeastern Michigan and has a population of 694,000 (1980 census). Of that population, 21,500 are, according to the Macomb County Community Mental Health Agency (MCCMH), developmentally disabled. The population of interest in this study was the 860 persons living in Macomb County who are classified by the MCCMH records as being severely retarded. A severely retarded individual is defined by the American Association on Mental Deficiencies as "One who has significantly subaverage intellectual functioning existing concurrently with deficits in adaptive behavior which are manifested during the developmental period" (Fogelman, 1974, p. 5). The term adaptive behavior is defined as the effectiveness of an individual in coping with the natural and social demands of his or her environment.
Instrumentation

The American Association on Mental Deficiencies (AAMD) Adaptive Behavior Scale was used for data collection. The scale (see Appendix A) is a behavior rating scale for mentally retarded, emotionally maladjusted, and developmentally disabled individuals. It can be used with other handicapped persons as well. It was designed by the AAMD to provide objective descriptions and evaluations of an individual's adaptive behavior.

The Development of the Scale

The original Adaptive Behavior Project was jointly sponsored by Parsons State Hospital and Training Center in Kansas; the American Association on Mental Deficiency, Washington, D.C.; and the National Institute of Mental Health, Bethesda, Maryland. The scale consists of two parts. Part One is the product of a comprehensive review of the existing behavior rating scales in the United States and Great Britain. The scale has undergone numerous modifications as a result of intensive items analysis. The scale items were evaluated and selected by the AAMD on the basis of (a) their interrater reliability, (b) their effectiveness in discriminating among institutionalized retarded persons who had been previously classified at different adaptive behavior levels according to the AAMD Manual on Terminology and Classification in Mental Retardation, and (c) their effectiveness in discriminating among adaptive behavior levels while the variance due to measured intelligence was controlled.
The Organization of the Scale

Part One of the Adaptive Behavior Scale (see Appendix A) is organized along developmental lines and is designed to evaluate an individual's skills and habits in 10 behavior domains (coherent groups of related activities) considered important to the development of personal independence in daily living. It is composed of two broad sets of behaviors. The first includes those which are common to all and which facilitate easy social functioning in any setting. The second includes those which, while essential in some settings, are varied in both their importance and their mode of performance between different age groups, different cultures and subcultures. The 10 behavior domains and 21 subdomains are illustrated in Table 1.

Part Two of the scale is the product of extensive survey of the social expectations placed upon retarded persons, both in residential institutions and in the community. The description of these social expectations was obtained empirically from an analysis of large numbers of "critical incident" reports provided by ward personnel in residential institutions, by day-care instructors, and by special education teachers in public school systems.

Part Two of the scale is designed to provide measures of maladaptive behavior related to personality and behavior disorders. The 14 domains enveloped by Part Two of the scale are enumerated in Table 2.
Table 1
American Association on Mental Deficiency
Adaptive Behavior Scale\(^a\)

<table>
<thead>
<tr>
<th>Behavior domains</th>
<th>Subdomains</th>
</tr>
</thead>
<tbody>
<tr>
<td>Independent functioning</td>
<td>Eating</td>
</tr>
<tr>
<td></td>
<td>Toilet use</td>
</tr>
<tr>
<td></td>
<td>Cleanliness</td>
</tr>
<tr>
<td></td>
<td>Appearance</td>
</tr>
<tr>
<td></td>
<td>Care of clothing</td>
</tr>
<tr>
<td></td>
<td>Dressing and undressing</td>
</tr>
<tr>
<td></td>
<td>Travel</td>
</tr>
<tr>
<td></td>
<td>General independent functioning</td>
</tr>
<tr>
<td>Physical development</td>
<td>Sensory development</td>
</tr>
<tr>
<td></td>
<td>Motor development</td>
</tr>
<tr>
<td>Economic activity</td>
<td>Money handling</td>
</tr>
<tr>
<td></td>
<td>Shopping skills</td>
</tr>
<tr>
<td>Language development</td>
<td>Expression</td>
</tr>
<tr>
<td></td>
<td>Comprehension</td>
</tr>
<tr>
<td></td>
<td>Social language development</td>
</tr>
<tr>
<td>Numbers and time</td>
<td></td>
</tr>
<tr>
<td>Domestic activity</td>
<td>Cleaning</td>
</tr>
<tr>
<td></td>
<td>Kitchen duties</td>
</tr>
<tr>
<td></td>
<td>Other domestic activities</td>
</tr>
<tr>
<td>Vocational activity</td>
<td></td>
</tr>
<tr>
<td>Self-direction</td>
<td>Initiative</td>
</tr>
<tr>
<td></td>
<td>Perseverance</td>
</tr>
<tr>
<td></td>
<td>Leisure time</td>
</tr>
<tr>
<td>Responsibility</td>
<td></td>
</tr>
<tr>
<td>Socialization</td>
<td></td>
</tr>
</tbody>
</table>

\(^a\)Reprinted with permission from the American Association on Mental Deficiencies.
Table 2

American Association on Mental Deficiency
Maladaptive Behavior Scale Domains

<table>
<thead>
<tr>
<th>Domain</th>
</tr>
</thead>
<tbody>
<tr>
<td>Violent and destructive behavior</td>
</tr>
<tr>
<td>Antisocial behavior</td>
</tr>
<tr>
<td>Rebellious behavior</td>
</tr>
<tr>
<td>Untrustworthy behavior</td>
</tr>
<tr>
<td>Withdrawal</td>
</tr>
<tr>
<td>Stereotyped behavior and odd mannerisms</td>
</tr>
<tr>
<td>Inappropriate interpersonal manners</td>
</tr>
<tr>
<td>Unacceptable vocal habits</td>
</tr>
<tr>
<td>Unacceptable or eccentric habits</td>
</tr>
<tr>
<td>Self-abusive behavior</td>
</tr>
<tr>
<td>Hyperactive tendencies</td>
</tr>
<tr>
<td>Sexually aberrant behavior</td>
</tr>
<tr>
<td>Psychological disturbances</td>
</tr>
<tr>
<td>Use of medications</td>
</tr>
</tbody>
</table>

\(^a\)Reprinted with permission from the American Association on Mental Deficiencies.

The lowest possible value on the scale that one could get is zero. Since the scale is directly related to the number of certain types of behaviors present, theoretically there is no upper limit for the scores. No normative data is available on these scales.

In interpreting the range of scores of the 10 individuals in the study herein, the age range and the total possible scores for
the specified number of persons in residential institutions are illustrated in Appendix F.

To maintain confidentiality the 10 clients are not identified by age. In Part One, the higher the score the more adaptive behavior skills the individual has in that domain.

The interpretation of adaptive behavior by the individuals in Part One ranges in the 30th to the 70th percentile when compared to institutionalized persons.

In Part Two, the higher the score, the more behavior problems the individual has in that domain. The interpretation of maladaptive behavior by the individuals in Part Two ranges in the 50th to the 90th percentile when compared to institutionalized persons.

The Administration of the Scale

The scale is designed to permit administration by people without a great deal of special training, as well as by professionals. It is used by institutional aides and nurses, parents, outreach workers, community service technicians, teachers, workshop supervisors, home trainers, and protective service workers, as well as by psychologists, social workers, speech and hearing personnel, and other more specially trained professions.

Some users of the scale ignore certain domains, subdomains, and items which are not useful or needed in a specific circumstance. For example, the ability to change money is irrelevant where no cash is provided.
Some items deal with behaviors which are discouraged by institutions in which residents are housed. An example of such a discouraged activity might be the use of a telephone. In some cases, behaviors that are not possible for some people to perform because the opportunity to do so does not exist are also included. An example of such a behavior would be eating in a restaurant, since a resident of an institution rarely has the opportunity to do so. Finally, some of the items in Part Two describe behaviors which need not be considered maladaptive for very young children. For example, pushing others is a normal trait for young people. In these instances, you must still complete the rating; give the person credit for the task described in the item if you feel absolutely certain that he or she can and would perform it without additional training had he or she the opportunity to do so. When you are later scoring the scale, you will be granting the appropriate numbers of points for these items, so that no one is penalized because of situations beyond his or her control. It must be kept in mind that the ranges of scores do not indicate an average for people in general and do not connote normality, rather they imply an average for developmentally disabled persons in institutions, within the limits of the normative sample used.

The Reliability and Validity of the Scale

In order to assess the reliability of the AAMD Adaptive Behavior Scale, it was administered by the American Association on Mental Deficiency to a total of 133 residents at three state training
schools in 1973. According to Fogelman (1974), each resident was rated independently by two ward personnel. Reliabilities of Part One domain scores were estimated by Pearson product-moment correlation coefficients between the pairs of independent ratings from two different shifts.

The reliabilities differ from one domain to another. In some domains, the reliabilities differed considerably between the institutions. The mean reliabilities for the three institutions ranged from .93 for "Physical Development" to .71 for "Self-Direction." An .86 mean reliability was developed for all domains in Part One.

Factor analysis of all domains scored delineated three major dimensions: personal independence, social maladaptation, and personal maladaptation. Personal independence was defined by (a) the behavior domains that represent the individual's skills and abilities required to maintain his or her personal independence, and by (b) the behavior domains that suggest the presence of autonomy or motivation to manage his or her personal affairs. Social maladaptation suggests a general dimension of extra-punitive antisocial behavior disorders defined by the social maladaptation factor.

According to Fogelman (1974), only a few studies have been done with regard to the practical validity of the scale. However, there is evidence, based on a study of 41 institutionalized retarded persons ranging in age from 10 to 13, that all of the Part One domain scores discriminated significantly between those who had been previously classified at different levels of adaptive behavior by clinical judgment. Another study, based on 531 institutionalized
retarded adults, indicated that all of the Part One domain scores and some of the Part Two domain scores significantly discriminated among those people who had been placed into five homogeneous administrative units such as medical, educational, vocational, preplacement, and release units in a residential facility for the mentally retarded (Fogelman, 1974).

Procedures Utilized in the Study

The study was designed to answer research questions concerning the mean adaptive and maladaptive behavior scores of severely retarded and developmentally disabled persons who were served by the Macomb County Family Support Program from November 1980 to April 1982 compared to the mean scores of similarly disabled individuals who did not receive the full services of the program.

The initial step in implementing this study was to review 23 families, each of which had a severely mentally impaired developmentally disabled child. The child resided with the family in the natural home and continued maintenance was deemed by this researcher to be "at risk." "At risk" means the family members were undergoing extreme emotional, psychological, or financial stress and tension resulting from caring for their developmentally disabled child on an on-going basis without relief or assistance. Often, for example, when families reached the "at risk" stage, they request immediate removal of their developmentally disabled son or daughter from their home into a licensed facility under the auspices of the Department of Mental Health.
These same families had requested help from the local community mental health services. Often the type of help requested was assistance to the family in placement of the developmentally disabled child, in either a foster home, group home, or nursing home.

There were 23 families who, in 1980, agreed to participate in a program called the Family Support Program. This program was designed to provide parents with (a) direct financial assistance ($16.00 per diem) for the care of their developmentally disabled child, along with (b) the benefit of a 20-hour-a-week in-home trainer in order to provide the family with needed support so as to permit them to retain their child in their home, rather than requesting placement in a Department of Mental Health setting.

The 23 families were informed that only five families could be served by the program and that the participants would be drawn on a random basis. Each of the 23 individual names were singly placed on an identical sized piece of paper and placed in a box. The first five names drawn would comprise those members in the experimental group. The next five names drawn were to comprise the control group. The remaining 13 clients would continue to function as participants of the Macomb County Community Mental Health Agency. They would have access to supportive services as all clients are entitled to receive. They would, however, not be given any special consideration for specialized services at this time.

Control group members received only existing supportive services through the local community mental health agency. Experimental group members received the following services:
1. $16.00 per diem.

2. A 20-hour-a-week in-home trainer. A trainer is defined as a paraprofessional who works directly with the client to increase skills, development, and/or minimized inappropriate behaviors.

3. Existing supportive services through the local community mental health agency. Supportive services are defined as diagnostic evaluation, vocational development counseling, psychiatric assistance, residential and respite care.

Each client of the Macomb County Family Support Program was required to meet the following criteria:

1. Residency in county.

2. Severe mental retardation and one of the following:

   A. Multiple handicaps (mental retardation, cerebral palsy, epilepsy, and autism).

   B. Severe deficits in adaptive skills (independent functioning, physical development, economic activity, language development, numbers and time, domestic activity, vocational activity, self-direction responsibility, and socialization).

   C. Severe maladaptive behavior (violent and destructive behavior, antisocial behavior, rebellious behavior, untrustworthy behavior, withdrawal, stereotyped behavior and odd mannerisms, inappropriate interpersonal manners, unacceptable vocal habits, unacceptable or eccentric habits, self-abusive behaviors, hyperactive tendencies, sexually aberrant behavior, psychological disturbances, and use of medications).

Clients were screened through an intake process at Life Consultation Center (see Appendix D). Life Consultation Center is a direct service agency of Community Mental Health Services, and provides direct client services to developmentally disabled persons in Macomb County. Primary services are the services needed by clients...
as determined through intake and diagnostic evaluations.

Design of the Study

This study was designed to answer research questions concerning the hypothesized impact of the Family Support Program on the mean adaptive and maladaptive behavior scores of developmentally disabled persons. The adaptive and maladaptive behavior scores would be tested over three time periods resulting in a comparison of the change scores between each consecutive period.

It was hypothesized that there would result an improvement (i.e., increase) in the mean adaptive behavior scores for developmentally disabled persons who participated in the Macomb County Family Support Program compared to those developmentally disabled persons who did not participate in the Macomb County Family Support Program.

It was further hypothesized that there would result an improvement (i.e., decrease) in the mean maladaptive behavior scores for developmentally disabled persons who participated in the Family Support Program compared to those developmentally disabled persons who did not participate in the Family Support Program.

In order to investigate each of the hypotheses developed, and utilizing the data extracted from the evaluation instrument discussed previously, a comparison of mean scores using the \( t \) test for independent means for comparing adaptive and maladaptive behaviors of participants in the experimental and control groups was calculated. The .05 alpha level was used for all tests. These scores
were captured immediately prior to the onset of the program and for three consecutive 6-month intervals thereafter.

Comments relating to the analysis of data are included in the next chapter following the discussion of each hypothesis.

Summary

This chapter presented a description of the population of interest as well as a discussion of the instrument used to collect data. In addition, the design of the procedures used to interpret the data was given. The next chapter will address the results of the data interpretation procedures.
CHAPTER IV

RESULTS

In this chapter the findings of this study are reported. It should be remembered that the purpose of the study was to determine whether or not developmentally disabled individuals receiving in-home support services from the Macomb County Family Support Program would experience an improvement in their adaptive and maladaptive skill levels. In the first section of this chapter is a review of the data collection procedure, while the second section of this chapter reviews information regarding the types of supportive services provided to the two groups investigated. In the final section of this chapter, the results related to the two hypotheses investigated are presented.

Review of Data Information

Data collected contain information regarding characteristics of the individuals who participated in the Macomb County Family Support Program. The information collected regarding adaptive behavior (see Table 1) was extracted from Part One of the American Association on Mental Deficiencies Adaptive Behavior Scale (see Appendix A), and covered the following 10 domains: (1) independent functioning, (2) physical development, (3) economic activity, (4) language development, (5) numbers and time, (6) domestic activity, (7) vocational activity, (8) self-direction, (9) responsibility, and
(10) socialization.

The data collected regarding maladaptive behavior (see Table 2) were extracted from Part Two of the American Association on Mental Deficiencies Adaptive Behavior Scale and covered the following 14 domains: (1) violent and destructive behavior, (2) antisocial behavior, (3) rebellious behavior, (4) untrustworthy behavior, (5) withdrawal, (6) stereotyped behavior and odd mannerisms, (7) inappropriate interpersonal manners, (8) unacceptable vocal habits, (9) unacceptable or eccentric habits, (10) self-abusive behavior, (11) hyperactive tendencies, (12) sexually aberrant behavior, (13) psychological disturbances, and (14) use of medications.

Data captured regarding both adaptive and maladaptive behaviors, were collected beginning with the inception of the program and for each 6-month interval thereafter. The program covered the period from November 1980 to April 1982.

Review of Services Provided to Control and Experimental Groups

The control group received supportive services provided by the Macomb County Life Consultation Center. These services included: (a) diagnostic evaluation, (b) vocational development counseling, (c) psychiatric assistance, (d) residential placement, and (e) respite care. In addition to the supportive services provided by the Macomb County Life Consultation Center, the experimental group received: (a) $16.00 per diem and (b) a 20-hour-a-week in-home trainer.
Test of the Hypotheses

Hypothesis 1—There is a greater improvement in the mean adaptive behavior scores for developmentally disabled persons who participated in the Family Support Program compared to those developmentally disabled persons who did not participate in the Family Support Program.

In order to measure the hypothesized increase (i.e., improvement) in adaptive behavior skills for the experimental group compared to the increase in adaptive behavior skills of the control group, both groups were tested at the inception of the Macomb County Family Support Program. Subsequent testing was conducted for three 6-month intervals thereafter. Changes which occurred in each group were then compared to each other. The measurement instrument used to produce the mean adaptive skill level of each group was Part One of the American Association on Mental Deficiencies Adaptive Behavior Scale (see Appendix A).

The results of the testing of the American Association on Mental Deficiencies Adaptive Behavior Scale present the following information: (a) Part One mean scores (see Table 3) and (b) comparison of change scores (see Table 4).

The mean adaptive behavior skill level score (see Table 3) produced at the inception of the program (Time 1) for the experimental group which received the full services of the Family Support Program was 84.60. This score increased to 100.80 after 6 months (Time 2). For the control group which received only existing supportive
### Table 3
**American Association on Mental Deficiencies**
**Adaptive Behavior Scale—Part One**
**Mean Scores**

<table>
<thead>
<tr>
<th>Data Collection Period</th>
<th>Time 1</th>
<th>Time 2</th>
<th>Time 3</th>
<th>Time 4</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Experimental group</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(n = 5)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>84.60</td>
<td>100.80</td>
<td>106.60</td>
<td>109.60</td>
</tr>
<tr>
<td>SD</td>
<td>10.18</td>
<td>1.79</td>
<td>.1</td>
<td>.58</td>
</tr>
<tr>
<td><strong>Control group</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(n = 5)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>111.80</td>
<td>110.40</td>
<td>112.00</td>
<td>110.40</td>
</tr>
<tr>
<td>SD</td>
<td>6.19</td>
<td>6.90</td>
<td>2.51</td>
<td></td>
</tr>
<tr>
<td><strong>Difference</strong></td>
<td>27.20</td>
<td>9.60</td>
<td>5.40</td>
<td>.80</td>
</tr>
</tbody>
</table>

### Table 4
**American Association on Mental Deficiencies**
**Adaptive Behavior Scale—Comparison of Change Scores**

<table>
<thead>
<tr>
<th>Time 1 to Time 2</th>
<th>Time 2 to Time 3</th>
<th>Time 3 to Time 4</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Experimental group</strong> (n = 5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>16.20</td>
<td>5.80</td>
</tr>
<tr>
<td>SD</td>
<td>10.18</td>
<td>1.79</td>
</tr>
<tr>
<td><strong>Control group</strong> (n = 5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>-1.40</td>
<td>8.80</td>
</tr>
<tr>
<td>SD</td>
<td>6.19</td>
<td>6.90</td>
</tr>
</tbody>
</table>

**Comparison of the difference**

<table>
<thead>
<tr>
<th>t score</th>
<th>.94</th>
<th>3.10*</th>
</tr>
</thead>
</table>

*p < .05, df = 8, *t* .05 = 1.86.

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services from Macomb County Community Mental Health, the mean score initially (Time 1) was 111.80, which at the end of 6 months (Time 2) was 110.40. A comparison between the two groups of the change scores for Time 1 versus Time 2 (as illustrated in Table 4) produced a student's $t$ ratio of 3.30 with 8 degrees of freedom which allows one to reject the null hypothesis of no difference between the means using an alpha level of .05.

A comparison of the change scores after 6 months (Time 1 compared to Time 2) demonstrated an increase in the change in adaptive skill levels for those in the experimental group compared to those in the control group. It was, for this time period, appropriate to reject the null hypothesis against the alternate hypothesis at the .05 level that there is an increase in the mean adaptive behavior score for those who participated in the Family Support Program compared to the score of those who did not participate in the Family Support Program.

In comparing the change in adaptive behavior between the two groups for Time 2 (6 months) and Time 3 (12 months), a student's $t$ ratio of .94 is produced which is not sufficiently large to reject the null hypothesis of no difference between the means using an alpha level of .05.

A comparison of the change scores after 12 months (Time 2 compared to Time 3) demonstrated that the change in adaptive skill levels for those in the experimental group compared to those in the control group was not significant at the .05 level. The null hypothesis is, therefore, not rejected for this time period.
In comparing the change in adaptive behavior between the two groups for Time 3 (12 months) and Time 4 (18 months) a student's t ratio of 3.10 was produced, which is sufficiently large to reject the null hypothesis of no difference between the means using an alpha level of .05.

The comparison of the change scores after 18 months (Time 3 compared to Time 4) demonstrated that a comparison of the change in adaptive skill levels for those in the two groups was significant at the .05 level. It was, for this time period, once again possible to reject the null hypothesis against the alternate hypothesis at the .05 level that there is an increase in the mean adaptive behavior score for those who participated in the Family Support Program compared to the score of those who did not participate in the Family Support Program.

Hypothesis 2—There is a greater improvement in the mean maladaptive behavior scores for developmentally disabled persons who participated in the Family Support Program compared to those developmentally disabled persons who did not participate in the Family Support Program.

In order to measure the hypothesized decrease (i.e., improvement) in maladaptive behavior for the experimental group compared to the decrease in maladaptive behavior for the control group, both groups were first tested at the inception of the Macomb County Family Support Program. Subsequently, subjects were tested at the conclusions of each of the following 6-month intervals. Changes which occurred in each group were then compared to each other. The
measurement instrument used to produce the mean maladaptive skill level of each group was Part Two of the American Association on Mental Deficiencies measuring maladaptive behaviors (see Appendix A).

The results of the testing in the American Association on Mental Deficiencies Adaptive Behavior Scale present the following information: (a) Part Two mean scores (see Table 5) and (b) comparison of change scores (see Table 6).

The mean maladaptive behavior skill level score (see Table 5) produced at the inception of the program (Time 1) for the experimental group which received the full services of the Family Support Program was 29.80. This score decreased to 20.60 after 6 months (Time 2). For the control group which received only existing supportive services from Macomb County Community Mental Health, the mean score initially measured (Time 1) equaled 75.60, while at the end of 6 months (Time 2) this group's mean score increased to 78.80. A comparison between the two groups of the change scores for Time 1 versus Time 2 (as illustrated in Table 6) produces a student's $t$ ratio of 1.94 with 8 degrees of freedom which allows one to reject the null hypothesis of no difference between the means using an alpha level of .05.

In comparison the change scores after 6 months (Time 1 compared to Time 2) demonstrated a decrease in the change in maladaptive skill levels for those in the experimental group compared to those in the control group. It was possible for this time period to reject the null hypotheses against the alternate hypotheses at the .05 level that there is a decrease in the mean maladaptive behavior
### Table 5
American Association on Mental Deficiencies
Maladaptive Behavior Scale--
Part Two Mean Scores

<table>
<thead>
<tr>
<th>Data Collection Period</th>
<th>Time 1</th>
<th>Time 2</th>
<th>Time 3</th>
<th>Time 4</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Experimental group (n = 5)</strong></td>
<td>29.80</td>
<td>20.60</td>
<td>13.20</td>
<td>11.60</td>
</tr>
<tr>
<td><strong>Control group (n = 5)</strong></td>
<td>75.60</td>
<td>78.80</td>
<td>86.80</td>
<td>89.60</td>
</tr>
<tr>
<td><strong>Difference</strong></td>
<td>45.80</td>
<td>58.20</td>
<td>73.60</td>
<td>78.00</td>
</tr>
</tbody>
</table>

### Table 6
American Association on Mental Deficiencies
Maladaptive Behavior Scale--
Comparison of Change Scores

<table>
<thead>
<tr>
<th>Time 1 to Time 2</th>
<th>Time 2 to Time 3</th>
<th>Time 3 to Time 4</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Experimental group (n = 5)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>-9.20</td>
<td>-7.40</td>
</tr>
<tr>
<td>SD</td>
<td>11.34</td>
<td>5.22</td>
</tr>
<tr>
<td><strong>Control group (n = 5)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>3.20</td>
<td>8.00</td>
</tr>
<tr>
<td>SD</td>
<td>15.59</td>
<td>14.95</td>
</tr>
</tbody>
</table>

**Comparison of the difference**

| t score | 1.94* | 2.17* | 3.11* |

*p < .05, df = 8, t .05 = 1.86.*

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scores for those who participated in the Family Support Program compared to the scores of those who did not participate in the Family Support Program.

In comparing the change in maladaptive behavior between Time 2 (6 months) and Time 3 (12 months), a student's $t$ ratio of 2.17 was produced, which at the .05 level is significant.

A comparison of the change scores after 12 months (Time 2 compared to Time 3) demonstrated that the change in maladaptive skill levels for those in the experimental group compared to those in the control group was significant at the .05 level. The null hypothesis is, therefore, rejected for this time period.

In comparing the maladaptive behavior between the two groups for Time 3 (12 months) and Time 4 (18 months), a student's $t$ ratio of 3.11 was produced, which at the .05 level is significant.

The comparison of the change scores after 18 months (Time 3 compared to Time 4) demonstrated that a comparison of the change in maladaptive skill levels for those in the two groups was significant at the .05 level. It was, for this time period, once again possible to reject the null hypothesis and accept the alternate hypothesis at the .05 level that there is a difference in decrease in the mean maladaptive behavior score for those who participated in the Family Support Program compared to the score of those who did not participate in the Family Support Program.
Summary

Specifically, there occurred an increase in mean adaptive skill level scores for those who received the full services of the Macomb County Family Support Program compared to those who did not receive these same services in two of the three time periods investigated.

It was further observed that there occurred a decrease in mean maladaptive skill level scores in all of the three time periods investigated, for those who received the full services of the Macomb County Family Support Program, compared to those who did not have the benefit of these same services.

Chapter V offers observations and conclusions that can be extracted from the data analysis presented in this chapter. In addition, recommendations are made for subsequent research and use of this study.
CHAPTER V

OBSERVATIONS, CONCLUSIONS, AND RECOMMENDATIONS

Observations

The purpose of this study was to provide information which would make it possible to determine whether or not the Macomb County Family Support Program has resulted in improvement of adaptive and maladaptive behavior of developmentally disabled persons.

Prior to initiating the study, this researcher had reason to believe that developmentally disabled individuals possess the ability to increase their adaptive behavior and decrease their maladaptive behavior if given financial assistance and in-home support services. For this reason, the hypotheses regarding the suspected change in these behavior levels, following participation in the Family Support Program, were presented and investigated.

Conclusions have been stated regarding the two hypotheses considered in this study. The conclusions were based on the data analysis and on the results of the statistical tests of significance at the .05 alpha level. The data analysis suggested that developmentally disabled persons who receive the full services of the Macomb County Family Support Program can increase their adaptive behavior skills and decrease their maladaptive behavior skills to a greater degree than can those individuals who receive only those services offered by the Macomb County Life Consultation Center.
The changes made by the experimental group in increasing their adaptive behavior and decreasing the maladaptive behavior skill level are greater in the desirable direction, as was hypothesized, than are those changes demonstrated in the control group.

Table 3 provides graphic evidence of the increase in scores measuring mean adaptive skills experienced by the experimental group which received the full services of the Family Support Program. After participating in the program for 18 months, the experimental group experienced a 25-point increase in their adaptive behavior skills by raising their initial mean score of 84.60 to 109.60. Although the control group had an initial mean score measuring their adaptive skill level of 111.80, their mean score after 18 months changed to 110.40, which illustrated a decrease of -1.40.

Table 5 provides evidence of the effectiveness of the Macomb County Family Support Program in effecting a reduction in mean maladaptive behavior scores on the part of those who received its full services as compared to the group which received only limited services from the Macomb County Life Consultation Center. Those who received full services experienced reductions in the mean score measuring their maladaptive behavior of 9.20 after 6 months, 16.60 after 12 months, and 18.20 after 18 months in the program. Those in the control group experienced an increase in the mean score measuring their maladaptive behavior during each of the same time periods. The mean maladaptive behavior score for the experimental group was significantly reduced at the conclusion of the first, second, and third time periods measured.
Only 10 individuals participated in the study. Five of these individuals were chosen at random for the experimental group and five for the control group. The mean adaptive and maladaptive scores, that were initially measured, differed substantially (see Appendix E). A review of Table 3 demonstrates that the initial difference of 27.20 between the two groups in mean adaptive skill levels was reduced to .80 at the end of the program. The wide difference in the initial mean maladaptive score which is attributable to random selection is illustrated in Table 5.

Family Support Program Monthly Evaluation

The parents of each participant in the Family Support Program were asked to complete a monthly evaluation form (see Appendix B). The purpose of this form was to provide information which offered an assessment of the impact of the program on the participants.

The monthly evaluation form itemized the purchases which families made as a result of the financial component of the program. Comments which were made on the form by the parents provided information as to how the Macomb County Family Support Program changed the quality of their family lives on a day-to-day basis. Throughout the duration of the 18-month study, the parental comments made were positive in nature. Comments which provided evidence of the value that the families placed on the services provided by the Family Support Program included:
"By being in the Family Support Program my child and I are working toward common goals stressing greater independence on my child's part and less dependence on me as primary caretaker."

"This program has given us greater incentive to work on objectives enabling our son to be more independent."

"The support program is working to make my household and family function more and more like a normal family."

"Our son is able to get speech therapy twice a week to assist him in his development."

"Since we have had the in-home trainer, our son is more alert and does a lot more things. His attention span is much longer now."

"I've said many times, this is an excellent program for the NATURAL parents, who are trying to keep their children in the home."

"Our 14-year-old son had his first vacation from us in his entire life."

The Family Support Program Monthly Evaluation comments are offered to the readers so as to permit an assessment of the unique concerns of participating families.

Limitations of the Study

A study encompassing a greater number of subjects would have provided greater credibility. There existed, however, financial constraints on the program which resulted in the necessity of limiting the number of participants to 10 developmentally disabled individuals. These same financial constraints resulted in limiting the financial assistance which could be provided to the families of those participating in the experimental group to $16.00 per day.
There did exist a bias in the instrumentation utilized in this study since the AAMD Adaptive Behavior Scale was validated on persons residing within an institutionalized environment. The use of the scale was given to individuals who had spent their entire lives residing in their natural homes. Therefore, some bias was introduced in the scaling of some items. It is apparent that close family members and the social workers administering the instrument could bias in favor of the developmentally disabled person residing in the home.

Another consideration which needs to be mentioned is the fact that receiving financial assistance could be considered a potential bias for the way the parents responded to the evaluator's questions. Some parents could have indicated favorable responses to the questions because of the financial component attached to the program.

It should be noted that the evaluator who did record the data at each time interval, although not directly involved in the ongoing case management of the clients, was nevertheless involved in the process of the program's evaluation.

Conclusions

Developmentally disabled persons who are placed within an institutional setting receive numerous benefits provided through the Department of Mental Health. Such services include day programming, medical attention, and professional supervision. Developmentally disabled individuals who are retained in the family home are penalized by not having access to such support services.
The inequity of service delivery between developmentally disabled persons residing in residential facilities under the auspices of the Department of Mental Health and developmentally disabled persons who reside within the natural home was evidenced by the review of literature. This review indicated that deinstitutionalization of developmentally disabled individuals requires the development of community resources so as to ensure that everyone is able to live in the least restrictive environment.

After 6 years as a professional social worker working with developmentally disabled individuals, this researcher has concluded that the best way to deinstitutionalize individuals is to prevent them from being admitted to an institution in the first place. It is believed that this prevention is best accomplished through early intervention, with parents serving as primary change agents. The Family Support Program, which relied upon parents as primary change agents, gave to those parents the opportunity to maintain their developmentally disabled member in the home. This fact was evidenced by the following comment which was made on the Family Support Program Monthly Evaluation Form (see Appendix B) by the mother of a developmentally disabled person: "The improvements and the financial assistance lets me do normal things I've never been able to do because of the financial drain our child's needs have caused."

Family Support Program—Long-Range Effect

The current trend in the field of mental retardation is toward enabling those who are developmentally disabled to achieve greater
autonomy in community life. The use of a one-to-one relationship has been found by social workers to be effective in accomplishing this and, also, in enriching the social functioning of the individual.

The financial remuneration afforded through the Macomb County Family Support Program to parents who have chosen to retain their developmentally disabled child within the natural home, rather than placing this same person in an institution provided for more autonomy to all family members concerned. Families were able to secure, at their own discretion, the goods and services necessary for their family to survive, cope, manage, and effectively deal with the developmentally disabled member. Further, they were able to secure these goods and services when needed and in the manner most suitable and appropriate for their individual situations.

The Family Support Program resulted in enhancing the individual integrity and dignity of the participating families within their society because they were able to make their own choices regarding their needs. The financial assistance given directly to the participating families permitted this to happen.

The in-home trainer, a unique component of the Family Support Program, offered unlimited value in enhancing the growth and development of the developmentally disabled persons. These paraprofessionals provided invaluable assistance to the families of the developmentally disabled individuals in dealing with the varied behaviors of those individuals. The unique components of assistance afforded by the in-home trainer are as diverse as are the individuals served.
Recommendations

It is hoped that this study will result in additional analysis and research concerning the impact on adaptive and maladaptive behaviors of developmentally disabled persons as the result of receiving resources in the natural home. If additional research is done, it is recommended that if possible, data should be secured from a larger population of developmentally disabled persons living in diverse geographical locations. It is also recommended that future research be conducted over a period of 5 to 10 years.

Expanding the number of subjects in future studies will make it possible to study many of the intervening variables that might affect the ability to alter a developmentally disabled individual's adaptive or maladaptive behavior. It is suggested that additional research may be able to provide answers to some of the unanswered questions which resulted from this study. For example, were the adaptive and maladaptive behaviors of some individuals altered to a great degree while other individuals receiving equal services experienced only slight modifications in their behavior (see Appendix E).

It is recommended that the evaluations at the various intervals be done by a professional who has no vested interest in the outcome of the testing. This would provide the least amount of bias which could creep into a study of this nature.

Each of the subjects in this study functioned in the severe range of developmental disabilities. It is recommended that future study be devoted to the adaptive and maladaptive behavior of those

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who function in other ranges of developmental disabilities. Such other ranges would include profound, mild, or moderate degrees of retardation.

Summary

The purpose of this study was to provide information regarding the effects of the Macomb County Family Support Program on the adaptive and maladaptive behaviors of developmentally disabled persons. The study focused on the adaptive and maladaptive behaviors of developmentally disabled persons for the time period from November 1980 to April 1982.

Subjects for the study were between the ages of 4 and 20, residents of Macomb County, and actively serviced by the Macomb County Life Consultation Center. Data used in the study were generated by the American Association on Mental Deficiency Adaptive Behavior Scale.

The effects of participation in the Family Support Program offered support for the two hypotheses tested. A measurable increase in adaptive behavior and a decrease in maladaptive behavior was evidenced by those developmentally disabled persons who participated in the Macomb County Family Support Program as experimental group members, compared to those members who comprised the control group.
APPENDICES¹

¹Note: Appendices A, B, and C have been reduced to 77% of their original size.
Appendix A

Adaptive Behavior Scale
PLEASE NOTE:

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56-80
83

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AAMD ADAPTIVE BEHAVIOR SCALE

1974 Revision

Charles J. Fogelman, Editor

AAMD ad hoc Committee on the Adaptive Behavior Scale

Chairman, Arnold A. Madow
Henry Leland
Bruce C. Libby
Kazuo Nihira

George Soloyanis, Executive Director

American Association on Mental Deficiency
5201 Connecticut Avenue, N.W.
Washington, D.C. 20015

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Appendix B

Family Support Program Monthly Evaluation
Appendix C

Family Support Program Extension Letter
October 1, 1981

C. Patrick Babcock, Acting Director
Michigan Department of Mental Health
Lewis Cass Building
Lansing, Michigan 48926

Dear Mr. Babcock:

Macomb-Oakland Regional Center and Macomb County Community Mental Health are co-sponsoring a "Family Support Project" funded through a D.M.H. grant. In a nutshell, the project is demonstrating that direct family support, in the form of financial assistance ($16.00 per diem), in-home trainers, and casemanagement services, can often prevent institutionalization. At this point, 12 months into an 18 month project, our data suggests that we can maintain a severely impaired developmentally disabled person in his/her own home for about $12,000 per year (plus day program costs for adults - an additional $5,500). This compares to $50,000 per year total cost for inpatient services at M.O.R.C. and $30,000 per year total cost in small group home placements.

As we move into the last 6 months of the project, we are specifically concerned about the effects of withdrawing support to participating families, and more generally concerned at the prospect of families resorting to institutional admission in lieu of coping with the often overwhelming financial burden of maintaining their developmentally disabled offspring in their own home. We are proposing that the Department of Mental Health adopt a policy that would allow per diem payments and in-home trainer services to families of "at risk" (institutional chronic) developmentally disabled persons, who are willing to maintain these people in their natural homes.

We are presently in the process of evaluating our data with John Jokisch from your staff, and we hope to secure his support for the proposal to formally incorporate "family support" into the array of service alternatives available to developmentally disabled people and their families. We would appreciate the opportunity to further discuss this proposal with you and your staff at the earliest mutually convenient time.

Sincerely,

Donald I. Hembirk, Jr.  
Program Director  
Developmental Disabilities Services  

Donald I. Hembirk, Jr.  
Program Director  
Developmental Disabilities Services  

DIH/GP/sg

Gerald Provencal  
Facility Director  
M.O.R.C.
Appendix D

Life Consultation Center Intake Process
Intake Interview—Preparation of all necessary forms:

1. DMH statistical face sheet.
2. Medical overview.
3. Request for physical.
4. All academic background and records.
5. Macomb County Community Mental Health face sheet.

Social Summary Evaluation:

1. Description of client.
2. Family background.
4. Educational/vocational history.
5. Financial status.
6. Medical/dental history.
7. Reason(s) for request of mental health services.
Appendix E

Adaptive and Maladaptive Behavior Scores
### Part One—Adaptive Behavior Scores\(^a\)

<table>
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\(^a\)Subjects were not mentioned by name so as to maintain confidentiality.
### Part Two—Maladaptive Behavior Scores\(^a\)

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\(^a\)Subjects were not mentioned by name so as to maintain confidentiality.
Appendix F

Score Interpretations
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