An exploratory study of family care in the redesign of a system of human services for the mentally retarded in upstate New York.

Vincent P. Lombardi

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AN EXPLORATORY STUDY OF
FAMILY CARE IN THE REDESIGN OF A
SYSTEM OF HUMAN SERVICES
FOR THE MENTALLY RETARDED IN UPSTATE NEW YORK

A Dissertation
by
Vincent P. Lombardi

Submitted to the Graduate School of the University of Massachusetts in partial fulfillment of the requirements for the degree of
DOCTOR OF EDUCATION

December 1974

Human Systems Design and Administration
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AN EXPLORATORY STUDY OF
FAMILY CARE IN THE REDESIGN OF A
SYSTEM OF HUMAN SERVICES
FOR THE MENTALLY RETARDED IN UPSTATE NEW YORK
(December 1974)

Vincent Lombardi, M.S. in Education, Wagner College, N.Y.

Directed by Dr. Susan M. Campbell

This is an exploratory study the purpose of which is to systematically examine one aspect of a variety of alternatives to institutional care. Because of the paucity of research in the area, uncertainties about the nature of home care and the supportive and programmatic services, the small size of the population to be studied and the acceleration of changes stimulated by the Unified Services Act it was not possible to offer hypotheses. Instead this survey attempted to obtain data that could shed some light on the factors which positively and negatively influence the quality of life of home care residents.

A forced choice questionnaire was developed after extensive consultation with staff members from the two Davies Developmental Center Departments concerned with home care - The Community Services and the Social Services Departments. A search of the literature did not yield substantive information that could be used in the construction of the questionnaire. In essence
the study explored virgin territory particularly in relation to the implementation of the policies of the state Department of Mental Hygiene and its Developmental Center. The data collected by mail had a one-hundred per cent response from the population of thirty-six home care parents who collectively have assumed responsibility for a total of seventy-seven mentally retarded children and adults. Because of the lack of resources and the pressure of departmental and administrative fiats frequency distributions alone were utilized in the analysis of data.

Four areas of the home care setting were addressed:
a) demographic information on residents, b) supportive services, c) characteristics of the setting and d) the perspectives of the family care parents. The latter, since it was considered by numerous professional colleagues to be the crucial variable was the focus of fifty percent of the questions. The remaining questions were evenly distributed on the three remaining variables.

In terms of the data, the findings present a rather mixed picture. On the one hand family care parents are the most effective recruiters of new homes. At the same time there is a willingness to take in more residents. The fact that they are not more "multiple-resident" homes may be explained in part by the lack of space, size of family and so forth. The small number of problems reported by home care parents is rather surprising; the fact that they feel the need to
discuss resident care techniques is not. However their expressed preference to "talk things over" with peers rather than with staff may be significant for a number of reasons. The fact that they were recruiters and were willing to take more residents suggests that whatever the problems or difficulties in providing home care suggests a number of possible conclusions: a) the satisfactions experienced by these surrogates is adequate; b) the income derived provides a stable base for relatively low income families in a region in which significant areas can be characterized as economically depressed. In support of this conclusion, a number of social workers have reported that several home care parents have indicated a willingness to move into larger homes in order to take more residents. Thus home care serves the larger purposes of improving the quality of life not only of the residents, but for the home care family itself.

The personal development which occurs through enriched human relationships for the individuals placed is a major goal of the Developmental Center in placing the mentally retarded in home care. There is modest support in the finding that this goal is achieved in many, if not most instances.
TABLE OF CONTENTS

LIST OF TABLES

ABSTRACT

Chapter I Purpose and Background

Mental Retardation: Historical Perspective

The Mentally Retarded As A Hazard

The Divine Visitation And The Demonic Possessed View of the Retarded

The Retarded As The Eternal Child

The Retarded As A Social And Economic Burden

The Retarded As A Sub-human

The Retarded As A Social Menace

The Retarded As A Medical Problem

The Development Of The Custodial Model

Effects of Custodial Care

Objective Of The Study

Family Care: History And Current Status

The Delivery of Family Care Service

Home Care: The Facts of Life

Review of Relevant Studies

Page

1
2
4
4
4
4
5
7
9
12
14
19
20
23
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Chapter II</th>
<th>Institutional Change: Internal and External</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>The Change Problem Defined..................</td>
</tr>
<tr>
<td></td>
<td>The Need For Change...........................</td>
</tr>
<tr>
<td></td>
<td>The Setting For Change.......................</td>
</tr>
<tr>
<td></td>
<td>The Davies Developmental Center: History....</td>
</tr>
<tr>
<td></td>
<td>Improving The Quality Of Life................</td>
</tr>
<tr>
<td></td>
<td>Returning Residents To The Community.........</td>
</tr>
<tr>
<td></td>
<td>Family Care....................................</td>
</tr>
<tr>
<td></td>
<td>Vocational Rehabilitation....................</td>
</tr>
<tr>
<td></td>
<td>New Program Approach..........................</td>
</tr>
<tr>
<td></td>
<td>Accreditation..................................</td>
</tr>
<tr>
<td></td>
<td>Program Coordination..........................</td>
</tr>
<tr>
<td></td>
<td>Community Service Team.......................</td>
</tr>
<tr>
<td></td>
<td>Reducing Overcrowding and Resettlement of Residents Closer to Home.</td>
</tr>
<tr>
<td></td>
<td>Goals And Objectives Of Change..............</td>
</tr>
<tr>
<td></td>
<td>Unified Services..............................</td>
</tr>
<tr>
<td></td>
<td>Implementation At The Davies Developmental Center.</td>
</tr>
<tr>
<td></td>
<td>The Continuum And Spectrum Of Services.......</td>
</tr>
<tr>
<td></td>
<td>Evaluation.................................</td>
</tr>
<tr>
<td></td>
<td>Factors Impeding Change.....................</td>
</tr>
</tbody>
</table>
## TABLE OF CONTENTS

### CHAPTER II (Continued)

Factors Impeding Change (Continued)

<table>
<thead>
<tr>
<th>Topic</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Institutional Inertia As An Obstacle</td>
<td>50</td>
</tr>
<tr>
<td>Financial Problems</td>
<td>51</td>
</tr>
<tr>
<td>Stereotype Perception Of The Retarded</td>
<td>52</td>
</tr>
<tr>
<td>The Momentum of System Maintenance</td>
<td>52</td>
</tr>
<tr>
<td>The Law As An Obstacle</td>
<td>53</td>
</tr>
<tr>
<td>Polarization As An Obstacle</td>
<td>53</td>
</tr>
<tr>
<td>Factors Conducive To Change</td>
<td>55</td>
</tr>
<tr>
<td>Public Awareness</td>
<td>55</td>
</tr>
<tr>
<td>Advances In Science</td>
<td>55</td>
</tr>
<tr>
<td>Increased Professional Interest</td>
<td>56</td>
</tr>
<tr>
<td>The Parents Of Retarded Children</td>
<td>57</td>
</tr>
</tbody>
</table>

### CHAPTER III Design And Methodology

<table>
<thead>
<tr>
<th>Topic</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Need For The Study</td>
<td>60</td>
</tr>
<tr>
<td>The Study Design</td>
<td>61</td>
</tr>
<tr>
<td>Selection Of The Respondent's Data Collection</td>
<td>62</td>
</tr>
<tr>
<td>Measurement Device</td>
<td>64</td>
</tr>
</tbody>
</table>
TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>CHAPTER IV</th>
<th>Characteristics of the Family Care Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Selected Characteristics of Family Care Home</td>
<td>67</td>
</tr>
<tr>
<td>Characteristics of the Residents</td>
<td>71</td>
</tr>
<tr>
<td>Supportive Services</td>
<td>76</td>
</tr>
<tr>
<td>Perspectives of Family Care Parents</td>
<td>80</td>
</tr>
<tr>
<td>CHAPTER V</td>
<td>Summary and Implications</td>
</tr>
<tr>
<td>93</td>
<td></td>
</tr>
<tr>
<td>APPENDIX</td>
<td>111</td>
</tr>
<tr>
<td>BIBLIOGRAPHY</td>
<td>158</td>
</tr>
<tr>
<td>TABLE</td>
<td>PAGE</td>
</tr>
<tr>
<td>-------</td>
<td>------</td>
</tr>
<tr>
<td>1</td>
<td>68</td>
</tr>
<tr>
<td>2</td>
<td>69</td>
</tr>
<tr>
<td>3</td>
<td>70</td>
</tr>
<tr>
<td>4</td>
<td>73</td>
</tr>
<tr>
<td>5</td>
<td>74</td>
</tr>
<tr>
<td>6</td>
<td>75</td>
</tr>
<tr>
<td>7</td>
<td>77</td>
</tr>
<tr>
<td>8</td>
<td>78</td>
</tr>
<tr>
<td>9</td>
<td>79</td>
</tr>
<tr>
<td>10</td>
<td>82</td>
</tr>
<tr>
<td>11</td>
<td>83</td>
</tr>
<tr>
<td>12</td>
<td>84</td>
</tr>
<tr>
<td>13</td>
<td>86</td>
</tr>
<tr>
<td>14</td>
<td>87</td>
</tr>
<tr>
<td>15</td>
<td>88</td>
</tr>
<tr>
<td>16</td>
<td>90</td>
</tr>
<tr>
<td>17</td>
<td>94</td>
</tr>
<tr>
<td>18</td>
<td>95</td>
</tr>
<tr>
<td>19</td>
<td>96</td>
</tr>
</tbody>
</table>
CHAPTER I

Mental Retardation: The Historical Perspective

It is generally recognized that no disadvantaged group has suffered more from society's abuse, neglect and misunderstanding than the mentally retarded. Simple historic facts substantiate this accusation. But merely recounting these occurrences of abuse, neglect and misunderstanding would fail to present the drama (for it is no less than that) of the evolution of our concepts and treatment of the retarded. For the concepts behind this evolution are indeed in the realm of the spirit and of human understanding and moral values. A brief review of some of the differing historical concepts of mental retardation which have influenced the treatment, practices and kinds of facilities for those identified as mentally retarded can help pinpoint this process of evolution.

The Retarded as a Hazard. History has left no account of the status of the mentally limited in legendary times, nor is there much of a record of mental retardation among the earlier races of men. What little is known is learned from the skeletal remains. From these relics we know that microcephaly and hydrocephaly existed and therefore mental retardation was also present. It is likely that from man's earliest thinking moments exceptional children and adults have been recognized as a group of individuals needing special treatment.
In hunting societies nature herself eliminated the handicapped and the exceptional by the process of "survival of the fittest." They were unable to combat or collaborate nature, nor could they fight their enemies with efficiency; premature death was the most frequent result.

As small hunting groups developed into tribes, the mentally handicapped became a more serious problem. They lacked judgment, could not assume responsibility for their own persons and slowed the movements of the roving tribe.

They probably were poor hunters, made little contribution to the group and became an actual economic hazard to the whole tribe. They were in danger from wild beasts and tribal foes. They could not be trusted to stand guard. In attacks they often needed the help of their fellow tribesmen. They were more easily captured, were thought to give information as to the tribes' battle plans, hiding places and food caches. Moreover, when captured, they often were the victims of cruel tribal customs. It is also believed that some were put to death by their own tribesmen as a means of protecting the entire group.

The Divine Visitation and Demoniac Possessed View of the Retarded. Epic poems and other verbal accounts now transcribed often describe certain individuals as being possessed or irresponsible because of their behavior and unusual conduct. With physical afflictions the medical men
of that day intuitively turned to the afflicted part in their treatment. However, with illness of a mental nature they did not know how to administer treatment or where the treatment should be applied. With no physical basis being found, it is not surprising that such unusual conditions were viewed as a divine visitation.

With the exception of Hippocrates who disputed the idea of divine visitation as a cause of "mental maladies", there was no outstanding medical man to contend that some causes of mental dysfunction could have a physical base until almost modern times. The ancient Greeks, however, continued the practice of early primitive tribes by putting "the unfit" to death. It is usually reported that in Spartus, under the Laws of Lycurgus, imperfect children and idiots were exposed to the elements in the great pit of Taygetus and that the Athenians put deaf children to death.

In the early Christian era we find that a change to a newer philosophy was beginning to grow. The care of the feeble-minded as well as the "demon-possessed", the physically infirmed and the poor was preached by Christ as well as Confucius and Mohammed. Under the liberalizing influence of Christianity, a greater concern for the less gifted grew and many of the old fears and cruel treatment were mitigated or disappeared altogether. Other more contemporary concepts of the mentally retarded include:
The Retarded as the Eternal Child. This view suggests that the retarded individual will never grow to emotional and psychological adulthood. He suffers in silence in a condition over which he has no control and should not be held responsible for his actions. He will never fully develop, therefore, why try to make him more independent.

The Retarded as a Social and Economic Burden. Here the retarded are considered unable to take part in ordinary social life or contribute to the nation's security and economy. They must be taken out of society and cared for as a necessary burden. They are, in effect "surplus population".

The Retarded as Subhumans. This concept is closely akin to the retarded as a social and economic burden, but more insidious. It often equates the functioning and behavior of retarded individuals with that of animals. They are considered subhuman and must be separated from society. Since they are less than human, the facilities which provide care should take on aspects of a zoo or warehouse.

The Retarded as a Social Menace. Dr. Henry Goddard's book published in 1914 titled, Feeble Mindedness - Its Causes and Consequences, has done enormous harm and a great injustice to the mentally retarded. This volume was accepted as a scientific effort which "proved" that the mentally retarded were responsible for almost all moral decay, crime, prostitution, mental and physical ills in society. This book's distortions
were responsible for the many laws in various states permitting authorities to sterilize the mentally retarded and to institutionalize great numbers of individuals so labeled. In New York State, one institution (now known as The Newark State School) originally was built and named The Institution for Feeble-Minded Women of Child-Bearing Age.

The Retarded as a Medical Problem. Here the retarded are viewed as chronically ill individuals. Because of this, although there is no known cure for mental retardation, the physician becomes the key person in making decisions which effect the retarded individual and his family.

Even today, physicians have been known to advise parents to institutionalize an apparently retarded newborn baby without considering the effects on the child and its family. In institutions run on the medical model the physician has the responsibility and right in making educational and social decisions which will effect the child. Within this treatment model all institution personnel emulate the medical model. Fun and games become play or recreation therapy. Art is relegated to a more lowly position and is no longer painting, music, dance or drama but rather art or occupational therapy or music therapy, dance therapy or drama therapy.

The evolution of some of the historical concepts of mental retardation described above are heavily interrelated and indeed persist today. It is evident upon close scrutiny that
many of them do not view the retarded individual as a developing person entitled to rights and privileges generally granted to other members of society. Some of the concepts fail to recognize that the retarded can and should be trained in every way possible to function in and to contribute to society in order that they may better share in the benefits of that society.

In today's society we are socialized to value many qualities and characteristics the mentally retarded do not possess. The retarded for the most part are not the best looking people in our society; generally they are not the wealthiest, or the most verbal. They are the least capable of great individual social or economic accomplishments. They do, however, possess all the human-emotional qualities found in the non-retarded. They feel a need to be loved and to love; they can be generous, kind or compassionate as anyone else; they require acceptance and a worthy self-image. Conversely they can be self-centered, unduly ambitious and in their limited way remarkably manipulative.

However, once society has identified a group as being different, it becomes relatively easy to say and do all sorts of unwholesome things to that group. Our history is replete with examples of such stigmatization; the American Indian became a savage who could be killed without compunction as were the "Japs" or "Krauts" in World War II. In similar fashion our society had identified the retarded as individuals whose care, treatment and training are not a first priority
within the community or within the institution we provide for them. This attitude has been prevalent throughout the United States and is partly responsible for allowing the unproductive mode of custodial care to develop and persist as an acceptable model of service to mentally retarded persons in the community and in institutions.

The Development of the Custodial Care. It is important in tracing the development of this model to state that the first institutions in America began with the highest principles of community service in mind. Massachusetts opened the very first institution for the retarded on October 1, 1848; this example was followed by New York in 1851, Pennsylvania in 1854 and Ohio in 1857. In less than a decade four states had committed themselves to serving the retarded whose needs were almost totally neglected up until this time. Their founders never intended them to become what has been termed 'custodial bins' or 'human warehouses'.

These first facilities were greatly influenced by the work of Edouard Seguin who was the major force in developing the physiological method which furnished the principles of, and impetus to, the first organized efforts in behalf of the retarded in practically all the European countries and in the United States. Seguin's physiological program was divided into two main areas, the training of muscles and the training of senses. All of the early institutions were organized with the
hope that by applying the physiological method they could largely overcome, if not entirely cure, the limitations mental retardation imposes on its victims and that these individuals would improve to such an extent that they could return to the community able to manage their own affairs and earn a living.

It became apparent in time that severe retardation could not be cured or even greatly improved by the physiological method or any known treatment modality. Emphasis was then placed on the less severely retarded children. In fact, one of these early facilities changed its admission criteria and would only accept higher functioning retarded individuals, leaving the difficult task of training and caring for the more severely retarded to other institutions. In many instances improvement in self-help skills, in behavior, in physical and occupational ability was achieved. However, only a very few of the residents after years of training were able to return to the community on a self-supporting basis. This development had a profound effect upon the original purposes and goals of the institution to train and habilitate retarded children and then return them to the community better able to contribute to and benefit from social living.

Now the boys and girls who were admitted to these facilities were young men and young women. They were still highly dependent individuals and their parents (older now) besieged, begged and pressured the institution to retain their children
instead of returning them to a community which offered little or nothing to sustain them. To compound this problem the institution was faced with overwhelming demands to accept more individuals of all ages and all degrees of retardation.

Gradually it became clear to the state authorities that the original intents and hopes of the institution had to be abandoned. There were almost no services in the community to which residents of the institution could be released other than their own families who, for the most part, were strong in their desires to have their child or relative remain at the facility. More and more parents looked to the institution as perhaps the only hope in obtaining service for their children or relief for themselves and they clamored for admissions to these facilities. Various states responded by enlarging facilities and admitting residents of all ages and degrees of retardation on an indefinite basis. This was to become a pattern of care. The era of custodial care had begun and, by 1958 all of the states except one maintained institutions for the retarded. In 1970 over 200,000 persons in the United States were maintained in publicly-operated facilities.

Effects of Custodial Care. Many negative effects followed the acceptance of the custodial care model of service for the retarded in both the institution and the community. Some of the historical concepts about the retarded people were reinforced and compounded. The community, for the most part,
continued to make only the feeblest of efforts in their behalf. Now the rationale became — if they are that bad, they belong in an institution where they will receive the care they require; The "out of sight, out of mind" notion combined with the self-fulfilling prophecy of "there is so little you can do with them" to affect an incalculable amount of psychosocial damage. Not only were the retarded harmed, but their families were harmed too. It is impossible to estimate to what degree our society's uncaring and self-satisfied attitudes effected the development, emotions and stability of family units.

The custodial care model coupled with societal and legislative attitudes have caused institutions to become chronically overcrowded, understaffed and underfinanced. Through commendable and noteworthy efforts in habilitation, education, care and training are not unusual, for the most part the institutions in the United States must be characterized as failures. Many have become self-contained, dehumanized, and isolated from the community. Some find it difficult to recognize and guarantee human and civil rights to their residents because of the physical environment they must work in and lack of personnel and financial resources. Programming very often is based on diagnostic classification rather than the individual resident's level of functioning. Many abilities or potential abilities of the residents go undeveloped or underdeveloped with institutions based on both the custodial
care and medical models of service.

The history of care for the retarded in the United States differs little from that of several other industrialized nations, except that its size has led to poorer services for more people. On the other hand, the United States also has a history of moderate interest in social legislation and has allocated more to the mentally retarded than to any other stigmatized class of comparable size. Our optimism that services may begin to improve is based partly upon the latter consideration.

As was indicated earlier, the first institution for the mentally retarded in New York State was established in 1851. Emphasis on institutional care gained momentum and continued well into the twentieth century. By 1962, 18 state schools and divisions had been established in New York State. In that year these schools were collectively housing nearly 28,000 residents, though their rated capacity (even by archaic standards) was closer to 20,000. This overcrowding in the institutions, coupled with projections that the population base would continue to grow, led to the announcement in 1962 of a $600 million building program. Seven new mental retardation facilities were to be constructed at a cost of $150 million. The construction of these facilities — evidence of an era where an "edifice complex" prevailed — was aimed at relieving the overcrowding and reducing the size of existing schools, the largest of which (Willowbrook State School) housed a population of 6,000.
**Objective of the Study**

It is the intent of this study to explore one aspect of the Davies Developmental Center's plan for the community placement of the mentally retarded. More specifically the study will concern itself with some of the more salient characteristics of home care - one of the host of options to institutional care. The paucity of research in this area\(^1\), the transfer of total responsibility for the quality of life of the mentally retarded from the institution or developmental center and the need to know the extent to which the program can be expanded (if appropriate) stimulate and indicate a more systematic assessment in this area.

The central question of this study is "How do home care parents view or define the home care situation?" Are they comfortable with arrangements as they now exist? What are the areas of tension in the setting, in the relationship between residential setting and developmental center that could or should be modified with the goal of improving the quality of care?

These questions constitute the interest and foci of this exploratory study and as such will be systematically examined.

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Without considering the question of effectiveness of current methodologies for the community placement of the mentally retarded some general implications seem clear. If the family care parents are not satisfied with supportive services, financial arrangements, ease of communication with the Center personnel and so forth, then major changes in policies relevant to home care may be indicated, even mandatory. Some modification in service programs and resource allocation may be required. Further, policy-makers, planners and program specialists as well as line staff are becoming increasingly aware of their dependence on non-professionals and para-professionals in the delivery of a broad array of services, including home care. Finally with the incipient movement towards the unionization of home care parents, a countervailing power to the heretofore monolithic authority of the Department of Mental Hygiene and its developmental centers may have to be reckoned with. Challenges to the system are more comfortably met if the establishment has firm data on which to base its change decisions. A major policy issue that derives from the above is the extent to which home care parents are accepted as full-fledged team members. With that recognition, it would appear much of the tension that apparently exists between the institutional and home care setting can be reduced to a more manageable level.
Family Care: History and Current Status

History and Need. The Family Care Program is a state-wide program which has functioned at various levels of operation for many years. Basically, family care is the mechanism to help those patients or residents in mental hygiene or mental retardation institutions to return to the community through residence in a family-like setting.

Theoretically, while in the family care program, the resident is provided with room and board, a setting that is more 'normal' according to society's expectation, and an on-going program of training and rehabilitation outside of the home to help the resident become self-sufficient and "on his own".

These are the tangible benefits of family or home care. However it is hardly to be expected that people living in close proximity - in a family life style will not develop relatively strong feelings - both positive and negative - about each other. Inasmuch as the family assume day to day responsibility for the mentally retarded resident, the institution should provide all the necessary amenities to enhance a positive growth producing relationship between surrogate parents and their charges. This can be accomplished in a number of ways:

a) By placing with the family care parent the preferred type of resident by age, sex and level of retardation.
This allows the surrogate parent the choice of a resident who may, according to the parent's own perception, better fit into that family structure and life style. However, this process, this selection tends to "cream".²

b) By establishing recruitment standards that assure a high quality of care. At this point in time to adopt this practice could limit placements only to those families who have had appropriate experience and training in working with the retarded. This would automatically preclude those families who have not had the advantage of experience and training but were willing to try and learn.

c) By providing pre-payment or reimbursement rate that enables those interested in becoming family care parents but who are unable to do so because of financial limitations. This is not a viable option at this time because finances are not available to advance monies to interested parents for the rent or purchase of appropriate living quarters and to provide them with training prior to accepting a retarded person from an institution.

d) By promoting legislation that allows the legal custody and/or guardianship of the mentally retarded child or

² Creaming is the Department of Mental Hygiene's vernacular for placing or training only those whose success probability is high.
adult to be vested with the parent surrogate. Presently
when a retarded child or adult leaves an institution
and is placed in family care the legal responsibility for
that individual remains with the placing agency. Well
conceived legislation which would protect the mentally
retarded from exploitation or other abuses could transfer
legal responsibility to family care parents. The matter
deserves serious study and discussion as it may well be
another step in the normalization of the mentally re-
tarded into our society. This is based on the assumption
that when people "own" each other legally there is a
greater sense of mutual caring and responsibility in
that the relationship is safe from external forces.

Of these and other options only the first has been
achieved to any significant degree.

Unhappily a major unanticipated consequence has occurred
in the achievement of this goal. According to the Statistical
Profile of Home Care Residents Report (See Footnote #1,
page 12) completed by the New York State Department of Mental
Hygiene only the most attractive, only caucasians, only the
moderately retarded and only those with relatively minor
secondary disabilities have been placed in any significant
numbers. If we adhere to the principles of equal benefit
or benefit according to the need then this "creaming"
process must cease. In fairness to the Department of Mental Hygiene and its developmental centers, the family care parents are a self-selected population who retain the right to select residents of their choice. However, the question must be asked, "Has the Department of Mental Hygiene and its staff made a serious effort to educate home care parents to the needs of all the mentally retarded?" This is a tough moral and philosophical question which also deserves attention, but is not within the scope of this study.

The focus of this study is home care as one faucet of a comprehensive delivery system that is primarily community located. In effect home care can be viewed as an end product of a series of events that can be diagrammed as follows:
1962
A. The President's Panel on Mental Retardation, a National Plan to Combat Mental Retardation in which the program and service needs of the mentally retarded are specified.

1963
B. Public Law 88-164 - Federal Grants to the states for program planning.

1965
C. The New York State Plan for the Mentally Retarded. A comprehensive Plan to meet the need of New York mentally retarded citizens.

1970
D. Unitization - the Department of Mental Hygiene's first steps towards regionalization.

1974
E. The Unified Services Act which creates a partnership between the state Department of Mental Hygiene and counties for the delivery of services.

1974
F. The Davies Developmental Center Plan

1974
G. Home care as a major focus and concern of the Davies Developmental Center and as the central topic of this study.
In essence the current emphasis on community services to the mentally retarded and more specifically on residential services is the product of federal and state legislation and the rules and regulations which have as their purpose operationalizing those laws.

The Delivery of Family Care Services. In 1969 there were approximately twenty-four thousand residents in developmental centers. According to a study done in the same year at least one third of these people could and should have been in community residence (Rosenberg, 1969).

Currently the community residential population is housed as follows:

<table>
<thead>
<tr>
<th>Statewide Community Residential Services</th>
<th>Average Number of Residents per Unit</th>
<th>Number of Units</th>
<th>Total Number of Residents</th>
<th>Per Cent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home Care</td>
<td>2</td>
<td>1,137</td>
<td>3,105</td>
<td>57.8%</td>
</tr>
<tr>
<td>Half Way Houses</td>
<td>15</td>
<td>24</td>
<td>360</td>
<td>6.8</td>
</tr>
<tr>
<td>Hostels</td>
<td>12</td>
<td>44</td>
<td>528</td>
<td>9.8</td>
</tr>
<tr>
<td>Intermediate Care Facilities</td>
<td>2</td>
<td>7</td>
<td>14</td>
<td>.2</td>
</tr>
<tr>
<td>Nursing Homes</td>
<td>2</td>
<td>25</td>
<td>51</td>
<td>.9</td>
</tr>
<tr>
<td>Private Residential Schools Licensed by the N.Y.S. Dept. of Mental Hygiene*</td>
<td>57</td>
<td>23</td>
<td>1,312</td>
<td>24.5</td>
</tr>
<tr>
<td><strong>TOTALS</strong></td>
<td>90</td>
<td>1,260</td>
<td>5,370</td>
<td>100.0</td>
</tr>
</tbody>
</table>

*Although located in the community, these schools frequently are more institutional in the negative sense than are the developmental centers themselves.
With a total of less than 5,370 in placement the magnitude of the resettlement task is obvious. Clearly all forms of substitute care will be extensively used.

Although home care has the longest history and is a significant provider of alternative care, few regulations and standards have been established to guide direct service professional staff in the recruitment, selection, training and supervision of family care parents. Indeed it was not until early in 1974 that the Department of Mental Hygiene convened an *ad hoc* committee to study the existing situation and to offer suggestions for standards, regulations and licensure. The recommendations were confined to life safety code almost exclusively with little attention given to the qualities that produce a comfortable and enriching life style. Beyond the safety code the only other aspect of family care that is standardized statewide is the reimbursement rate.

Given this lack of guidelines the following definition of family care is used for the purpose of this study.

Home care is a residential service offered by a private family. Its purpose is to provide a normalizing experience through which the child or adult can be expected to develop family type relationships.

*Home Care: The Facts of Life.* In return for providing
such an experience, the family caretaker is reimbursed $195.00 per month per resident for room, board and laundry. The resident receives $17.00 per month for spending. The institution retains responsibility for all health needs of the resident; counselling assistance; supervision, and training of the caretaker; screening and preparation of residents; and the development and implementation of an appropriate program for each resident in family care.

As indicated above however, in practice, there is much room for improvement. For the most part, institutions are left to their own devices in recruitment of family care homes. This often results in disorganized efforts of promotion with the outcome resulting in most referrals being made by word of mouth through people who are familiar or have worked with the program. There is such a low rate of referral that it is usually impossible to maintain a high quality criteria of selection and still maintain the program.

With the exception of a Statewide Family Caretakers Association which has not appreciably focused on the training family caretakers, the actual training of a caretaker is almost always done by a single social worker. The social worker is assigned to the home with very few, if any guidelines to follow other than what is spelled out in law and which has little to do with actually working with the residents.

The screening, training and preparation of the residents
for admission to family care is almost left up to the discretion of the institution. This procedure varies from institution to institution and can span a period of time from as little as a week or two to several months and, in some cases, a very elaborate release procedure is used. The quality of actual training and preparation of the resident is rather nebulous and probably could be vastly improved in all institutions.

Other areas that need improvement are the training and orientation of institutional staff to family care so that they may become actively involved in suitable preparation of residents for the program. It is estimated that the overwhelming majority of institutional employees have never visited or seen the family care homes to which they are sending residents and, conversely, most of the family caretakers have never visited the institution from which they receive residents and they also have little input into policy making for the program.

The family care program, if run as a solid, unified program has potential. Compared to hostels and halfway houses, the family care home for children and for many adults is considerably more 'normalizing'. The family is a natural setting within which residents may be integrated. The caretakers are parent surrogates as opposed to professional staff. These are real people, who, because they are physically near, are the targets for residents reactions, this point was made by Reistroffer in his paper of 1972. The residents relate to
caretakers 24 hours per day, seven days per week as opposed to swing shifts of attendants or changing of personnel in institutions. Family care atmosphere is more home-like and is relatively inexpensive a program to maintain.

**Review of Relevant Studies**

In support of the current trend to return retarded individuals to the community, a review of studies on self attitudes of the retarded by Lawrence and Winchell in 1973, indicates that segregated placement patterns are not ordinarily conducive to overall positive concept of self and cannot be justified on that basis.

The need for alternatives to institutionalization for the mentally retarded has been clearly documented (Roos, Kirkland, Meyer, R., Kugel and Wolfensberger). Furthermore, Rosenberg, in his study of 1969 concerning the appropriateness of the continued institutionalization of the state school population in New York State, concluded that almost one-third of the entire state school population was considered suitable for placement in the community. As family care programs and other alternatives continue to expand, it is reasonable to speculate that an even greater proportion of residents will be placed into community settings in the future.

It is clear that a large percentage of the retarded population is capable of living in the community providing that these individuals receive the necessary support and advocacy
to help them surmount some of the more taxing problems of
every day living. Numerous follow-up studies of former res-
didents discharged from institutions to various community
settings have been conducted during the past fifty years.
Some of the more notable of these studies include: Foley, 1929,
Kinder et al., 1941; Wolfsen, 1956; and Windle, et al., 1961.
The majority of these studies showed that the major reasons
for failure in the community on the part of some former
residents could be attributed to factors such as personality
problems, marital problems, antisocial conduct, poor occupational
adjustment, and health problems. These findings suggest that
training programs both within the institutions and community
settings must continually emphasize the personal-social
adapational skills in addition to training in the persisting
life problem areas of health, safety, transportation, communica-
tion, responsible citizenship, homemaking and family living,
the wise use of leisure time, earning a living, and management
of money.

Finally, comprehensive sociological follow-up studies of
former residents living in the community (Edgerton's in 1967
and Muehlberger's in 1972) have suggested a high degree of
adaptive behavior in most aspects of community living for these
mildly retarded persons, despite the fact that most were in-
stitutionalized for many years prior to discharge. However,
most lacked the necessary and practical "know how" to handle
problems of every day living and required a benefactor (employ-
er, landlord, neighbor) to help them resolve these problems.
One may speculate that, had these individuals been placed in alternative settings such as family care homes at an early age where more normalized patterns of every day living and methods of problem solving were available through the crucial years of development, later life adjustment would have been far easier; moreover, the predominately negative feelings toward their past institutionalization would not have occurred, and the strong desire that the great majority of these individuals had for living in a normalized community setting from an early age would have been a reality.

In summary, Thurman and Thiele made the observation in 1973 that "the research strongly supports the establishment of many new family care settings of high quality, and a strong training program for both the family caretakers and the residents within the institution who will be undergoing preparation for placement in family care homes."
CHAPTER II

Institutional Change: Internal and External

The Change Problem Defined. The concepts of the Community Mental Health Act of 1963 have fired the imagination of many people concerned with the limitations of institutional care for the treatment of the mentally retarded. (Appelberg, 1968, Edgerton, 1967, Wolfenberger 1969). The community mental health approach emphasizes the humanitarian and economic benefits of community care over institutional care. This approach however, places responsibilities on communities that, in most instances, are not ready, or are reluctant to assume.

In order to encourage local governments to develop community based services for the retarded as well as the mentally ill, state mental hygiene departments have agreed to pay part of the money needed to make these services available. In the 1960's, the federal government also agreed to help communities by granting funds for construction and staffing.

Uncertainty exists among some of the specialists in the field of mental retardation as to whether treatment of the retarded can or should become part of a general community mental health program, resulting in a lag in community services for the retarded. This continuing issue and lag exists despite recognition by many of the therapeutic and developmental benefits of community based services for the retarded discussed in the 1962 report of the President's Panel on Mental
Mental Retardation.

The Need for Change. The heritage of decades of chronically over-crowded, understaffed and under-financed institutions for the retarded which resulted in sub-human treatment has prompted justified concern with the de-humanizing conditions in large residential facilities (Dybwad, Kugel & Wolfensberger, 1969).

There is little doubt that the sharp attacks on the past practice of institutionalization, with its separation of the retarded from the community social setting, has much justification. Two current publications which focus on the need to re-examine these former practices are: Changing Patterns in Residential Services for the Mentally Retarded, edited by Robert Kugel and Wolf Wolfensberger. This book examines and evaluates our historical and current philosophies of institutionalizing the retarded and looks toward other viable alternatives to "human warehousing".

Another publication, Dynamics of Institutional Change by Greenblatt, Sharaf and Stone (1971) describes the reorganization of a large public institution in Massachusetts and begins with this observation:

"Few social issues are more important today than the questions of changing our public institutions so that they are more responsive to human want. Our cumulative knowledge of what people need far outstrips our current capacity to translate this information into concrete service for our citizenry. This problem is likely to become more severe as our population expands as people become better informed, through broader education and mass media, of the gap between what is and what should be."
Institutions which are attempting to become part of the community rather than separate social systems are finding the process is not without problems (Meyer, Makcay 1970). In New York State, a new Unified Services Act was signed into law on June 12, 1973, which embodies the concepts of community mental health. (Mental Hygiene News April 1974). It is intended to make better use than in the past of combined federal, state and local resources to complete the development of a single system of mental hygiene care throughout the state. Its purpose is to transform what has been a loose cooperative relationship between state and local government into a full partnership. Soon after this bill became law Dr. Alan Miller, Commissioner of the New York State Department of Mental Hygiene commented in the Mental Hygiene News:

The basic problem on which we all must focus now is how better to meet the needs of vulnerable people in the community whose mental disability and related difficulties once led us to develop separate communities for them.

This study centers around how one institution for the retarded in New York State, the Davies Developmental Center is working to redesign a system of human services to the retarded in three upstate New York Counties based on the principles of community mental health. Special emphasis is placed on family care as one of the important elements of providing an alternative to institutionalization. It attempts to describe
what the Davies Developmental Center views as important concepts and actions involved in overcoming the traditional isolation of a residential facility from its community and joining with other public and private agencies to ensure the delivery of comprehensive services to retarded persons through planned and unified services delivery system.

In 1963, an important piece of the Kennedy administration's legislative program passed the Congress making funds available for each state to plan comprehensive statewide mental health and mental retardation services. All 50 states took advantage of this opportunity, and since that time many states and state developmental centers have produced outstanding plans which call for dramatic changes in outmoded systems of service and which embody the best contemporary thinking to ensure appropriate services and protection of individual rights.

These plans have helped clarify thinking and, in general, have aided services to the disabled. However, the rate of progress, especially for the mentally retarded has been painfully slow. Briefly exploring some of the historical factors impeding change may be helpful in assessing the slow progress.

The process of change is long and complex (Pearlman & Garvin). It involves reshaping attitudes, not only society's willingness to accept the mentally retarded, but also staff's willingness to exchange old ways of doing things for new. It requires building bridges between state and local communities and paving them with a willingness on the part of each to join
in a common cause. It means replacing past patterns with new modes of treatment, training and education that will enhance the mentally retarded's ability not only to live in the community, but to lead productive lives.

This exploratory study has as one of its major purposes providing the empirical data on which to base soundly conceived change decisions.

The Setting For Change

The Davies Developmental Center is a new name given to an established 'state school'. The renaming is significant in that it sets the tone for the necessary internal and external changes that must take place in redesigning of services. It is operated through the New York State Department of Mental Hygiene. Presently, the school has a population of approximately 400 residents and a growing Community Service Program which serves Curia, Macon and Thomas Counties. The combined population of these three counties is approximately 242,000 with an estimated population of 7,000 mentally retarded persons. When the community's answer to the problem of the mentally retarded had been to place many of them in institutions for the rest of their lives, the Davies Developmental Center was known as a 'state school', giving little more than custodial care. This custodial care philosophy was quite respectable at the time (Rothman, 1971). As social progress finally began to focus on
the unacceptability and hopelessness of the custodial care model which for so long had distorted the civil and human rights of the retarded however, this particular institution took advantage of this attitudinal change and as advocates for its residents resettled mildly and moderately retarded into the community in work or community school situations. This was done prior to this writer's joining the staff. Since joining the staff as Chief of Community Services, this investigator's task has been one of re-organizing and supervising the internal services at the Center for the severely and profoundly retarded as well as planning and implementing the community service program. The elements of changes the center aims to achieve are contained in the Five Year Plan appearing in the Appendix, and was written by this investigator.

To conclude this section a brief history of the Davies Developmental Center is presented as a background for describing some of the interventions designed to change services at the facility, and as an evaluation of the results as they appear today.

The Davies Developmental Center - History. From 1960 to 1968, the Davies Developmental Center was operated as an annex for the Ross Developmental Center. Ross's service area up to that time included 26 counties. In a humane effort to place residents closer to their homes and families and provide a more effective delivery of services, Ross transferred residents from seven counties to its annex at the Davies
Developmental Center.

In 1968, when the Davies Developmental Center became an independent entity accountable for mentally retarded residents from Curia, Macon and Thomas counties, it was faced with the fact that the institution was overcrowded and in addition there were some 200 individuals from the Davies Developmental Center's catchment area remaining to be transferred principally from Ross as well as from other state facilities. An appraisal of the total population at that time showed that approximately 200 of the more than 400 residents being served at the Davies Center came from counties outside its service area, mostly from three adjacent counties. The program at that time was largely custodial care and there were few professionals on the staff.

Improving the Quality of Life. Since 1968 the programs at Davies have been developed to prepare the mildly and moderately retarded for living in the community and to increase the level of functioning of the severely and profoundly retarded, while at the same time attempting to elevate standards consistent with national norms.

Since 1969 Davies residents under the age of 21 have been increasingly placed in community homes. Twenty-eight students have been enrolled in the Boards of Cooperative Educational Service Centers, five in public schools, one student returns to Davies for her educational program. Nine residents
from the Davies Center attend the B.O.C.E.S. Center in the community on a daily basis. Sharing of public school and state school services prevents duplication of services within the geographic area and facilitates the integration of residents into the community and is in keeping with unified services concepts.

**Returning Residents to the Community.** Since 1969 through the collective efforts of the staff and other disciplines at the Center, 317 residents through our Social Services Department have been returned to the community. Of these, 118 persons have been placed in family care homes and 129 have been placed on community status. An additional 70 persons have been discharged. In 1974 a new placement level will be set for Family Care with over 100 in the community.

Of those individuals on community status, 64 have returned to live with relatives while 65 have been placed on their own. Similarly, 35 of our discharged clients have been placed with their families, while 27 have gone on to independent living situations.

**Family Care.** At the Davies Developmental Center the family care program currently consists of 77 residents placed in 36 homes. This is a continually expanding program with new homes being developed by our Social Services Department. Several homes in adjoining catchment areas have also been developed in order to utilize workshops, special schools, etc.
which are unique to those catchment areas. Mobile homes comprise more than 21% of our family care dwellings which reflects the general housing pattern in our catchment area. Our homes are located in both rural and urban settings. Each family care home is supervised by our Social Services Department and an individual program is developed for each resident, utilizing community facilities and resources as well as institutional resources when services in the community are unavailable.

**Vocational Rehabilitation.** Out of a mean population of 418 residents at the Davies Developmental Center from 1969 to 1974, 160 residents received vocational rehabilitation services. All of these residents were, and many still are employed in the competitive labor market, receiving training and adjustment orientation at sheltered workshops and rehabilitation centers, or involved in pre-vocational evaluation job try-outs or work-testing.

**New Program Approach.** Decentralized programming is also being implemented at Davies. This program is based on the concept that the retardate is best served by a program which is based upon the total individual needs and which is tailored to provide a coordinated, total approach to meet all of his needs. Normalization is the guiding principle (Adams, Kugel & Wolfensberger)*. Our primary emphasis has been on utilizing

* Normalization is both a principle and a process that means making available to the mentally retarded patterns and conditions of every day life which are as close as possible to the norms and patterns of the mainstream of society. (Roos 1966)
this program to reduce custodial conditions for the severely and profoundly retarded at the center. This program began to move away from the traditional medical model and moved decision making closer to the residents being served with an interdisciplinary training approach to meet individual needs. An important part of the decentralized programming is to establish approximately a one to one staff to resident ratio to provide effective service to the retarded. (See appendix ii) which was the model used for decentralized programming at the Davies Developmental and written by this investigator.

**Accreditation.** Early in 1974 Davies began a process to qualify for accreditation by the Joint Commission on Accreditation of Hospitals. We have completed the self-evaluation phase and since that time have been reorganizing our administrative policies and practices, resident living units, our delivery of professional and specialized program services, records, research efforts, safety and sanitation and administrative support services. We expect a site visit late in 1975 by the Accreditation Council for Facilities for the Mentally Retarded and with concentrated effort we believe we will be accreditable.

**Program Coordination.** The Placement and Discharge Committee is a multi-disciplinary group which meets weekly and includes a representative from the Mental Hygiene Information Service to represent the legal and civil rights of residents. The Committee acts as a coordinating, decision
making body which considers a host of questions which include: The recommendations of the various departments concerning the programs and movements of residents within the facility and back to the community. It handles referrals for services to the institution, it actively seeks to find alternates to institutionalization and assists in developing adequate programs within the community for those retardates living outside the center. It is charged with the responsibility that residents returning to the community have appropriate programs and living arrangements and there after receive periodic reports on the progress of these former residents. The Committee also considers admission to the center for respite, short term and long term stays.

**Community Service Team.** The Community Service Team is essential to the development of a comprehensive system of services to the retarded within the service area (Adams, 1971, Rosenberg 1969, Kugel & Wolfensberger 1969). While the team serves the population in the Developmental Center service area, it should be stressed that The Community Service Team does not duplicate services already provided under local auspices. The team articulates the center's service with all other services available to the mentally retarded in its service area. This includes specialized and generic services provided by various public and private organizations.

In brief, the Community Service Team directs service to
individual retardates wherever such services are not otherwise available, placing heavy emphasis on alternatives to institutionalization. They act as advocates for the retarded denied specialized services in the home community. The team actively participates in community organization activities in order to aid in their services to the mentally retarded. Some tangible results of these planning activites of the Community Service Team are the Tri-County Committee for Planning for the Mentally Handicapped. This body represents almost all of the agencies whose mandate includes servicing the mentally retarded in the three counties.

Some of the public and private agencies represented are: The Community Mental Health Boards, Community Social Service Departments, the Association for Retarded Children, County Health Department, Cerebral Palsy Association, representatives from the local school districts, State Division of Vocational Rehabilitation representatives, and from time to time, individuals representing organizations such as those interested in transportation, community planning and community health planning. The Community Service Team was also instrumental in developing the Health Education and Assessment Review Teams (H.E.A.R.) in the three counties. This group was formed to give comprehensive assessments to those individuals who found it difficult in receiving services from any one agency because of the complex nature of their problems. The assessment or evaluation, though important, is not viewed as a goal in itself. What is important is the
commitment on the part of the agencies who form this body, namely the Community Health Clinic, the Association for Retarded Children and representatives from the Board of Cooperative Educational Services, and the Davies Developmental Center to join with this individual and his family on an on-going basis to see that appropriate services, that will meet the special needs of this individual are provided. The Community Service Team also had an active part in seeing that our halfway house was transferred to The Curia County A.R.C. as a hostel. Members of the group continued to plan with the community agencies in developing and expanding their services within the community with the ultimate aim in establishing a comprehensive spectrum of services within the service area.

Reducing Overcrowding and Resettlement of Residents Closer to Home. The steady movement of center residents back to the community has had a dramatic effect on our resident profile. There is a significantly larger number of severely and profoundly retarded at the Center. At the present time, 197 residents may be classified as severely and profoundly retarded and 138 fall within the moderate level of functioning and above. In the future, it is anticipated that the number of severely and profoundly retarded will increase even more. The increase will be due, in part to the fact that as higher functioning residents return to the community, their accommodations at the Center will be used for more limited and/or multiple handicapped individuals
for whom residential placement is required. These more limited individuals will come from the community or other state residential facilities.

With continued efforts in the program areas to ready individuals to return to the community and with continued efforts to find alternatives to institutionalization, the administration of the Davies Developmental Center feels that it is possible to eliminate all overcrowding in our living units during 1974 and thus achieve our present program goal occupancy of 289. The Center's Five Year Plan (Appendix i) which was written by this investigator clearly details how the Center intends to discharge its responsibility to resettle residents now residing at Davies back to their home service areas. As indicated earlier, most of these individuals at the Center come from other counties. The Administration had discussed the return of these individuals with the appropriate developmental centers concerned before completing the Five Year Plan, and felt that an understanding had been reached as to the numbers of residents and approximate dates they were to be returned to their home communities. To date, very few of these residents have been returned and this development has given us some concern. Clarification of this agreement will permit orderly planning and development for the opening of a new facility and partially phase down the present facility.
Goals and Objectives of Change

Ideally, the ultimate goal of social change in the delivery of human services is to reduce the threat to life, to expand life's chances and to improve the quality of life for a given population. No one seriously argues with this principle of the American value system. Thus, President Nixon, immediately after his re-election espoused and extended John F. Kennedy's philosophy by declaring that all institutions in the nation would reduce their populations by one-third by 1980. Implicit in this statement is the fact that institutions as they are currently operating are adverse to the health, safety and development of the residents.

The New York State Department of Mental Hygiene responded to the challenge by accelerating its "Operation Exodus" and by attempting a "middle range" operationalization of the concept of normalization (Kugel and Wolfensberger 1969). In effect it provided Davies Developmental Center and its sister institution with a mandate and guidelines for implementation of the new philosophy.

For the past seven years the Department of Mental Hygiene, through its Division of Local Services has been implementing important parts of the State Plan which was formulated in 1965.

This plan is founded on several basic premises regarding the mentally retarded. The major premise is that the mentally retarded are as much members of society as anyone else and as
members are entitled to all regular benefits and privileges as well as to any special privileges they may need. If the retarded are so regarded and so treated, it is believed that they can share social responsibilities and are capable of making a contribution to society. In order to assure that the retarded are given their rightful opportunities it is recognized that greater public understanding and change of attitude are also basic. It is also recognized that society has both the responsibility and potential to increase both its knowledge and resources directed toward the goal of prevention of mental retardation. The last important premise of the plan is that the obligation to provide services and research for the mentally retarded belongs to the government, at the Federal, State and local levels.

The State Plan envisioned various partnership efforts involving Federal, State and local government in cooperation with voluntary organizations to implement prevention programs, provide ameliorative services, recruit and train personnel, finance construction and programs and conduct organized public education campaigns.

The Unified Services Act. The 1965 plan was strengthened recently and given more meaning when, on June 12, 1973, a proposal for unified services was signed into law, making it possible to complete the development of a single system of state and local services in the field of mental hygiene.

Under unified services, the state and local communities
will share the cost of providing mental retardation, mental health and alcoholism services according to a specific formula, regardless of who is providing the services.

There are three other important features to unified services. These are: a) the substantive involvement of citizens and consumers in the planning of services and their delivery; b) the establishment of an information system to monitor services and ensure accountability; and c) the mandate to coordinate the programs within the comprehensive service proposal.

Each of these has been an anathema to the professions and agencies historically. Each purveyor of services, because of training, the need for organizational autonomy and so forth have shunned or avoided the imposition of what they consider governmental regulation. Therefore it is to be expected a major source of resistance will be from those individuals and organizations that offer service. Another, of course, are the county legislatures which will be expected to increase allocations.

The Department of Mental Hygiene in their recognition of this have attempted to neutralize the resistance through a new funding mechanism.

The present cooperation between the state and local government can now be expanded into a full partnership. With a merging of their separate resources into a single funding pool, with the joint development of a single plan, a comprehensive mental
hygiene delivery system can be achieved for a specific population. Most important of all, from the client's standpoint, movement to appropriate programs it is hoped will be unhampered by the question of jurisdiction or funding. The new law took effect upon signing by Governor Wilson. But, the earliest that counties can take advantage of the plan is July 1st, 1974 for New York City and January 1st, 1975 for other counties.

Counties are not required to join in the unified services plan, they have the option of staying in the present local services program and will continue to receive aid according to the present statutory formula of 50 percent for net operating costs, with counties under 200,000 population receiving 75 percent of the first $100,000 of such costs.

Under the unified services fiscal formula, and based on present program levels, 43 counties and New York City would pay less than they pay under local services program and 14 counties would pay more. If a county will be required to spend more money under unified services a six year phase-in provides that there will be no additional cost to the county in the first year. In the following years, any increased cost to the county will be phased in at 20 percent of the increase per year until the full increased cost is met over six years. The three counties served by the Davies Developmental Center have express intent to participate in unified services.

**Implementation at the Davies Developmental Center.** Since 1968
the Davies Developmental Center has been making many internal changes and has established working relationships with public and private agencies within the specific area and for the population for which it has responsibility. These changes and relationships are intended to facilitate the transition to unified services.

These efforts have resulted in the following: Completion of a five year plan for the center which is designed as a flexible guide to action and intended to get individuals and agencies thinking about services to the mentally retarded and not as mandated steps which must be followed. The plan identifies the goals and objectives of programs and services seen as appropriate for the Davies Developmental Center and other human service agencies over the next five years to assure the development of comprehensive services.

The Continuum and Spectrum of Services. Mandates are one thing; the provision of resources in terms of staff, money, new programs, etc. is indeed, something else. The Developmental Centers were asked to extend their already thin resources even more. The spectrum of services envisioned and anticipated by the planners and administrators at the Davies Developmental Center was beyond realization.

While it would serve no purpose here to spell out in detail all the community services required by the mentally retarded, it is important to outline a minimal functional program. A functional program can be conceptualized in two ways;
a) as a spectrum that is, all services required by a mentally retarded person at any given point in his/her life; or b) as a continuum - that is, all of the services required over the lifetime of a mentally retarded person. Thus, a spectrum for a preschool mentally retarded child might include one or any combination of the following services that might be offered in specialized or generic agencies.

**Functional Spectrum of Services**

1. Diagnosis and Evaluation
2. Preschool nursery
3. Health Care
4. Recreation
5. Developmental Stimulation (physical)
6. " " (social skills)
7. Public Assistance
8. Respite Care (temporary substitute overnight care)
9. Homemaker services

During a life time a retarded person could be expected to utilize any or all of the following services and programs.

**Functional Continuum of Services**

1. Diagnosis and evaluation
2. Pre-school nursery
3. Health care
4. Recreation
5. Special Education
6. Vocational Education
7. Occupational Training
8. On the Job Training
9. Aid to the Disabled (SSI)
10. Substitute living arrangements (home care hostel care or institutionalization)

The Continuum and Spectrum above are not complete, but serve the purpose of illustrating the needs of a high-risk class of citizens. The provision of a service can be considered as
an objective, that is, as instrumentality to be utilized in achieving a measurable improvement in the quality of life.

**Evaluation.** Because the attitudes or perspective of home care parents is considered to be the crucial factor in this institutional alternative, the focus of this study is on that variable. This is a departure from the historical method of "evaluating" human service agencies. The usual method is to presume that the agency is providing effective (although not necessarily efficient) service. Thus a simple "body count" is kept of number of interviews, number of people seen and so forth.

Neither the Department of Mental Hygiene nor the Davies Developmental Center could accept this approach and the writer was assigned the responsibility (but not the requisite resources) for developing a conceptual plan for implementing that plan and constructing a preliminary evaluation instrument.

The management by objective planning format was selected because it directs attention to the three major planning phases – conceptualization of goals and programs, implementation and evaluation.

The method of achieving these goals will be based primarily on the management by objectives format. This technique adapted from business is being utilized increasingly in the provision of human services. The essential steps in management by objectives are:
1. Identifying the problem
2. Defining clearly stated objectives, each within a specified time frame
3. Developing an inventory of all possible implementation options
4. Assessing resources and resistances to goal achievement
5. Selecting the most desirable and feasible method for accomplishing the end
6. Implementation
7. Evaluation of results based on feed-back from consumers, community and institutions.

Most of the steps in the above are clearly self-defining. However, since the investigator is concerned with the practicability of utilizing the data collected and analysed in this study special attention will be given to the issue of feasibility. The chart below illustrates the equation:

\[
\text{Resources} - \text{Resistances} = \text{Feasibility}
\]

Feasibility depends upon a multitude of factors only one of which is empirically based knowledge. Many of these factors are beyond the control of any program planner, particularly one that is institutionally based. Among those variables are: a) limitations of legislation and the regulations written by the Department of Mental Hygiene to implement legislation, b) financial constraints, c) tension in organizational jurisdiction and professional domain, d) a control of information by the Department of Mental Hygiene's Central Office personnel opposed to innovation.

The chart which follows is an attempt to incorporate two ideas: a) the process of program planning, and b) the notion of feasibility.
## INTENSIVE TRAINING CENTER - A FEASIBILITY STUDY

Resources = Feasibility

<table>
<thead>
<tr>
<th>Process of Program Change</th>
<th>Resources</th>
<th>Resistances</th>
</tr>
</thead>
</table>
| **Problem Recognition**   | Davies Devel.Ctr.Plan Admin. Support  
Assoc.Ret.Children  
Parents on Unit Teams | Staff insensitivity or denial that problem exists.  
Medical model (cleanliness or protection rather than development).  
Lack of personnel and other resources (money, space, etc.) |
| **Conceptualized Program Proposal** | Dept of Ment.Hyg. approval of Davies Devel. Plan  
Davies Devel.Plan Admin.Support  
Support of 5% of therapy aides affected | Primary professionals, Ch. Nurse, M.D.s  
Lack of interest in total staff  
Domain disputes (in middle mgmnt)  
95% of therapy aides to be affected  
Lack of trained staff  
Lack of resources (space, money) |
| **Generating Resources** | Director's support Admin.Mandate  
Joint Comm.Accred. of Mental Ret. Fac. (Standards)  
Recognition by staff that innovation process is real.  
Increased hope by 5% of therapy aides  
Support of A.R.C. & Team parents | Business office  
Conventional custodial care and not not habilitation program services  
95% of the therapy aides  
Primary professionals' opposition |
| **Implementation** | Momentum of change Administrative mandates. Reduce population; reallocation of residents; new staff.  
10% of therapy aides  
A.R.C. and Team parents | Union  
Some professional societies  
Convention (tradition) |
Joint Comm.Ch.of Service Accred.Ment.Ret.Facilit. | A.R.C.  
Team Parents  
30% therapy aides |

*Business Manager originally opposed: he became a resource after recognizing the Director's commitment to innovation.*
Management by objectives was not designed for social welfare, rather its original purpose was to reassure business and commercial progress towards the achievement of concrete objectives such as the number of units produced. In social welfare it is almost impossible to define our "product" in concrete measurable terms. However, it is an approach that has a considerable potential. This is the rationale for using this derivative of the Program Planning Budgeting System in this planning and evaluation effort.

Simply stated an adaptation of GANT Charting (Battersby 1966) will be used to measure progress towards the implementation of new programs. This charting approach takes into account some of the major characteristics of the Program Evaluation Research Technique (PERT), these are; a) establishing a time frame, b) scheduling and sequencing of events, c) estimating ranges of uncertainties and so forth. It is not an attempt to do a critical path analysis or to take into account the reallocation of resources when the problems develop in the critical path; nor does it attempt to describe in a sophisticated way the network of occurrences and processes predicted to be operative in a particular change situation. See APPENDIX iii which is an example of an attempt to project in a rather simplistic way the steps involved in implementing a new program at the Davies Developmental Center.
Factors Impeding Change

As suggested above many factors, singly or in combination have had the effect of blunting the promises of the original President's Panel Report. Among these have been the lack of empirical data on which to base soundly conceived planning; the lack of well-thought out plans for the implementation of those plans; the absence of a viable public education program and so forth. These are rather general flaws in transforming the human services delivery system for the mentally retarded. Below are some of the more specific and concrete obstacles to change.

Institutional Inertia as an Obstacle. Most people who have tried to bring about change in an established institution will attest to the fact that it can be a challenging, if not impossible task. The resistance to change in an institution that has functioned in the same manner for years is enormous. The forces and counter-forces are in such fine play that to change almost anything requires a whole series of other changes. For example, to extend and expand the programming for the severely and profoundly retarded may not only require the reorganization of the staff directly caring for these individuals, but also requires that serious attention be given to changes in job status and working conditions of the supportive staff from several disciplines and trades, such as, occupational therapy, physical therapy, speech and hearing, building
maintenance, food service and laundry. See APPENDIX ii.

It is not uncommon for the union to become suspicious about changes proposed by the administration and ascribe nefarious motives to changes intended to aid in the care, treatment and training of residents. The planner, in short, must learn to think and act within a social system framework.

**Financial Problems.** Financing quality programs costs money. In this period of inflation and economic stress, allocation of necessary resources to implement programs poses a substantial obstacle all across the country. New programs such as New York State's Unified Service, which is based on State and local government monies for the expansion and upgrading of on-going programming may expect a significant degree of increased resistance in funding through tax dollars.

It is interesting enough to note that historically the United States, the richest nation in the world, has spent proportionally less money on providing services for the mentally retarded than the small Scandinavian countries of Sweden and Denmark. (Kugel & Wolfensberger, 1969).

This may be accounted for by the Scandinavian social philosophy which directs to a greater extent public funds toward the health, welfare and social benefits of its citizens. This approach is more easily extended to the handicapped.

A number of writers have suggested the homogeniety of the population in Scandinavian countries facilitates identification with the mentally handicapped, conversely the pluralism or
heterogeneity in the United States expressed in terms of racism, sexism, ageism and so forth make every effort at social allocation a major political battle. (Kugel & Wolfensberger 1969, Rothman 1971, Pearlman and Gurin 1971).

**Stereotype Perception of the Retarded.** Over the years, the retarded have been perceived as subhumans, objects of pity, and eternal children, as a menace to society, as an economic burden for society, as a medical problem, as insane and possessed by demons. Elements of this sort of stereotyping still exist in our society. (Farber, 1968).

This unjust set has had a negative influence in the kind of care and treatment provided in the past. It is still a negative influence to be reckoned with in establishing community programs for the retarded. Some people feel that funds spent on individuals with mental limitations are wasteful. Others feel that any attempt to establish community residences for these individuals poses a threat to the community.

**The Momentum of System Maintenance.** Large government systems generate an enormous amount of momentum continually pushed by the personal and financial interests in so many of the facets of the systems. Some examples are: the economic investment in and maintenance of buildings, the economic dependency of businesses and small towns on the institution operation. Civil Service and union agreements which can inhibit innovative programming and bureaucratic practices that result in red tape
and delay of services. Perhaps these practices are less obvious obstacles than some others, but they are indeed formidable.

**The Law as an Obstacle.** Well intentioned law originally designed to protect the retarded all too often deals in absolutes. The President's Panel pointed out in 1962, that

> While legal authorities consider the chronic character of mental retardation and the differences in abilities and disabilities within the group, the law itself has tended to be rigid.

Before the law the retarded are either legally competent or incompetent. The defendant is either responsible or not responsible, punishable by ordinary standards or subject to a variety of examinations to determine the degree of responsibility.

With the development of new alternatives in treatment many community and residential institutions are attempting to overcome certain rigidities of the law in the interests of giving the retarded individual the benefit of modern knowledge concerning his growth and development, his ability to learn, and the modification of his behavior in response to various social stresses and situations.

**Polarization as an Obstacle.** Dr. Phillip Roos, Executive Director of the National Association for Mental Retardation in an address at the inter-disciplinary conference sponsored by the N.Y.S. Department of Mental Hygiene made the following
point about the tendency to polarize in dichotomies as an obstacle to implementation of programs for the retarded.

It is so easy to divide the world into the "mes" and the "yous" the white hats and the black hats, the good guys and the bad guys, the institution and the community, the professional and the non-professional, the medical and the non-medical, the parent and the non-parent, etc. To the extent we dichotomize, that we polarize into good and evil, we make it much more difficult to fight successfully against our real enemy which is mental retardation.

For example, some community agencies serving the retarded occasionally have ambivalent feelings about accepting complementary service in their area. There have been, over the years, active groups that have advocated the needs of the mentally retarded and who now feel themselves in competition with, and in some cases, taking a back seat to newly formed groups representing the retarded. The older and often well-established groups frequently find it hard to accept groups who would seek to plan for and minister to the needs of the community's retarded children and adults. Unless the established group is willing to take others into its confidence, the degree to which the plan and the developed program will suit the total needs of the retarded in that community will not be optimal.

In brief there are a number of obstacles impeding the movement towards improving the quality of life of the mentally retarded. Each is formidable in itself: taken as an aggregate they tend to overwhelm. Further, for change to take effect
all must be dealt with, to one degree or another, simultaneously. Fortunately there are a number of positive forces that can support change efforts.

**Factors Conducive to Change**

**Public Awareness.** Public awareness about the needs of the mentally retarded helps to bring about greater support of programs. The public has a somewhat more accurate understanding of the mentally retarded than ever before thanks to the efforts of such organizations as the National Association for Retarded Children, The American Association on Mental Deficiency and the Council on Exceptional Children, as well as federal and state agencies and various professional groups.

Continued and expanded efforts about the causes of mental retardation and the needs of those afflicted will help influence the attitudes of legislators as well as the community supporting prevention and habilitation programs.

**Advance in Science.** With our present knowledge, we could almost eliminate several types of retardation; for instance, those due to certain infections, inborn errors in metabolism, and blood group incompatibilities. New discoveries will extend this potential.

Clinical experience and research findings are beginning to form a firm base for recommending modification in child rearing practices. The changes will aim to improve the chances for maximal development of retarded children. They also will

**Increased Professional Interest.** Twenty years ago only the most optimistic people were predicting the current upsurge of professional and public interest in retardation (Adams 1971, Dybwad, 1964).

Medical specialties and other disciplines almost vied in showing the greatest indifference toward the retarded. Public institutions were overcrowded and underbudgeted. Though they were the major resource of care, they could not cope with their long waiting lists for admission (Tarjan, 1958). Their attempts to establish closer ties with the community usually met with disinterest and resistance. Public schools often avoided the establishment of special classes. Several health and welfare programs excluded the retarded. Professionals, including research people, considered interest in retardation as a sign of mediocrity. Those who sought progress were without financial and other resources.

The scene has changed considerably. State and federal departments, professional classes and specialty groups are actively seeking to become involved in planning efforts for the retarded. Included in the ranks of new champions are persons, who, but a short time ago, could only be drafted into service efforts for the retarded. Although there is still a
a long way to go we can no longer complain of a significant lack of professional resources in certain areas.

The Parents of Retarded Children. Through individual and group actions the parents of retarded children have been responsible for stimulating and implementation of numerous community programs. Each state has an Association for Retarded Children organization and the various local chapters are generally divided on a county basis.

Since the Association was formed in 1950, it has sought to improve conditions in institutions. Sometimes these efforts have placed the institution and parent group in adversary roles, in most instances, however, joint efforts by parents and institutions have focused on improving the institution.

The A.R.C. organization continues to grow, and hopefully, with greater amounts of state support for a number of the kinds of community programs they sponsor they will be able to broaden their services for the retarded in the community.

The parents' role at institutions has taken on increased responsibility. At the Davies Developmental Center parents who volunteer are members of the Living Unit Teams and serve as full and equal partners in guiding the care, treatment and training of the residents living in a particular unit.

Several recent publications have described the challenge of this decade as the development of comprehensive human service systems which will integrate traditionally separated
services into comprehensive programs for human assistance (Demone 1973; Schulberg 1972; Schulberg, Baker & Roen, 1973).

There appears today an awareness of the shortcomings and problems in our ability to provide services for the retarded. There is much agreement that services can be provided in a better way. Strategies of change have been developed which appear to be consistent with sociological and psychological knowledge and established experience. However, strategies must be translated into action before they can be evaluated. One purpose of this study is to provide planners and program developers with empirical data which should be a useful tool for them in their efforts to improve the quality of life of our mentally retarded population.

Of all the variables supporting change perhaps the most significant is "The retarded children's movement" engineered and propelled by middle and upper middle income, politically astute, emotionally invested and sophisticated parents. Aborted by both the Great Depression and World War II the movement emerged in full force in the mid 1950s. The emergency was more like an explosion, for in 1955 the federal commitment to mental retardation was $5.5 million. In only a decade federal appropriations expanded to over $218 million, for research, professional training, community facilities, construction and staffing and so forth. The magnitude of the
increase, while not equally matched by the individual states provided an impetus to both state and community programming. With the availability of funds, professionals were now able to enter a heretofore financially neglected social problem area.

However, the dream cherished by many - the "partnership of parents and professionals" - has been only partially realized. Parent associations today, while cooperating with social agencies and professionals on many levels, maintain that the "watch-dog" function is among their most important. For example, changes in the Mental Hygiene, Department of Education and Public Health laws and regulations are due in large part to the efforts of the New York A.R.C. and its local chapters.

As inpenetrable as the institution once seemed to be, it is now slowly giving ground to the relentless efforts of this highly organized constituency and its professional allies both within and beyond the developmental center.
CHAPTER III
Design & Methodology

The design and methodology of this exploratory study are intended to be responsive to the purposes outlined in Chapter I. The central purpose is to systematically examine several important aspects of substitute home care for the mentally retarded who are "on release" or community status from the Davies Developmental Center. These variables are:

a) perspectives of home care parents, b) supportive services, c) demographic information of the substitute home, and d) characteristics of residents. A second important purpose is to establish baseline data for subsequent studies.

The Need for This Study. To the knowledge of this investigator only one study has been done previously that is in any way similar to this one. The Statistical Profile of Home Care Residents Report (see Footnote 1, page 11) was completed in October 1973. A computer print-out of the "Profile" focused exclusively on the characteristics of the residents.

The variables studied included: age, sex, level of mental retardation, secondary disability and degree of severity, ethnicity, religion, as well as socio-economic status of parents or nearest living relative, behavior problems in the home, difficulties in the community, degree or level of sexual activity and so forth.
From these data it is absolutely and expressingly clear that the developmental centers are "creaming", with few exceptions. Only those who are "problem-free", who are white and so forth are placed in family care.

This survey is not particularly relevant to this study but is included to illustrate the paucity of research in the area of concern of this study.

The Study Design. This study is an attempt to survey a number of characteristics of the home care situation. The central concern is to uncover the factors that influence the quality of care offered in these substitute living arrangements.

In choosing to study this facet of community care several avenues are open to the investigator. One is to electronically record interviews between the social workers and family care parents. Another is to review case records. A third is to interview social workers only. A fourth option is available and that is to ask home care parents to respond to a mail questionnaire. This was the method selected in that it offered some degree of anonymity which it is felt promotes candor and frankness in home care parents responses. Second it involves respondent for only a brief period and addresses issues that this investigator and colleagues in the Community Services and Social Services departments feel are important to family care patients and that are assumed have a direct bearing on the mentally retarded's quality of life.
The questionnaire asks for information in the four areas mentioned above. Demographic and attitudinal information is gathered via forced choice responses to a questionnaire. Because of the need of the Davies Developmental Center's administration for the data a pre-test was not possible.

The cohort of respondents is a population rather than a sample and simple descriptive statistics are employed in the tabulator presentation of the data. Further, because of time pressures, the lack of money, the total absence of computer-time and so forth, frequency distributions alone are presented.

There is a dearth of empirical research in the general areas of home-care. The Davies Developmental Center in recognizing this fact and being under pressure of the New York State Department of Mental Hygiene mandate to reduce its population assigned responsibility for the collection and analysis of relevant data to this investigator. Of crucial importance to the administration of the Davies Developmental Center were a) a realistic appraisal of the quality of home care, b) suggestions, if necessary, on how to improve community living arrangements, and c) the establishment of a data baseline to be used in future studies.

Selection of the Respondents and Data Collection. Consideration was given to doing a comparative analysis of home care situations under the auspices of a number of the Davies Developmental Center's sister institution. For political and
bureaucratic reasons as well as the limitations of resources it was decided to survey only those homes working with this center.

There are currently 77 residents in 36 family (or home care settings). Thirty six home care mothers were asked to respond to the survey. The protocol for gathering data was as follows:

1. Social workers were asked to inform and explain the project to their home care parents of the survey. The latter were told that a) responding to the questionnaire was voluntary, b) anonymity was guaranteed, and c) if, by chance, a respondent was identified the responses would not be shared with the Center's administration or social service staff.

2. Within a week a notice was sent by the Director of Community Services alerting the home care parents to the survey and stressing the "safety" of their responses.

3. A week later the questionnaire was sent with a stamped self-addressed return envelop.

4. A week later a second questionnaire was sent informing the respondents that most had returned their questionnaires. They were asked to fill in the questionnaire if they had not done so before.

5. A memo of thanks was sent to them thanking them for their cooperation.
All thirty-six home care parents responded within two weeks.

Measurement Device. This survey is concerned with the quality of life of residents from the Davies Developmental Center who are in home care. In order to measure this phenomenon a questionnaire was developed (Appendix iv) that addressed four variables considered by professional staff to be crucial in the delivery of this service. These are: a) demographic information on the residents, b) home care families, c) supportive services, and d) perspectives of the family care parents.

Since the consensus of the professional staff is that the perspective of caretakers is most important, ten of the twenty questions are concerned with this variable, with an even distribution of the other questions focusing on other areas.

Ideally, research on perceptions or perspective should utilize standardized and validated instruments with a randomly drawn sample, individual interviews under uniform conditions. Because of the limitations mentioned above these scientific conditions could not be met. This study does not attempt to evaluate the accuracy of the perceptions under investigation. Rather it is concerned with the question, "to what extent do home care parents recognize and cope with disruptions in their lives because of the presence of a mentally retarded person?"
Family care parents were asked to respond to a uniform stimulus designed to elicit their perception of problems and their use of professional staff in resolving them.

The construction of response categories was based on the impressions of the investigator and colleagues in the Community Services and Social Services Departments. The limitations of this approach will become apparent in the interpretation of data section below. However, it is important to note two problems that may have affected the quality of the data. The first is that a few responses are not mutually exclusive. This flaw is mitigated somewhat in that a) most categories are straightforward and explicit, b) an "other (please specify)" response was always allowed.

The second limitation of the questionnaire is the unanticipated high rate of "no responses". This is indicative of a number of issues and is rather fully explicated in the Interpretation of Data Section below.

It is trite to say that "hindsight is better than foresight" however what has been learned here is that data collection instruments must be so constructed that the data must be collected with utmost precision and uniformity. Modifications in this questionnaire are called for if the instrument is to be a viable device for restablishing baseline and comparative data.

**Summary.** This is an exploratory study of home care settings
currently being utilized by the Davies Developmental Center. Through the use of a questionnaire data were gathered on demographic characteristics of family care families, supportive services and perspectives of parent surrogates who were asked to respond to forced choice questions.

No effort was made to validate the instrument. Frequency Distribution were a major mode of data analysis. Because this is an exploratory study hypothesis were not offered. Rather the focus was on responding to the mandate of the New York State Department of Mental Hygiene, the general administrative needs of the Davies Developmental Center and more specifically to the community planning requirements of two departments within the Center.
CHAPTER IV

Characteristics of the Family Care Setting

The objective of this exploratory survey is to describe in a systematic manner what are generally considered by professionals in the field of mentally retarded to be the salient and important features of home care settings. Since the atmosphere created by surrogate parents is considered crucial the central concern is to gather and interpret data on how the family care parents view their situation. Of secondary importance are the characteristics of the residents and supportive services.

This information has been and will continue to be utilized by Davies Developmental Center in its efforts to resettle in the most creative and humane way a large number of mentally retarded persons from an institutional setting to a community one.

Inasmuch as the study was confined to a single developmental center no attempt is made to generalize the significance of the findings beyond the Davies Center. Upstate New York varies widely in the continuum highly urbanized - suburban - rural, making comparison at best a risky business.

Selected Characteristics of Family Care Homes

Table I indicates that almost half (48.2%) of the family care homes have only one resident while well over one
quarter (27.5%) provide care for two or three. This suggests that there may be a significant number unused home care beds available to further implement and accelerate the Department of Mental Hygiene's "Operation Exodus". This is highly speculative since we do not have data on the size of homes, number of bedrooms, number of persons in the family and so forth.

More importantly a highly personalized relationship between a single resident and his substitute parent (s) is not only possible but probable in the "single resident home". For the vast majority of children who have come out of institutional care it can be asserted that this can only have a salutary effect. The same argument cannot be made for adults, who even though mentally handicapped, by definition, should function with greater independence.

<table>
<thead>
<tr>
<th>NUMBER OF RESIDENTS**</th>
<th>NUMBER OF HOMES</th>
<th>PERCENTAGE OF HOMES</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>17</td>
<td>48.2%</td>
</tr>
<tr>
<td>2</td>
<td>7</td>
<td>16.6</td>
</tr>
<tr>
<td>3</td>
<td>4</td>
<td>11.1</td>
</tr>
<tr>
<td>4</td>
<td>3</td>
<td>8.9</td>
</tr>
<tr>
<td>5</td>
<td>3</td>
<td>8.9</td>
</tr>
<tr>
<td>No Response</td>
<td>2</td>
<td>5.5</td>
</tr>
<tr>
<td>TOTAL</td>
<td>36</td>
<td>99.0%</td>
</tr>
</tbody>
</table>

*At the time this data was collected the maximum number of residents under care in a single home was five. On the basis of this study this number has been reduced to four (4).

** N=77 residents in care in 36 family care homes at the time of this study.
However, as can be seen in Table 2, a significant number of family care parents seem willing to consider the placement of more residents.

**TABLE 2**

**FAMILY CARE PARENTS INTEREST IN HAVING MORE RESIDENTS IN THEIR HOMES.**

<table>
<thead>
<tr>
<th>RESPONSE</th>
<th>NUMBER</th>
<th>PERCENTAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>14</td>
<td>38.8%</td>
</tr>
<tr>
<td>No</td>
<td>13</td>
<td>36.1%</td>
</tr>
<tr>
<td>Would like more information</td>
<td>4</td>
<td>11.1%</td>
</tr>
<tr>
<td>Not at this time</td>
<td>5</td>
<td>13.8%</td>
</tr>
<tr>
<td><strong>TOTALS</strong></td>
<td>36</td>
<td><strong>99.8%</strong></td>
</tr>
</tbody>
</table>

The fact that almost two fifths (38.8%) responded affirmatively to the question "would you accept more residents in your home?" (see Table 2) strongly suggests that this is a distinct possibility. This willingness however may not be supported by the resources of the family (e.g. size of home, etc.) Combining the categories willing to consider, but need more information yields the findings that at least one half (49.9%) of the home care parents, whatever the limitations or difficulties, are satisfied enough to take on extra responsibility.
This is apparently reflected in Table 3. Over one-half (55.3%) of all home care parents are recruited by people who had already assumed this responsibility. It is reasonable to argue that only a reasonably satisfied person could convince another that the experience is worth the effort. The enticement to be a home care parent must be on the basis of tangible or intangible benefits (Blau, 1967).

<table>
<thead>
<tr>
<th>response</th>
<th>number</th>
<th>percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>From a friend or acquaintance who is a family care parent</td>
<td>21</td>
<td>55.3%</td>
</tr>
<tr>
<td>By radio announcements</td>
<td>2</td>
<td>5.3%</td>
</tr>
<tr>
<td>From local community organization</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Through church</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>In newspaper ad</td>
<td>3</td>
<td>7.9%</td>
</tr>
<tr>
<td>On T.V.</td>
<td>2</td>
<td>5.3%</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>10</td>
<td>26.2%</td>
</tr>
<tr>
<td>total</td>
<td>38*</td>
<td>99.9%</td>
</tr>
</tbody>
</table>

* N=38  It is assumed that two parents learned about the program from more than one source.

On the basis of this data it is safe to assert that from the home care parents perspective morale is reasonably
good, and that this is reflected in the care offered to residents. Experience in other areas of social welfare tend to neutralize the argument that money as a motive is necessarily bad. In child welfare, non-proprietary nursing homes, and so forth, the research tends to support the notion that financial payments generally enable those people who are so inclined to become family caretakers (Meyer 1967). The data to this point suggests an overall general satisfaction with the privileges and responsibilities of the role.

Characteristics of the Residents. There is a moderately larger proportion of women than men in placement. (61.9 to 38.9%) (See Appendix). There are a number of possible interpretations. There may be fewer adult retarded men than women qualified for home care because of premature death, behavioral problems, chronic illness and so forth. While we do know that the life expectancy for non-institutionalized men is shorter than for women we have no firm data about the possibility of an institutional analogue.

Another possible interpretation of these data is that women may be considered by family care parents to be more pliable and manageable. The movement towards Women's Liberation probably has not yet reached the institution (Adams, 1971). It is interesting to note a report that a 35 year old moderately retarded woman, recently placed in a hostel, has begun to assert her rights rather vigorously after attending a series
of consciousness raising sessions sponsored by well-organized moderately militant Womans Liberation group. A third speculation is that family care parents are not as concerned about out-of-wedlock pregnancy than are professionals. It is professions, of course, who are charged with protecting the community from certain social problems (Traunstein & Steinman 1974, Vollmer 1966) including the management of pregnancies that do not have the sanction of the community (Faber 1968, Traunstein & Steinman 1974, Vollmer 1966). The apparent paradox (professionals as social control agents vs therapists) can be explained in part, at least, by the mandate for resettlement, by the lack of advanced professional training by those making family care referrals and placements, and by the community orientation of the new breed of social workers in mental retardation (Ramonyshyn 1971). Nonetheless it is an interesting finding that merits further investigation.

In relation to secondary disabilities (see Table 4) the data supports the impression that while many home care residents have physical problems (41.7%) of these limitations do not seriously interfere with their community life style.*

* In a recent survey of the Department of Mental Hygiene of those placed in home care from institutions several factors were immediately and painfully obvious. The most blatant is that the State Developmental Centers are indeed "creaming".
<table>
<thead>
<tr>
<th>RESPONSE</th>
<th>NUMBER</th>
<th>PERCENTAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>15</td>
<td>41.7%</td>
</tr>
<tr>
<td>No</td>
<td>20</td>
<td>55.5%</td>
</tr>
<tr>
<td>No response</td>
<td>1</td>
<td>2.8%</td>
</tr>
<tr>
<td><strong>TOTALS</strong></td>
<td><strong>36</strong></td>
<td><strong>100.0%</strong></td>
</tr>
</tbody>
</table>

As indicated in Table 5 only 11.1% require any form of special physical therapy. There may be ominous implications from this data. It might be argued that the center is "creaming", that is, placing only those whose success probability is high**. This is the usual occurrence in new programs, and if operative, it should not be allowed to continue. While it is politically and bureaucratically expedient and it probably has a sound public relations value it flies in the face of, indeed rejects, the humanitarianism and professionalism of the community orientation service model (Dybwad 1964). Subsequent surveys of home care resident population will be a principal means of monitoring this or other trends that in any way, positively or negatively, influence the level or quality of care.

**"Creaming" in and of itself is not evil if the intent is to work towards the release of all institutional residents who can benefit from community placement.
### TABLE 5

**RESIDENTS REQUIRED TO ATTEND PHYSICAL OR SPEECH THERAPY**

<table>
<thead>
<tr>
<th>RESPONSES</th>
<th>NUMBER</th>
<th>PERCENTAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>4</td>
<td>11.1%</td>
</tr>
<tr>
<td>No</td>
<td>30</td>
<td>83.4%</td>
</tr>
<tr>
<td>No response</td>
<td>2</td>
<td>5.5%</td>
</tr>
<tr>
<td><strong>TOTALS</strong></td>
<td><strong>36</strong></td>
<td><strong>100.0%</strong></td>
</tr>
</tbody>
</table>

There are a growing number of professionals who argue that home or family care is inherently unstable in relation to life-time disability. One parent may die or become disabled, their natural children may develop an indifference or resentment that can adversely effect the placement. Beyond this is the question "Is home care the 'residence of choice' for the mentally retarded adult?"

In addition there has been a strong tendency to "infantalize" the mentally retarded (Dybwad 1964, Edgerton 1969, Farber 1968). In 1966 Cardinal Cushing of Boston referred to the mentally retarded as "Gods special children." In the late 1950s and early 1960s a large number of writers characterized them as "eternal children". There is an analogue in education. Because of the limitations of the mentally
retarded students, many teachers frequently failed to establish learning objectives that challenged their abilities. Indeed the usual conceptualization of the mentally retarded is in terms of disabilities rather than in the recognition of their abilities and talent. The pessimism about the capacity of the mentally retarded to lead "normal" lives remains pervasive and continues to have a strong negative influence on program development, particularly those oriented to a community lifestyle (Kugel and Wolfensberger 1969).

<table>
<thead>
<tr>
<th>AGE</th>
<th>NUMBER</th>
<th>PERCENTAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 to 12</td>
<td>7</td>
<td>9.0%</td>
</tr>
<tr>
<td>13 to 19</td>
<td>17</td>
<td>22.0%</td>
</tr>
<tr>
<td>20 to 30</td>
<td>8</td>
<td>10.4%</td>
</tr>
<tr>
<td>31 to 50</td>
<td>24</td>
<td>31.2%</td>
</tr>
<tr>
<td>51 to 65</td>
<td>15</td>
<td>19.5%</td>
</tr>
<tr>
<td>Over 65</td>
<td>4</td>
<td>5.2%</td>
</tr>
<tr>
<td>Not sure</td>
<td>2</td>
<td>2.6%</td>
</tr>
<tr>
<td>TOTALS</td>
<td>77</td>
<td>99.9%</td>
</tr>
</tbody>
</table>

The pertinence of this question is highlighted in Table 6. About two-thirds (69%) of all home care residents are at least
twenty years of age. The relevant question is, "Do the adult mentally retarded require the protection of a family life-style or can they develop their independence and abilities in a larger communal residence (i.e. hostel) and by that means lead more enriched lives?"

Since the 77 residents now in home care have few if any serious physical disabilities and fewer speech or communication problems it would seem that many could well use the developmental milieu model of a hostel.

In New York State the development of half-way houses and hostels (community residents housing ten to fourteen residents on an indefinite basis) is still in the early stages.* Impressionistically we have concluded that it is a viable alternative to institutional and family care for adults.**

SUPPORTIVE SERVICES

Supportive services are integral to any sound comprehensive community program. The difficulties associated with retardation especially for those who are being de-institutionalized are formidable indeed. Among the many problems the resettled mentally retarded experience are learning to live with privacy, establishing social relationships, coping with the freedom of a relatively unregimented life and so forth (Edgerton 1969 Krugel & Wolfensberger 1969).

*To date only sixty-eight hostels and half-way houses have been established in the State of New York. These house a total of 864 residents. The Developmental Centers' population currently, throughout the state stand at 24,000 residents.

**Hostels for the mentally retarded have not been criticized as have been many similar programs for the mentally ill and mentally recovered.
The home care parents bear the major brunt of the responsibility for helping the new resident adapt to and learn to live with ambiguities in life that he has heretofore not had to face. For these reasons this investigation examines the assistance offered to the surrogates by the institution.

It is generally believed that social workers can be helpful to both resident and caretaker in the transition and adjustment period between institutional life and family care. Therefore the amount of help offered to (but not the quality) and sought by family care workers as well as day programs were surveyed.

<table>
<thead>
<tr>
<th>RESPONSES</th>
<th>NUMBER</th>
<th>PERCENTAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 or 2 times a month</td>
<td>14</td>
<td>38.8%</td>
</tr>
<tr>
<td>3 or 4 times a month</td>
<td>1</td>
<td>2.8%</td>
</tr>
<tr>
<td>Only when requested</td>
<td>16</td>
<td>44.4%</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>No response</td>
<td>5</td>
<td>13.8%</td>
</tr>
</tbody>
</table>

**TOTALS** 36  99.8%
There are several possible interpretations to Table 7. In about two-fifths (41.6%) of the homes the social worker visits at least once a month, while in 44.4% of the situations the social worker is "on call". Based on our observations of and discussions with social service staff our impressionistic conclusions are: a) that social workers are considerably more active during the initial phase of placement and that as the placement stabilizes over time, consultation visits are, for the most part, at the request of the home care parents, and b) that as the social worker gains confidence in the home care parents' ability the worker tends to become less active, or c) a combination of a) and b). Combining these data with that from Table 8 it can be inferred that the rate of home care placements is accelerating. Almost three-fifths (59.5%) of all home care parents indicated that the social worker had visited within the month.

<table>
<thead>
<tr>
<th>TABLE 8</th>
</tr>
</thead>
<tbody>
<tr>
<td>LENGTH OF TIME SINCE SOCIAL WORKERS LAST VISIT</td>
</tr>
<tr>
<td>------------------------------------------</td>
</tr>
<tr>
<td><strong>RESPONSES</strong></td>
</tr>
<tr>
<td>------------------------------------------</td>
</tr>
<tr>
<td>Less than 2 weeks</td>
</tr>
<tr>
<td>About one month</td>
</tr>
<tr>
<td>Two or more months</td>
</tr>
<tr>
<td>Other (please specify)</td>
</tr>
<tr>
<td>No response</td>
</tr>
<tr>
<td><strong>TOTALS</strong></td>
</tr>
</tbody>
</table>
Home care parents also reported (See Table 9) that they feel the need for support by the social worker at the current level of consultation. It can be argued that this dependency decreases as they gain experience since 44.4% (See Table 7) responded that they want the social worker on an "on call" basis only.

### TABLE 9

<table>
<thead>
<tr>
<th>RESPONSE</th>
<th>NUMBER</th>
<th>PERCENTAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>25</td>
<td>69.3%</td>
</tr>
<tr>
<td>No</td>
<td>10</td>
<td>27.9%</td>
</tr>
<tr>
<td>Most of the time</td>
<td>1</td>
<td>2.8%</td>
</tr>
<tr>
<td><strong>TOTALS</strong></td>
<td><strong>36</strong></td>
<td><strong>100.0%</strong></td>
</tr>
</tbody>
</table>

Considering all relevant problems it was rather unexpected to find that almost seven-tenths (69.3%) of all home care residents are in organized day programs. Briefly stated these resident related problems are: a) the stultifying effects of institutionalization; b) the poor medical care, especially corrective surgery; c) age - at least four are over age 65; d) the lack of community programs; and finally e) several have only recently been placed on home care.
It is a tribute to the social service staff's ingenuity and resourcefulness that in an area so devoid of services that a significant majority of resettled retardates could be placed in day programs. While data is not available our impression is that all children are in special education or day care programs and that adults up to about the age of fifty years are in occupational training, sheltered workshops or competitive employment. Those not in day programs probably have the more severe physical disabilities and are probably older. The questionnaire did not directly address this issue however, it might have been possible to cross tabulate age and disability with program placement had a computer and programming expertise been available.

PERSPECTIVE OF FAMILY CARE PARENTS

Up to this point our analysis and interpretation of data has been focused on three important but secondary concerns of this study. These are: a) characteristics of residents, b) characteristics of family care homes, and c) supportive services.

However since it is widely accepted that the perception and attitudes of people who become home care parents are crucial to the successful placement of the mentally retarded in community residential care the major concern of the remainder of this chapter will be devoted to an examination of the findings in this area.
Not only is the quality of the home care influenced— for better or for worse—by surrogate parent attitudes, but the number of homes available is affected. For example, earlier it was reported that home care parents themselves are the best contacts in the community for the recruitment of others willing to assume the same responsibility. A third reason is that in the catchment area served by the Davies Developmental Center home or family care is currently the only viable alternative to institutionalization.* Fourth, home care parents are known to be excellent advocates for their handicapped charges. As such, they provide a major stimulus for the development of new programs and opens the doors for existing or established agencies. Fifth, they educate the general and professional publics to abilities as well as the needs of the mentally disabled.

To achieve these social and humanitarian goals, however, home care parents must experience a sense of satisfaction and personal fulfillment. This can only be achieved if the circumstances of the placement are reasonably congruent with the family care parents' expectation, needs and wishes.

The foregoing is the rationale for devoting fifty percent of our questions to this area.

Table 10 should be analysed with Table 11 because of the

* A new state-wide social agency is currently being developed. Its plans include the establishment of two hostels in the Davies Developmental service area, however this will not occur during the calendar year 1974.
similarities of issues, problems, emergencies, and crises. The first observation that must be made is the extra-ordinarily high incidence of "no response" (14.8% and 42.1% respectively). The second feature of the tables is the fairly even distribution of what might be characterized as disruptions in family life. No problem or emergency was reported by more than 14.8% of the family care parents in the cohort.

There is not a single problem shared by more than a fraction of all home care parents. The most common problems are having residents use their leisure time constructively, spending their money "wisely" and complying with family rules. These might be considered "behavioral problems" about which the home care parent talks with their social worker (see Table 12). The low frequency of all responses suggest that no generalizations about family disruptions can be made. This does not imply that there may be some families that are in distress because of the placement. It indicates only that as a whole the family care parents are not experiencing common problems that can be dealt with on a common basis. Additionally it does not address the issue of the degree of severity of a problem or emergency that a particular family and/or resident may be experiencing.

Four interpretations of Tables 10 and 11 are possible.

1. The incidence of family disruptions as reported are representative of real life.
2. The respondents did not accept the guarantees of anonymity by the researcher.

3. The family care parents do not trust the professionals who place residents and supervise them and therefore deliberately distorted their responses for fear of retaliation.

4. The home care parents are intentionally withholding information.

TABLE 10
PROBLEMS AS PERCEIVED BY THE FAMILY CARE PARENTS

<table>
<thead>
<tr>
<th>RESPONSES</th>
<th>NUMBER</th>
<th>PERCENTAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Getting residents to adjust to family schedules and routines</td>
<td>5</td>
<td>9.2%</td>
</tr>
<tr>
<td>Residents causing disturbances in family or community</td>
<td>5</td>
<td>9.2%</td>
</tr>
<tr>
<td>Teaching residents to use local services</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Keeping residents interested in a hobby or other activities</td>
<td>8</td>
<td>14.8%</td>
</tr>
<tr>
<td>Getting residents to make wise purchases with their money</td>
<td>6</td>
<td>11.1%</td>
</tr>
<tr>
<td>Providing companionship and counsel to the resident</td>
<td>1</td>
<td>1.9%</td>
</tr>
<tr>
<td>Stays by himself too much</td>
<td>4</td>
<td>7.4%</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>17</td>
<td>31.5%</td>
</tr>
<tr>
<td>No response</td>
<td>8</td>
<td>14.8%</td>
</tr>
<tr>
<td>TOTAL NUMBER OF RESPONSES</td>
<td>54</td>
<td>99.9%</td>
</tr>
</tbody>
</table>
### TABLE 11

**EMERGENCIES OCCURRING IN THE FAMILY CARE HOMES**

<table>
<thead>
<tr>
<th>RESPONSES</th>
<th>NUMBER</th>
<th>PERCENTAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Involved in an accident</td>
<td>3</td>
<td>6.9%</td>
</tr>
<tr>
<td>Became quite ill</td>
<td>1</td>
<td>2.3%</td>
</tr>
<tr>
<td>Had a death in his family</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Accused of a crime</td>
<td>1</td>
<td>2.3%</td>
</tr>
<tr>
<td>Hurt another person or himself</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Absent from home for unusually long period</td>
<td>1</td>
<td>2.3%</td>
</tr>
<tr>
<td>Fights or constantly argues with others</td>
<td>3</td>
<td>6.9%</td>
</tr>
<tr>
<td>Would not comply with family rules</td>
<td>5</td>
<td>11.6%</td>
</tr>
<tr>
<td>Intentionally broken or damaged property</td>
<td>4</td>
<td>9.3%</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>7</td>
<td>16.3%</td>
</tr>
<tr>
<td>No response</td>
<td>18</td>
<td>42.1%</td>
</tr>
</tbody>
</table>

**TOTAL NUMBER OF RESPONSES** 43  100.0%

All are plausible, but the logic of the situation and of professional experience suggests that distrust or at least the lack of trust between the parties is the major operating dynamic (Traunstein & Steinman 1974). This is not to be construed as a reflection on the quality of care provided. That can only be determined by a study focusing on that dimension of family care. However, the fact that only
one-quarter of the responses (24.5%) discuss any single problem with social workers (Table 12) does indicate that a tension exists that inhibits the family care parent from openly communicating with a person who may be viewed as a threat rather than a collaborator. This may reflect on the professional's ability and willingness to accept the family care parent as legitimate and full-fledged team member (Farber, 1968; Traunstein & Steinman, 1974). If this is so it violates a major cannon of the community orientation service model. The pertinent question is who needs the training (or retraining)? The work of Goffman (1961) and Rothman (1971) among others, strongly suggest it is the professional.

TABLE 12
TYPES OF PROBLEMS FAMILY CARE PARENTS MOST OFTEN DISCUSS WITH THE SOCIAL WORKER

<table>
<thead>
<tr>
<th>RESPONSES</th>
<th>NUMBER</th>
<th>PERCENTAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recreational activities for the resident</td>
<td>3</td>
<td>6.0%</td>
</tr>
<tr>
<td>Behavioral problems</td>
<td>12</td>
<td>24.5%</td>
</tr>
<tr>
<td>Budgeting money for resident</td>
<td>2</td>
<td>4.0%</td>
</tr>
<tr>
<td>Personal hygiene of resident</td>
<td>7</td>
<td>14.2%</td>
</tr>
<tr>
<td>Teaching resident to be more independent</td>
<td>2</td>
<td>4.0%</td>
</tr>
<tr>
<td>Reports and forms required by the Department of Mental Hygiene</td>
<td>3</td>
<td>6.0%</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>7</td>
<td>14.2%</td>
</tr>
<tr>
<td>No Response</td>
<td>13</td>
<td>26.5%</td>
</tr>
<tr>
<td><strong>TOTALS</strong></td>
<td><strong>49</strong></td>
<td><strong>99.4%</strong></td>
</tr>
</tbody>
</table>
The tension in the professional home care parents relationship may also suggest the latter's distrust of large social institutions - in this case a government agency. Be that as it may the data does seem to indicate the presence of a lack of confidence and suspicion by members of a lower income group of professionals - a not at all uncommon observation (Farber 1968). This is hardly a new phenomenon for immediately after the French Revolution professionals were forbidden to gather even for professional meetings. (Vollmer & Mills 1966). The tension in the relationship then is a given that must be dealt with.

This conclusion is supported by comparing the tables that focus on "help seeking with problems" (See Tables 12 and 13). Only 24.5% of the family care parents reported that they discuss behavioral problems with the social workers who place and supervise residents in their home. On the other hand two-thirds (66.6%) would be "interested in joining a small, local group of family caretakers to discuss mutual problems . . . ."
The line of argument that family care parents do not have faith in the professionals who have a significant control over a major aspect of their lives is further strengthened by a large number of "no response" in Table 12. Over one quarter (26.5%) of the respondents evidently do not discuss any type of problems (with their social workers) that are bound to occur in an intimate life-style.

However, there is another interpretation that is possible. During the past four decades there has been a major resurgence in the self-help organizations in that members feel strongly that one must experience a condition before one can fully understand and be helpful (Tarjan 1956). The retarded
children's movement has been, and continues to be, in the forefront of the self-help movement (Traunstein & Steinman 1974). Indeed, parents of retarded children and members of alcholics anonymous have been major forces in the establishment of this standard (Rothman 1971). The corrolary, the rejection of professionalism is not so impartant here as the principle that personal experience is prerequisite to being helpful. It may simply be that home care parents, as surrogate parents, simply do not believe that professionals can be of assistance simply because professionals have not experienced the problem directly (Adams 1971, Foley 1924, Nuehlberger 1972, Rothman 1971).

<table>
<thead>
<tr>
<th>RESPONSES</th>
<th>NUMBER</th>
<th>PERCENTAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>14</td>
<td>38.8%</td>
</tr>
<tr>
<td>No</td>
<td>2</td>
<td>5.5%</td>
</tr>
<tr>
<td>Possibly</td>
<td>17</td>
<td>47.2%</td>
</tr>
<tr>
<td>Other (Please specify)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>No response</td>
<td>3</td>
<td>8.3%</td>
</tr>
<tr>
<td><strong>TOTALS</strong></td>
<td><strong>36</strong></td>
<td><strong>99.8%</strong></td>
</tr>
</tbody>
</table>
On the other hand, Table 13 strongly suggest that home care parents, given the opportunity, feel they could learn from each other. Eighty-six percent indicated that family care sessions on the management of residents would or could be helpful. A major limitation of this question is that home care parents were not asked if a professional should be present as a group leader or resource person, (See Table 14). What is obvious however is that there is an expressed need that is not being met and that the data suggests the home care parents themselves feel they can best meet themselves.

**TABLE 15**

**SPECIFIC NEEDS IN RESIDENT CARE TECHNIQUES**

<table>
<thead>
<tr>
<th>RESPONSE</th>
<th>NUMBER</th>
<th>PERCENTAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>How to teach the resident a skill</td>
<td>15</td>
<td>30.0%</td>
</tr>
<tr>
<td>How to help resident adjust to community living</td>
<td>6</td>
<td>12.0%</td>
</tr>
<tr>
<td>How to involve resident in family life</td>
<td>5</td>
<td>10.0%</td>
</tr>
<tr>
<td>How to help resident maintain good personal hygiene</td>
<td>11</td>
<td>22.0%</td>
</tr>
<tr>
<td>Other (Please specify)</td>
<td>7</td>
<td>14.0%</td>
</tr>
<tr>
<td>No response</td>
<td>6</td>
<td>12.0%</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>50</strong></td>
<td><strong>100.0%</strong></td>
</tr>
</tbody>
</table>
Table 15 attempts to address the question of the nature of the training needs of the thirty-six respondents. Several expressed a desire to help in a number of areas. Because of the limitations mentioned above (time, money, computer time, etc.) it was not possible to do a sophisticated analysis of the data. The importance of this shortcoming, while significant for other areas is most striking and regrettable here. With a fairly even distribution of response (30% to 10%) to the issue of areas of training needs it is not possible to determine with any precision a) if there is a small group of home care parents who are floundering while the majority of surrogates feel comfortable in their roles, or b) if a fairly large number of home care parents are uncomfortable or frustrated in circumscribed areas.

Table 16 suggested that this is not the latter. It would appear that a majority of the home care parents (55.5%) feel they would be willing to talk with a social worker on "as if" basis. That is, "about specific training need . . . . that would help in better preparation for family care settings." Again it is not unreasonable to assert that their suggestions would be a reflection of their own feelings.
TABLE 16
WILLINGNESS TO DISCUSS
PROBLEMS WITH SOCIAL WORKER

<table>
<thead>
<tr>
<th>RESPONSE</th>
<th>NUMBER</th>
<th>PERCENTAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>20</td>
<td>55.5%</td>
</tr>
<tr>
<td>No</td>
<td>12</td>
<td>33.3%</td>
</tr>
<tr>
<td>Not sure</td>
<td>4</td>
<td>11.1%</td>
</tr>
<tr>
<td>No response</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>TOTAL</td>
<td>36</td>
<td>99.9%</td>
</tr>
</tbody>
</table>

Certainly the contrast between the data presented in Tables ten, eleven and twelve and that in Table sixteen support the thesis that home care parents are withholding. It is to their credit that, rather than lie they do not respond (42.19% in Table 11) to the question "Are you having problems?" If indeed the projection interpretation is valid then it can be argued that many are living a life of rather "quiet desperation" or that there are desperate moments between periods of satisfaction. These moments on balance provide the gratification for the home care parent to go on. According to Blau (1967) the exchange or reciprocal must be equitable and/or satisfying to both parties or it is discontinued.

The most often cited frustration for home care parents is
in the skill training area most notably personal hygiene. One can argue that home care parents as a class are compulsive, but this is hardly fair or justifiable. Rather, a more positive interpretation is that they are concerned about the health and welfare of their residents.

In essence it is suggested that by responding positively to a training course for beginning home care parents a slight majority of this experienced cohort may well be projecting their own frustration and uncertainties protecting themselves at the same time from criticism at best, or, at worst, removal of the resident from their care. Given the economic difficulties of the catchment area, and the socio-economic class from which the majority of the home care parents are drawn it is not at all surprising that such a process could well be operating.

This may appear to contradict our earlier preliminary interpretation that home care parents, like natural parents of retarded children feel a personal experience is necessary to understanding and helpfulness. However, for one thing, this question poses a hypothetical ("as if") situation. Secondly it is the consensus of a number of professionals in the field of mental retardation that the personal experience dynamic, while important for substitute parents is not as crucial a factor as it is for natural parents.

However, the three notions (financial need, the requirement of personal experience and training to reduce un-
certainty in resident care techniques) are not mutually exclusive or antagonistic. Rather, taken together, they illustrate well the complexity and intense pressures involved in the provision for home care. Several writers and researchers (including Margaret Adams, 1971) have commented on the relative simplicity of conceptualizing a social welfare plan; they are all so clear in their perception of and assertion that as the planner moves closer to implementation the process becomes increasingly complicated, difficult and intense.

In these data and the interpretation that derive from them the tension between the providers of direct care, the professionals who supervise them, and the institution as the auspices become quite clear. For example, in an informal study done less than two years ago by a consultant to the North Albany team of the Eleanor Roosevelt Development Center it was found that home care parents are underpaid, and in effect, subsidize the sponsoring agency. The $200 per month reimbursement rate does not begin to meet the requirements of the minimum wage law.

In response to the "desired frequency of visits by social worker" over two-tenths (42%) indicated that they are satisfied with the current level of consultation while less than one tenth (8.2%) indicated a need or desire to see a professional person more than once a month. Almost
a third (30.69%) want social workers to be "on call". The frequency of supportive or supervisory visits apparently satisfies most home care parents, however the quality of what is accomplished by these visits remains inponderable at this time.

Second, it is apparent that despite a lack of trust between home care parents and social workers, disruptions in family life, inadequate financing and so forth, the people providing home care are gaining satisfaction in performance of this voluntary role and are effective recruiters of other parents. This bodes well for the resident who is currently in placement and for those who will be returned to the community. This is not to suggest that monitoring and evaluation of home care be eliminated or even cut-back. The staff of the community oriented services model at the Davies Developmental Center is well aware of potential abuses in home care analogous to those reported in the New York Times last year in relation to housing for the "mentally recovered".
TABLE 17
DESIRED FREQUENCY OF VISITS BY SOCIAL WORKER TO FAMILY CARE HOMES

<table>
<thead>
<tr>
<th>RESPONSES</th>
<th>NUMBER</th>
<th>PERCENTAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Once a week</td>
<td>1</td>
<td>2.8%</td>
</tr>
<tr>
<td>As often as requested</td>
<td>11</td>
<td>30.6%</td>
</tr>
<tr>
<td>Once a month</td>
<td>6</td>
<td>16.4%</td>
</tr>
<tr>
<td>Twice a month</td>
<td>2</td>
<td>5.4%</td>
</tr>
<tr>
<td>As often as he is currently doing</td>
<td>15</td>
<td>42.0%</td>
</tr>
<tr>
<td>Other (Please specify)</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>No response</td>
<td>1</td>
<td>2.8%</td>
</tr>
<tr>
<td><strong>TOTALS</strong></td>
<td>36</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

It may be that since most residents are in organized day programs (72.1% - see Table 9) and that the overwhelming majority (83.4% - See Table 13) are in recreation programs that home care parents have adequate respite from whatever trials and tribulations they experience. This, of course, argues for the establishment of continuum and spectrum of services outlined above.
Respite for the natural parent who has his child at home has become the most widely utilized service of the major community-oriented mental retardation program in the service area adjoining that of the Davies Developmental Center. The underlying philosophy of respite care is that parents need a break in meeting the heavy demands of deviant children. For both the natural parent and surrogate, the services are similar; homemaker, day care, short term placement, recreation and so forth. In brief the fact that so few home care parents experience difficulty in getting their charges into recreation and day programs suggests that this is a key element in holding these placements together (see Table 18).

<table>
<thead>
<tr>
<th>RESPONSE</th>
<th>NUMBER</th>
<th>PERCENTAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequently difficult</td>
<td>3</td>
<td>8.3%</td>
</tr>
<tr>
<td>Occasionally difficult</td>
<td>2</td>
<td>5.5%</td>
</tr>
<tr>
<td>Seldom difficult</td>
<td>7</td>
<td>16.6%</td>
</tr>
<tr>
<td>Not at all difficult</td>
<td>21</td>
<td>61.3%</td>
</tr>
<tr>
<td>No response</td>
<td>3</td>
<td>8.3%</td>
</tr>
<tr>
<td><strong>TOTALS</strong></td>
<td>36</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Table 19 indicates that the home care parents feel there are few unmet needs on the part of their residents.
TABLE 19

UNMET RESIDENT NEEDS

<table>
<thead>
<tr>
<th>RESPONSE</th>
<th>NUMBER</th>
<th>PERCENTAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>21</td>
<td>52.1%</td>
</tr>
<tr>
<td>Transportation</td>
<td>1</td>
<td>2.4%</td>
</tr>
<tr>
<td>Medical - dental care</td>
<td>8</td>
<td>19.1%</td>
</tr>
<tr>
<td>Reimbursement</td>
<td>3</td>
<td>7.2%</td>
</tr>
<tr>
<td>Professional help</td>
<td>5</td>
<td>12.0%</td>
</tr>
<tr>
<td>Delay in medicaid card</td>
<td>3</td>
<td>7.2%</td>
</tr>
<tr>
<td><strong>TOTALS</strong></td>
<td><strong>41</strong></td>
<td><strong>100.0%</strong></td>
</tr>
</tbody>
</table>

The most prevalent concern is the adequacy of medical and dental care (19.1%). It is assumed that the 12.0% who suggested the resident's need for "professional" help were referring to personal adjustment counselling.

Since over one-half (52.1%) of the home care parents are satisfied that their charges' needs are being adequately met, there are fifteen surrogates who report one or more problems. It would be interesting to know again if these difficulties are clustered within a small group of home care parents who are floundering or whether the problems are evenly distributed.
In summary, the findings suggest that despite a number of problem areas, home care parents are at least reasonably well satisfied with the responsibilities that they have assumed. Indeed they are the most viable proselytizers. A number of unexpected findings were presented; a) more women than men are in placement; b) in an area where community services were felt to be almost non-existant a significant majority of home care residents are in organized day programs; c) a lack of effective communication between institutional representatives and home care parents was found despite the expressed need for some training in resident care techniques; c) home care parents tend to feel that they can learn these techniques more effectively from peers than from social workers; e) despite the fact that a large minority (41.7%) of the residents have a secondary physical disability these handicaps do not seriously interfere with the community adjustment of residents; and f) perhaps most surprising is that almost 70% of all residents are twenty years of age or older.

The frequency distributions presented in tabulator form were responsive to the four major areas of concern; demographic data on the resident and family care setting, supportive services and perspectives of the parent surrogates.
This is an exploratory study the purpose of which is to systematically examine one aspect of a variety of alternatives to institutional care. Because of the paucity of research in the area, uncertainties about the nature of home care and the supportive and programmatic services, the small size of the population to be studied and the acceleration of changes stimulated by the Unified Services Act it was not possible to offer hypotheses. Instead this survey attempted to obtain data that could shed some light on the factors which positively and negatively influence the quality of life of home care residents.

A forced choice questionnaire was developed after extensive consultation with staff members from the two Davies Developmental Center departments concerned with home care - The Community Services and Social Services Departments. A search of the literature did not yield substantive information that could be used in the construction of the questionnaire. In essence the study explored virginal territory particularly in relation to the implementation of the policies of the state Department of Mental Hygiene and its Developmental Center. The data was collected by mail with a one-hundred percent response from a population of thirty-six home care parents who collectively have assumed responsibility for a
total of seventy-seven mentally retarded children and adults. Because of the lack of resources and the pressure of departmental and administrative fiat's frequency distributions alone were utilized in the analysis of data.

Four areas of the home care setting were addressed: a) demographic information on residents, b) supportive services, c) characteristics of the setting, and d) the perspectives of the family care parents. The latter, since it was considered by numerous professional colleagues to be the crucial variable was the focus of fifty percent of the questions. The remaining questions were evenly distributed on the three remaining variables.

In terms of the data that the findings present is a rather mixed picture. On the one hand family care parents are the most effective recruiters of new homes. At the same time there is a willingness to take in more residents. The fact that they are not more "multiple-resident" homes may be explained in part by the lack of space, size of family, and so forth. The small number of problems reported by home care parents is rather surprising; the fact that they feel the need to discuss resident care techniques is not. However, their expressed preference to "talk things over" with peers rather than with staff may be significant for a number of reasons. The fact that they are recruiters and were willing to take more residents suggests that whatever the problems or
difficulties in providing home care suggests a number of possible conclusions: a) the satisfactions experienced by these surrogates is adequate; b) the income derived provides a stable base for relatively low income families in a region in which significant areas can be characterized as economically depressed. In support of this conclusion, a number of social workers have reported that several home care parents have indicated a willingness to move into larger homes in order to take more residents. Thus home care serves the larger purposes of improving the quality of life, not only of the residents, but for the home care family itself. It is noteworthy that in another economically depressed area home care families have organized to block the development of a new hostel program which is viewed as a threat.

This may well explain the reluctance of the home care parents to discuss their difficulties with social workers. If they complain, the resident(s) might be removed, thus jeopardizing a stable income. The need for help in the management of their mentally retarded residents was expressed by over one-half of the parents, however, they would prefer to talk over these problems themselves.

The financial motivation should not be considered bad in and of itself. For one thing home care does not become a profit making venture for the home care parents unless they provide care for four or five residents. Secondly, the seventeen
dollars a month allowance that each resident receives is barely enough for entertainment, let alone clothing, which they are responsible for providing. Third, the usual "wear and tear" on furniture, appliances and so forth wipes out any overage or profit. It can be argued then that a gratifying interpersonal relationship is a primary motivation for continuing, if not for initiating, the placement. This is a major reason for the placement on the part of the Developmental Centers. Large institutions, with their emphasis on protections against injury, health hazards and so forth tend to regiment activity and to be impersonal and to professionalize (or depersonalize) human relationships. Personal development through enriched human relationships is a major goal of the Developmental Center in placing the mentally retarded in home care. There is modest support in the findings that this goal is achieved in many, if not most instances.

Implications of the Study in Historical Perspective. Ever since the landmark social legislation in 1935 that established social security and public assistance benefits for children in poverty, aged, disabled and blind, this nation has become increasingly aware of the needs of the large numbers of persons who are at a disadvantage or high-risk.

In the public mind, only feeble attempts have been made to distinguish the various categories of recipients. In the popular press there are frequent exposes of "free-loaders" and "chislers" who are characterized as representatives of
all recipients. This has undoubtedly impeded progress in program development in mental retardation. Public attitudes not withstanding, significant progress has been made in establishing income maintenance and human service programs.

As public education programs become more effective progressive change should accelerate. Great events frequently are required to catalyze the nation toward change.

In 1954 the Supreme Court decision, Brown vs. the Board of Education, despite the "with all due haste" clause transformed the educational system of the country. Pope John's convocation of Vatican II propelled the world to ecumenism, toward greater toleration of religious differences and toward a more acute sensitivity to the needs of the poor, the dispossessed and the disenfranchised.

In 1961, President Kennedy's public acknowledgement of his mentally retarded sister and his national leadership galvanized federal and state governments and the population at large into actions on behalf of the mentally ill and mentally retarded. In 1971 Heraldo Rivera revealed the "scandals of Willowbrook", a sensational expose that left New York breathless and determined to improve the quality of life in its state institutions.

Other less spectacular social processes were operative in moving the nation to a transformation of some of its historically cherished social values. The values that are of
concern here are the substitution of rugged individualism
for the value of the assumption of social responsibility.
With the publication of the works of DuBuvoir and Frieden
the liberation movement began in earnest in this country.
With the conceptual frame offered by these women and leaders
in other social movements (e.g. civil rights, welfare rights,
student rights, gay rights, etc.) the thrust towards self-
determination - the right to choice in all aspects of
the "victims" lives accelerated.

To date these events have not profoundly effected the
lives of the retarded population. The adult mentally retarded
is still defined as a child incapable of making significant
life decisions. The general public, parents of the mentally
retarded and professionals, for example, debate the right
to sexuality. Most people stand firmly opposed to any sexual
activity. Some argue that sexual and marital roles should be
allowed but draw the line at permitting the parental role.
Nowhere in the debate is the voice of the mentally retarded
adult men and women heard. It is our impression that a major
reason for the popularity of home care over other forms of
community residences (see page 16) is that it effectively
denies sexuality to the retarded adult. The opportunities
for sexual encounter are effectively minimized by segregation
(five or less residents per home) and by the establishment of a
family life style that provides another safeguard (the taboo
against incest).
Other rights are denied as well. The "right to fail" as a way of learning from experience is prohibited on the basis of lack of judgment. The right to privacy, to be viewed as an individual and so forth for the institutionalized retardate is prohibited on the basis if an exception is made for one all others will demand the same privileges. It is an interesting aside that in a recently opened hostel one of the eight residents refuses to attend social events on the basis that he loves to walk the streets - a freedom denied for eighteen years he spent in an institution. Asked what he liked best about the hostel he replied, "I like being alone by myself." He thinks he might like to marry, but "I don't want no kids."

 Needless to say as more mentally retarded adults are placed in community care the issue of rights and privileges will become more pressing. The assention of rights and privileges means the end of defining the mentally retarded as a monolithic class. Total control that characterized institutions in the past should be eliminated (Goffman 1961, Rothman 1968). Care should be taken to prevent the development of such control in home care, hostels and so forth. Goffman's description of total institutions is graphic evidence of how easily this can occur. Rothman's brilliant analysis of the development of public policy in relation to all institutional groups documents the tendency to control
through regementation and standardization. He argues persuasively that a single notion has characterized institutional policy at different points in history. These ideas – retribution, reformation, rehabilitation and reintegration treatment of all institutional groups. Dybwad, Roos and others have repeatedly warned professionals about the continuation or transfer of the control and standardization functions to community programs. It may be that as the mentally retarded obtain a larger degree of freedom in community placements that they may well become their own most effective advocates. If this does not occur it will have to happen during the hiatus of the transitional period. This is not to assent that the mentally retarded will be as effective self-advocates as other social movement groups. However, on the basis of anecdotal experience there is reason to believe that they will, within the limitations of their ability, exploit opportunities for choice. This is the essence of the normalization principle.

Implications for Training. In order for the mentally retarded to manage their lives to the extent that they are able, the caretakers must be reoriented from the custodial model to the community service orientation model. This will involve a redefinition of mental retardation that has been predicated on the limitations of the conditions rather than on the strengths, talents and abilities. The teacher must extend the students to the limits of their ability; the home care parent should respect the mentally retarded's
right to fail, the rehabilitation consellor must provide opportunities for work choice, and so forth.

This implies training for the non-professional and the para-professional, the goal of which is to stimulate and broaden the vision of the child and adult. For the professional the retraining will be more difficult. Several decades ago Veblen coined a phrase "trained incapacity" the essence of which is that trained people tend to view problems and problem solving methods from a single perspective - that of their profession or discipline. This "tunnel vision", impedes inter-disciplinary communication, makes teamwork more difficult and precludes the acceptance and integration of newer and more effective problem-solving techniques.

Leadership in these efforts is currently being provided by the Developmental Disabilities Division of the United States Department of Health, Education and Welfare, the President's Committee on Mental Retardation, by the Bureau of Functional Programming of the State Department of Mental Hygiene.

However, the necessary training programs have yet to reach the level of the developmental center. A promising note is that three training films are now being produced by the Department of Mental Hygiene that focus on the process of integration of the mentally retarded into several
types of community programs, including home care.

Organizing Para-professionals. In an embryonic stage is the development of the New York Association of Home Care Parents. At this point in organizational development the Association is not a potent force. However, during the past year they have been able to achieve a thirty percent increase in the re-imbursement rate. This year they are requesting another increase of about fifteen percent.

Money is their central concern now. As the organization grows it can be assumed that their interests will widen into such areas as the criteria for selection, supervision, evaluation and discharge from the home care setting. For example, it is not at all unusual for a social worker to "drop by" informally and unannounced. Some home care parents have complained of this "meddling".

That the Association will become a countervailing power to the developmental center is almost a certainty, and, the Department of Mental Hygiene and its regional units should be prepared to deal realistically and equitably with them. Their success, of course, depends upon the quality of their leadership, the selection of the issues to be confronted, and their success or failure in their initial efforts to negotiate.

The data suggest that there is a tension (i.e. a lack of trust) between home care parents and the placement supervisors. It is not possible to infer from those data
the level of that pressure. However the issue does seem to revolve around who "owns" the resident.

For this reason (and some impressions from practice) the Association of Home Care Parents may move to guarantee placement after a probationary period. Thus they may opt for changes in legal custody and guardianship status. In effect they may vie for a legal vesting of the resident to the family surrogate. The analogue in child welfare is the subsidized adoption.

Some of these issues have already been discussed in areas where family care parents are better organized. These people gather primarily to discuss mutual problems and resident care techniques.

It is tentatively suggested that the organization will serve two purposes: 1) a peer therapy function by which home care parents will train each other with or without a professional as group leader or resource person, or b) a social action function by which the organization will attempt to improve their conditions of employment.

The Resident Population. The Statistical Profile of Home Care Residents alluded to above supports the findings of this study in several important areas. Those who have a better chance of going into home care are women above the age of twenty who function at a higher level, who have few behavioral problems and physical handicaps. Davies Developmental Center, as all
other developmental centers in New York State are "creaming", placing only those who have a high probability of success and who will be of little trouble to anyone. This is to be expected in a new program, but home care is no longer novel. Creaming rejects the principles of professionalism, of humanitarianism and the Community Orientation Service Model and, therefore if we are to be true to our ethical commitments, the practice must be stopped.

What is called for by this finding is that more preparation of the more severely limited must be inaugurated. As mentioned above institutional staff must be willing to spend more time and effort in preparing the more damaged people for community placement. Concurrently prospective home care parents must be made ready to accept such referrals. The experience of Families For the Future is an excellent precedent in this regard. The F.F.F. Chapter in an adjoining county currently has a membership of over three hundred families. Each family in that organization has a "hard to place" child(ren) - a child who is mentally or physically handicapped or "too old".

The Davies Developmental Center as well as the Department would do well to use experienced members of F.F.F. as consultants.

In summary, this exploratory study is an attempt to systematically explore a first attempt to implement one significant aspect of a program passed by the State Legislature in 1973 - The Unified Services Act. Both strengths and limitations
were found for the program. Data were analyzed, interpreted and preliminary conclusions and implications were drawn. These should not be generalized beyond the Davies Developmental Center in view of the uniqueness of the setting and limitations in the analysis imposed by the lack of resources.
DAVIES DEVELOPMENTAL CENTER LONG-RANGE PLANS
FOR MENTAL RETARDATION AND CHILDREN'S SERVICES

FIVE-YEAR PLAN

March 1974
TABLE OF CONTENTS
OF
FIVE YEAR PLAN

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Statement of Goals and Objectives.</td>
<td>111</td>
</tr>
<tr>
<td>B. Estimate of Size of Target Population.</td>
<td>113</td>
</tr>
<tr>
<td>Potential Service Needs.</td>
<td>113</td>
</tr>
<tr>
<td>Anticipated Changes Over The Next Five Years.</td>
<td>118</td>
</tr>
<tr>
<td>C. Services Now Being Provided.</td>
<td>119</td>
</tr>
<tr>
<td>1. Davies Developmental Center.</td>
<td>119</td>
</tr>
<tr>
<td>2. Other Departments of Mental Hygiene Facilities.</td>
<td>120</td>
</tr>
<tr>
<td>3. State Agencies Other than the Department of Mental Hygiene.</td>
<td>121</td>
</tr>
<tr>
<td>4. Local Government and Public Agencies.</td>
<td>123</td>
</tr>
<tr>
<td>5. Voluntary and Private Agencies.</td>
<td>125</td>
</tr>
<tr>
<td>6. Federal Agencies.</td>
<td>131</td>
</tr>
<tr>
<td>7. Other Agencies.</td>
<td>131</td>
</tr>
<tr>
<td>D. Resettlement of individuals from this area who are now residents in State facilities outside the service area.</td>
<td>133</td>
</tr>
<tr>
<td>E. Updated Plan for the Return of Davies Developmental Center Residents from outside this area back to their own service areas.</td>
<td>134</td>
</tr>
<tr>
<td>F. Program Priorities.</td>
<td>136</td>
</tr>
</tbody>
</table>
A. **Statement of Goals and Objectives.** The following goals and objectives are viewed as important elements to ensure the development of comprehensive services to the mentally retarded of all ages and children with developmental disorders and their families in Curia, Macon and Thomas Counties. The effective development and delivery of comprehensive services is highly dependent upon the interdependence, cooperation, joint planning and implementation efforts of all public and private human services agencies within a given area. Thus far, joint planning efforts by human service agencies give rise to some optimism that comprehensive services can become a reality in this area.

It is in this spirit of cooperation and interdependence that we outline the goals and objectives of programs and services we see appropriate to be undertaken by Davies Developmental Center and other human service agencies in the next five years as major steps required in the delivery of comprehensive services.

1. Programs and services taking place at or through the Davies Developmental Center to provide residential care, treatment and training consistent with the principles in a community services model. This calls for: decentralized service teams within the institution who have strong community orientation and ties; the full implementation of the principles embodied in the recodification of the Mental Hygiene law, namely, guaranteeing the human and civil rights of each resident; individual programming of residents based on
their functional ability rather than diagnostic classification; incorporation of more flexible use of human and financial resources; designing programs which will anticipate the development of new social arrangements and services within the community - in order to ensure each resident the opportunity to develop to the highest potential possible in order to participate as fully as possible in community living. The programs and services at Davies Developmental Center which can contribute to the wide spectrum of comprehensive services are:

a. Longer-term residential care and habilitation for severely and profoundly retarded individuals.

b. Short-term residential care for specific program needs of other individuals.

c. Increased day services at the Davies facility for programs that may meet the individual needs of community residents.

d. Increased respite services.

e. The development of a cadre capable of assisting with staff training at Davies and available to other community agencies on a staff-sharing basis with expertise in child-management techniques and behavior modification.

f. The development of additional halfway houses in order to prepare Davies residents for community living as well as service individuals from the community.

g. To explore the possibilities of joint use or community use of certain portions of our new facility in order to conduct needed programs.

h. Increased family care placements for appropriate residents.

2. Joint efforts with community, state and federal authorities to achieve the following:

   a. Prevention -- To work with all agencies in an effort to apply all known preventive techniques to avoid developmental disabilities during the pre-natal, post-natal and early developmental periods as well as striving for genetic and other forms of counseling for prospective parents identified as being at risk.

   b. The provision of comprehensive assessment for all children along the educational, medical, psychological and social standards.

   c. Continued planning for the retarded and children with developmental disabilities with other community and governmental agencies.

   d. Joining with other agencies in the more effective use of homemaker services as our own service expands.

   e. In close cooperation with other agencies, the stimulation, expansion or development of the following services:

      1) Pre-school education and training
      2) Vocational services
      3) Workshops
      4) Social and recreation programs
      5) Learning disabilities center
      6) Hostels and other group home situations
      7) Adult day activities centers

B. Estimate of size of target population and potential service needs

1. The total population in Curia, Macon and Thomas Counties, according to the 1970 census was 224,000. Projections for 1975 estimate the population in this service area will grow to 242,000 and in 1980 will reach 261,000. On a county basis these figures break down as follows:
Thomas 122,000 135,000 148,000
Curia 49,000 52,000 56,000
Macon 53,000 55,000 57,000

Mental Retardation

It is generally assumed that about 3% of a given population will be mentally retarded. Of this number, the degree of retardation can be approximated as follows:

87% would be mildly retarded
10% would be moderately or severely retarded
3% would be profoundly retarded

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</thead>
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<tr>
<td>All ages</td>
<td>224,000</td>
<td>242,000</td>
<td>3%</td>
<td>6,720</td>
<td>7,260</td>
<td>7,830</td>
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<td>5 and under</td>
<td>21,700</td>
<td>23,900</td>
<td></td>
<td>651</td>
<td>717</td>
<td>752</td>
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<td>6 to 20</td>
<td>63,600</td>
<td>66,900</td>
<td></td>
<td>1,908</td>
<td>2,007</td>
<td>2,200</td>
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<td>21 to 64</td>
<td>107,100</td>
<td>177,600</td>
<td></td>
<td>3,213</td>
<td>3,528</td>
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<td>65 and older</td>
<td>31,600</td>
<td>33,600</td>
<td></td>
<td>948</td>
<td>1,008</td>
<td>1,113</td>
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<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>All levels</td>
<td>6,720</td>
<td>7,260</td>
<td>7,830</td>
</tr>
<tr>
<td>Mildly retarded</td>
<td>87%</td>
<td>5,853</td>
<td>6,323</td>
</tr>
<tr>
<td>Moderately or severely retarded</td>
<td>10%</td>
<td>699</td>
<td>755</td>
</tr>
<tr>
<td>Profoundly retarded</td>
<td>3%</td>
<td>168</td>
<td>182</td>
</tr>
</tbody>
</table>
Emotionally Impaired

In estimating the number of children and adolescents who may be identified as having behavioral or emotional difficulties ranging from mild to severe levels, the 1969 report by the Joint Commission on the Mental Health of Children is useful. In this final report, Crisis in Child Mental Health, the Commission estimates "that .6% are psychotic, and another 2 to 3% are severely disturbed and an additional 8 to 10% are in need of some kind of help from knowledgeable people." Therefore, the percentages that may be applied to this age group in order to determine the broad range of behavioral or emotional impairments range from 10.6% to 13.6%. For the purposes of this estimate the figure of 12% is applied to all individuals up to the age 20 in Curia, Macon and Thomas Counties.

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</thead>
<tbody>
<tr>
<td>0 to 20</td>
<td>85,300</td>
<td>90,800</td>
<td>98,400</td>
<td>12%</td>
<td>10,236</td>
<td>10,896</td>
<td>11,808</td>
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</tbody>
</table>

Other Developmental Disorders

To estimate the number of young people with developmental disabilities other than mental retardation or emotional impairment, we have used that portion of Isle of Wight study completed in 1970 which identified the incidence of cerebral palsy, convulsive disorders, severe visual defects and severe hearing defects.
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</thead>
<tbody>
<tr>
<td>0 to 20</td>
<td>85,300</td>
<td>90,800</td>
<td>98,400</td>
<td>1.26%</td>
<td>1,073</td>
<td>1,144</td>
<td>1,239</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td></td>
<td></td>
<td></td>
<td>.03%</td>
<td>255</td>
<td>273</td>
<td>295</td>
</tr>
<tr>
<td>Convulsive Disorder</td>
<td></td>
<td></td>
<td></td>
<td>.72%</td>
<td>614</td>
<td>653</td>
<td>708</td>
</tr>
<tr>
<td>Severe Visual Defect</td>
<td></td>
<td></td>
<td></td>
<td>.12%</td>
<td>102</td>
<td>109</td>
<td>118</td>
</tr>
<tr>
<td>Severe Hearing Defect</td>
<td></td>
<td></td>
<td></td>
<td>.12%</td>
<td>102</td>
<td>109</td>
<td>118</td>
</tr>
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</table>

2. A description of the important characteristics of this estimated target population with respect to potential service needs included:

-- A prevention program. This complex problem requires simultaneous action in biological, psychological and sociological fields. The effort should include community and governmental agencies.

-- Diagnosis, comprehensive assessment, individual programming and treatment utilizing all professions and disciplines indicated by the needs of the child or the adult mentally retarded individual.

-- Day training centers for pre-school children directed to physical, mental emotional and cultural development to prepare youngsters for school and to be of aid to parents.

-- Home training programs together with parent education and homemaker services.
-- Day training centers for school-age children not able to attend special classes in the schools to prepare them, if possible, for special class admission and at least to provide basic training and development and to aid parents.

-- Hostels for continued domicile in post-school and adult years of those in vocational training, regular employment or long-term sheltered workshop employment and occupational day center programs when their own homes are non-existent, unsuitable or as a life plan goal.

-- Respite service in a group home or at State facilities for temporary care such as during diagnostic study or during family vacation or crises mainly for children normally residing with their families.

-- The continued use of State facilities for those who need intensive or long-term residential care.

-- Halfway houses for temporary domicile for those individuals from State facilities returning to community life or those individuals from the community who need not come to the institution before being placed in other domicile arrangements.

-- Family care or boarding home placement for selected individuals of all ages.

-- Nursing home placements for those in the target population for whom it is deemed beneficial and appropriate.

-- Community workshops for vocational training or continued
sheltered employment reinforced by continuing guidance and placement service.

-- Programs organized to meet social, recreational and religious needs of this target group which cannot be met currently in ongoing community programs.

-- A committee comprised of representatives of all agencies involved to develop and maintain close collaboration.

-- Appropriate and accessible training available to personnel involved in providing services to the target group in order to increase their effectiveness.

-- Public education about the needs and potential of the target group.

3. Additional factors which should be considered over the next five years which can affect the projected estimates in the general population as well as the target population are:

A growing tendency of inter- and out-of-state migration to Curia, Macon and Thomas Counties. Aside from the natural beauty and relatively uncrowded areas in significant portions of these counties, southern Saratoga appears to be a convenient bedroom community for three moderately large cities as these cities grow and as their borders become less distinguishable.

It appears to some that more people, among them a number of professionals, are seeking a change in living style to the less urban character which is still possible in portions of
these counties.
Strong efforts and progress is being made to have portions of these counties become a year-round resort area. It also appears possible that the City of Thomas may become a year-round sporting and gaming mecca.

C. A description of services now being provided.

1. The following is an annotation of services now being provided at the Davies Developmental Center. The average number of residents for whom these services are available on a daily basis is approximately 400.

   a) Habilitation Services.
      1. Special Education
      2. Occupational Therapy
      3. Psychology
      4. Recreation
      5. Speech and Hearing
      6. Respite and Day Care.

   b) Community Services
      1. Social Services
      2. Vocational Rehabilitation
      3. Homemaker Service
      4. Consultive Service
      5. Halfway House

   c) Medical Services
      1. Medical care
      2. Nursing
      3. Dental
      4. Laboratory
      5. Medical Records
      6. Physical Therapy
      7. Pharmacy
      8. X-ray

   d) Religious Services

   e) In addition to these services, there is a Volunteer Program and a Foster Grandparent Program.
2. The following State and community agencies provide the bulk of services for the mentally retarded of all ages, and children with developmental disabilities in Curia, Macon and Thomas counties. Since, at this point in time, all the needs of these individuals cannot be met within our service area, it is necessary to seek services for a number of these individuals outside our catchment area.

a. Thomas County Mental Health Clinic
   1211 Spring Street
   Thomas, New York 12866

   Dr. Harry Green Director
   Telephone 743-1076

   Thomas County Mental Health Board
   1366 Broadway
   Thomas, New York 12866

   Mr. Lewis Walker, Jr., Chairman
   Telephone 743-0063

   A multi-purpose county operated, out-patient psychiatric clinic serving adults, children and families who reside in Saratoga County. Services include diagnostic-evaluation; individual, group and family psycho-therapy; child guidance; consultation to community groups and professionals. Day care programs include activities and discussion groups.

b. Curia, Macon County Mental Health Center
   Newson Hospital
   27 Lark Street
   Curia, New York

   Telephone 839-1584

   Macon County Mental Health Clinic
   Macon Hospital
   Macon, New York 12816

   Donald Wagner, M.D. Director
Macon County Mental Health Board
Starbach Road
Macon, New York 12865

Mr. Roger Simms, Chairman  Telephone 584-9033

Services include individual and group therapy, children's services, play therapy, family therapy and after-care clinics, and halfway house.

c. Herman Little Developmental Services
Herman Little Memorial School
Oldtown Road
Walker, New York 12309

Harold Berman, M.D.  Telephone 703-7315

To assure the development of comprehensive community services for the mentally retarded of all ages and for children and adolescents with developmental disorders in a six county area. Functional assessment teams plan and collaborate with state and local resources. Each team also coordinates the screening and resettlement of this population to and from Department of Mental Hygiene facilities.

3. Other State Agencies

a. New York State Office of Vocational Rehabilitation
Willow Park, Bright Plaza
Albany, New York 12206  Telephone 754-3258

Mr. Walter Rounder, District Supervisor

Vocational rehabilitation is a public service organized to restore, develop or improve the working ability of mentally and physically disabled individuals so that they can become satisfactorily employed or self-supporting. Services rendered at no cost to the individual and medical and vocational evaluation, counseling and guidance, training, placement assistance. State residents with permanent disabilities that constitute handicaps to employment and who can become employable may apply.

b. New York State Employment office - Martinville and Greenbrook.

1) Employment Services
702 Broadway
Thomas, New York 12811  Telephone 485-1713
Both of the above provide complete employment service to employees and applicants. Career guidance, training and jobs.

c. New York State Department of Social Services
1450 Western Avenue
Albany, New York 12203
Telephone 474-6360

Mr. Abe Levine, Commissioner

Eastern Regional Office
New York State Department of Social Services
7476 State Street
Albany, New York 12201
Telephone 474-4140

Mr. Clifford Talcott, Director

The Department supervises local public and voluntary health and welfare organizations throughout the state. It administers institutions for the juvenile delinquents, a facility for veterans, and a variety of services through the Commission for the Blind. It registers charitable organizations, licenses dispensaries and boarding homes for children, and issues permits for day care centers.

d. New York State Department of Social Services
Commission for the Blind and Visually Handicapped
74 State Street
Albany, New York 12201
Telephone 474-1701

Mr. Sam Fisher, Supervisor, Field Services for the Blind

Provides vocational rehabilitation, home and community services for the blind. Also, guide service, talking books, mobility instruction, low vision aids, social case work and public education regarding blindness.

e. New York State Department of Health
84 Holland Avenue
Albany, New York 12203
Telephone 474-3003

Hollis S. Ingraham, M.D., Commissioner
New York State Department of Health
District Office
South Village
Martinville, New York 12431    Telephone 937-0893

Berwyn Mattison, M.D., District Health Officer

Branch of the Executive Department of State government, responsible for the administration and enforcement of the Public Health Law and the State Sanitary Code, and has general supervision of the work of all local health authorities. The activities of the Department of Health are administered through its divisions, bureaus, regional, and district offices. The Department also operates one rehabilitation hospital, and one cancer institute.

f. New York State Division for Handicapped Children
New York State Education Building
Albany, New York 12224    Telephone 474-3994

Mr. Raphael Sinches, Assistant Director

The Division for Handicapped Children attempts in many ways to develop a better understanding of and service to all handicapped children. In many instances, this is a matter of interpretation or education concerning the nature of these problems, of working out plans with local school systems, or of helping to develop more adequate services to such of these children as may be able to profit from classroom instruction. Services which local school districts can provide for all types of handicapped children include special classes, home teaching, special teachers, and transportation. Certain kinds of supplementary assistance can be provided for those children with serious degrees of vision, speech or hearing handicaps.

4. Local government and public agencies

a. Thomas County Department of Social Services
County Complex, P.O.Box 1638
Tartan, New York 202220

Mr. Joseph W. Loyd, Commissioner    Telephone 582-6381

Curia County Department of Social Services
Municipal Center
Curia, New York 12374    Telephone 883-8467

Mr. Joseph Ferro, Commissioner
Macon County Department of Social Services
Tillson, New York 12374

Mr. Joseph Brill, Commissioner Telephone 842-7800

Makes available to eligible persons appropriate social services that will enable them to become self-maintaining if possible or able to care for themselves in their own homes.

Helps people who are eligible for financial assistance to receive it promptly and adequately. Processes applications for Medicaid and Nursing Home Care. Provides institutional care for homeless and sick people.

b. Thomas-Curia County BOCES, Macon-Thomas County BOCES

Thomas-Curia County Boces
Light Road
Thomasville, New York Telephone 411-8032

Mr. Donald Lovejoy, District Superintendent

Curia-Macon County Boces
Macon County Building Annex
Millageville, New York 12839

Francis Wallin, M.D., District Superintendent

The above BOCES centers provide specialized curriculums in occupational education and special education for the component schools in the districts which they serve.

c. Clarkville Neighborhood Youth Corps
Ball Avenue
Clarkville, New York 12013 Telephone 985-8811

Mr. Henry Roberts, Director

Curia County Neighborhood Youth Corps
Curia County Municipal Center
Curia, New York 12606

Mr. Samuel Tuff, Director Telephone 792-9951

Macon County Neighborhood Youth Corps
Macon County Court House
Clifton, New York 12653 Telephone 747-0605

Susan Jiles, Director
Serves youths between the ages of 16 and 21 and provides job counseling and on-the-job training programs. Special emphasis is on help to disadvantaged youth.

5. Voluntary and private agencies

a. Association for Retarded Children -- Thomas and Curia County Chapter N.Y.S.
P.O. Box 1583
Thomas, New York 12765 Telephone 584-0471

Miss Helen Goodspeed, Executive Director

Association for Retarded Children
Curia-Thomas Counties Chapter N.Y.S.
11 Home Avenue
Glendale, New York 12801 Telephone 792-4658

Mrs. Robert Morris, President

Services: Co-sponsorship of Burbank Programs

b. Cerebral Palsy
United Cerebral Palsy Association of the Tri-Counties, Inc.
1121 Day Street
Glendale, New York 12101 Telephone 793-0725

Mrs. Martin Tallus, Executive Director

Services: include a medical and diagnostic clinic. Treatment supervision. Co-sponsorship of prospective programs.

Burbank Programs
1121 Day Street
Glendale, New York 12101 Telephone 793-0725

Mrs. Alice Wood, Administrator

Services: Nursery class two days per week. Preschool class 3 days per week. Special education class 5 days per week (N.Y.S. Education Department). Social Club three Friday evenings per month. Summer Day Camp 3 days per week in July.

c. Community Workshop
41 Thompson Avenue
Glendale, New York 12601 Telephone: 793-2306

Mr. Joseph Brown, Director
A sheltered workshop for the mentally retarded, physically handicapped and emotionally recovering. Vocational rehabilitation program of vocational evaluation, personal adjustment, and placement services offered. Also a Work Activity Center for the trainable retardate.

d. Newton Rehabilitation Center
14 Howe Avenue
Newton, New York 12308

Mr. John Lutze, Director
Telephone 846-9731

The pre-vocational unit admits psychiatric patients to its program of personal adjustment training and vocational testing, work tryouts, cooperative programs with Ellis Hospital Psychiatric Unit, and counseling. Admission to the prevocational unit is by Division of Vocational Rehabilitation referral. Consultative services to the unit are provided under contract with the Mental Health Board.

e. Maple Ridge Rehabilitation Center
299 Hamburg Street
Schenectady, New York 12303

Mr. Ronald Gates, Executive Director

This is a sheltered workshop that provides work experience for the retarded who may be employable. Job finding and placement are included in the service offered. Manufacturing processes are carried on to provide a sheltered workshop for those members who are unable to meet normal competitive standards in the community. Also provides day school. In conjunction with Maple Ridge, we also utilize the Westfall House which is their hostel located at 2415 Albany Street, Schenectady, New York 12304 (372-2315). Both of these programs are run by the Schenectady County Association for Retarded Children.

f. The Workshop, Inc.
339 Broadway
Menands, New York

Mr. Milton Goldstein, Executive Director

To rehabilitate vocationally those persons who were born disadvantaged, or those who have in the course
of their lives acquired a physical, mental or emotional handicap that has interrupted their gainful employment.

Programs are designed to meet individual needs in order to enable such persons to reach their maximum potentials in vocational and personal adjustment and to enable them to join or rejoin the labor market.

g. Lexington Training Center
15 Lexington Avenue
Gloversville, New York 12078

Mr. Paul Nigra,
Executive Director
Telephone 725-6472

This is a sheltered workshop which is sponsored by the Fulton County Association for Retarded Children and provides work experience for the retarded, physically handicapped and mentally ill. Job training and placement, group counseling, volunteer services, individual tutoring, religious instruction, recreation and social services are provided. They also operate a group home and a hostel.

h. Schoharie Valley Rehabilitation Center
Route 30, Schoharie-Middleburg Road
Schoharie, New York 21257 Telephone 295-8130

Mrs. Betty Southard, Executive Director.

Provides socialization program, pre-school program and sheltered workshop. Eleanor Roosevelt Developmental Services provides consultative services in Psychology, speech therapy and assessment.

i. Thomas County Chamber of Commerce
858 Broadway
Thomasville, New York 12146 Telephone 784-3213

Mr. Frank Tudor, Executive Director

Provides community development programs and works on attracting industry into the area.

j. Boy Scouts of America (Thomas Council)
14 Crest Avenue
Balwin, New York 12436 Telephone 974-3461
Services: Programs conducted by sponsoring institution for boys of community 8-16 years. Teaches boys patriotism, courage, self-reliance, and kindred virtues, using the methods which are now in common use by the Boy Scouts of America.

k. Thomas County Cooperative Extension Program
76 Walker St.
Thomasville, New York 12956  Telephone 895-0256

Divisions: Agricultural, Home E. 4-H

Curia County Cooperative Extension Program
Macon County Building Annex
West Main Street
Macon, New York 12938  Telephone 477-1682

Cooperative Extension is a public educational function concerned with helping people help themselves through knowledge gained from research at the N.Y.S. Colleges of Agriculture and Home Economics at Cornell University. It provides information and assistance to people to help them solve problems of the home and community.

1. 1. Glenville Hospital
720 Front Street
Glenville, New York 12108  Telephone 927-6431

2. Thomas Hospital
112 West Street
Greenfield, New York 12761  Telephone 481-6024

3. Sunnyview Hospital
1270 Belmont Avenue
Schenectady, New York 12300 Telephone 346-8731

4. Ellis Hospital
4th Street
Schenectady, New York 12300 Telephone 377-3361

5. Albany Medical Center
New Scotland Avenue
Albany, New York 12200  Telephone 462-7521

m. Planned Parenthood, Inc.
Washington Street
South Glenville, New York 12108

Mrs. Dacon, Director  Telephone 927-6341
A voluntary agency, affiliated with the Planned Parenthood Federation of America, providing medical service, abortion referrals, consultation and education for family planning. Includes child-spacing, infertility and education for marriage.

Y.M.C.A., Y.W.C.A.

Young Men's Christian Association
62 South Broadway
Thomasville, New York 12886  Telephone 846-1208

Mr. Horace Glick, Executive Director.

A membership organization serving boys and girls, men and women without restriction as to race or creed. Helps its members to understand themselves and to make the right choices in life; helps them to understand the world in which they live; helps them to maintain health and physical fitness; helps them to gain skill in personal relationships; helps to being about a fellowship characterized by understanding and friendship.

Young Women's Christian Association
44 Washington Avenue
Schenectady, New York 12300

Mrs. Ward, Director  Telephone 374-3394

A voluntary membership organization of women and girls from all economic, racial, religious and cultural backgrounds. As a local, national and world movement, it develops programs and services to meet the needs and concerns of the community. It serves the people of this area with an active program of classes, clubs, interest groups, leadership development, and all kinds of recreation.

FISH
c/o Mrs. Hazel Woods, Director
418 White Street
Glenville, New York 12686

FISH
St. Joseph Church
Lincoln, New York 12458
24 hour answering service. Volunteers offer the following services, some of which are done only on an emergency basis; babysitting, reading to the blind, providing a meal, housework for the sick, transportation, locating needed articles, shut-in telephone chain, companionship for the elderly, providing rides for shut-ins, teen-adult companionship, and referral service when professional help is needed.

p. Davies Developmental Center Parent's Association
Mr. Walter Clepp, President
Telephone 584-2936

This is an organization which is made up primarily of parents, staff and friends of residents at the Davies Developmental Center who are concerned with all aspects of care, treatment and training going on at the school.

q. Albany Association for the Blind
301 Washington Avenue
Albany, New York 12207
Telephone 463-1211

Mr. Joseph Pike, Executive Director

A non-sectarian agency providing multiple services to the visually handicapped. Programs include social casework and psychological counseling, recreation and group work, mobility instruction, vocational training and sheltered shop employment, sales program which helps to market goods produced in the workshop, low vision aids clinic, coordination of pre-school vision screening, public education and information regarding blindness. Offering a complete, comprehensive vocational rehabilitation program with a resident facilities for multi-handicapped blind people from the central upstate New York Region, specialized programs for blind teenagers. The Director of the Vocational Evaluation Program is Joseph Kirstein.

r. National Center for Deaf-Blind Youths and Adults
105 Fifth Avenue
New Hyde Park, New York 11040
Telephone 746-4440

Peter J. Salmon, M.D., Director

The National Center provides opportunity for individualized evaluation and training for deaf-blind youths and adults.
s. Adirondack Mountain Club, Inc.
R.D. #1, Ridge Road
Glens Falls, New York 12801 Telephone 793-2673

Mr. Grant Cole, Executive Director

Building two lean-tos at Lake Ann that will be used by their group members and by our physically handicapped and severely retarded residents who are able to participate in other camping programs.

6. Federal agencies

a. Social Security Administration
65 Bay Street
Glens Falls, New York 12801 Telephone 793-6666

Mr. Idwal Parry, District Manager

Administers the Social Security Act in the Albany area. The office assists claimants in filing for retirement, disability and survivor benefits payable under social security. It also provides assistance for persons in enrolling in Medicare and in obtaining payment for covered medical services. Contact this office for social security account numbers and for information and assistance in social security matters.

7. Other agencies which we might possibly utilize in the future.

a. Capital District Psychiatric Center
44 Holland Avenue
Albany, New York 12208 Telephone 474-6415

Dr. Alan Kraft, Director

Provides geriatric consultation for psychiatric problems of aging, consultation about any individual who has had prior psychiatric care, consultation with community agencies. In addition, provides an active day care program which is an effective alternative to full time in-patient hospitalization, even for seriously troubled. The only criteria is that a person has a place to live, and is able to get to the Center up to a maximum of five days per week.

b. Public Health Nursing Service - Thomas County
14 Worth Ave.
Thomasville, New York 12686 Telephone 845-6094
Public Health Nursing Service - Curia County
Municipal Center
Glenville, New York 12108 Telephone 972-5197

Public Health Nursing Service - Macon County
12 Forest Place
Hamilton, New York 12938 Telephone 477-2106

Services: Health guidance, physical care, demonstration and teaching care in home, clinic services, chest, rheumatic fever, medical rehabilitation, immunization.

c. American Red Cross
23 Broadway
Thomasville, New York 12686 Telephone 845-1025

Mrs. Janet Small, Executive Director
Capt. Robert Sharp, Chapter Chairman

American Red Cross
51 Carter St.
Glenville, New York 12108 Telephone 972-4556

Miss Susan Marchell, Executive Director
Mr. Frank Westfall, Chapter Chairman.

Services include: Blood Program, First Aid training, home nursing, water safety, disaster service, Canteen, Jr. Red Cross activities, service to military families, assistance to veterans.

d. Other groups and service organizations such as: Rotary, Lions, Kiwanis, Jaycees, and Elks

e. Thomas County Day Center
116 Madison St.
Thomasville, New York 12686 Telephone 784-3120

Mrs. Mary Willet, Director

An educational play group for pre-schoolers 3-5 years staffed by experienced teachers.

f. Physically Handicapped Children's Program
Dr. John Glennon, Granville Telephone 642-2510

Dr. William Lee, Glens Falls Telephone 792-9951

Dr. Edmond Suss, Saratoga Telephone 584-6580
The Physically Handicapped Children's Program covers things like blindness or impaired vision of the newborn (sometimes associated with mental retardation) and correction of orthopedic defects, such as it relates to cerebral palsy; also, correction of other congenital defects not necessarily related to mental retardation.

D. Presently, there are 377 Curia, Macon and Thomas County residents who reside in State Schools, one hundred twenty-two are already at the Davies facility. It would be anticipated that during the next five years, the remaining 255 residents could be returned to the Davies Developmental Center catchment area. The following is a breakdown as to the institution and number of residents in that institution from Curia, Macon and Thomas counties:

<table>
<thead>
<tr>
<th>Institution</th>
<th>Number</th>
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<tbody>
<tr>
<td>Ross</td>
<td>193</td>
</tr>
<tr>
<td>Coloney</td>
<td>35</td>
</tr>
<tr>
<td>Sharp</td>
<td>8</td>
</tr>
<tr>
<td>West</td>
<td>8</td>
</tr>
<tr>
<td>Newsone</td>
<td>5</td>
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<tr>
<td>Leemack</td>
<td>2</td>
</tr>
<tr>
<td>Wilson</td>
<td>2</td>
</tr>
<tr>
<td>Smith</td>
<td>1</td>
</tr>
<tr>
<td>West Haven</td>
<td>1</td>
</tr>
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</table>

1. Year 1 (1974) - In order to assume responsibility for residents belonging to Davies Developmental Center who are in other State facilities, we plan to:

a. Obtain all information on the current home and family situation of the residents belonging to the Davies Developmental Center who are in other state facilities.

b. Begin to phase in the new facility which will allow expansion and diversification of programs.

c. Set up priorities for transfers based on the resident's needs and capabilities and the expressed interest of the family.
d. The new Davies Developmental Center will provide accommodations for 96 residents during this fiscal year. This will allow an acceleration of the phasing in of new residents from other state facilities who belong to the Davies Developmental Center catchment area.

e. As there are approximately 200 residents belonging to the Herman Little Developmental Services catchment area now at the Davies Developmental Center, plans would be made with Herman Little Developmental Services to resettle at least 50 of these residents in their residential facilities. This would allow the Davies Developmental Center to accept responsibility for more residents in other State facilities who belong to the Davies Developmental Center.

f. It is planned to place approximately 30 residents in Family Care and other residential facilities.

g. Develop closer ties with existing community services to ensure success in maintaining residents in the community.

2. Year II - (1975)

a. Strive to return to the Herman Little Developmental Services all of the remaining residents for whom they have responsibility.

b. Resettle a portion of these residents of Curia, Macon and Thomas Counties currently in other State facilities.

c. Place approximately 20 residents in Family Care.

3. Year III - (1976)

a. Strive to complete the resettlement of those residents of Curia, Macon and Thomas Counties who are currently residents in other State facilities.

E. The Program Goal Occupancy for the Davies Developmental Center within the next three years will be approximately 300 residents plus 96 residents for the new Davies facility.
The phasing in of the new School with additional staff will meet accreditation requirements and permit development of a broad network of community based services in conjunction with agencies in the three counties served.

1. Year 1 (1974)
   a. There are approximately 200 residents identified as belonging to the Herman Little Developmental Services catchment area, the first year plan would reflect the resettlement of at least 50 of these residents.
   b. The resettlement of residents to the Herman Little Developmental Services will allow residents from Curia, Macon and Thomas counties who are in other State facilities, to return to or closer to their home communities.

2. Year 11 (1975)
   a. Plan the resettlement of the remaining residents whose county of origin is in the Herman Little Developmental Services catchment area.
   b. These resettlements will allow the release of Davies staff and enhance the capability for providing community based programs.
   c. Plan the placement of approximately 30 residents into hostels and on Community Status.

3. Year 111 (1976)
   a. In order to maintain the Davies Developmental Center at its optimal operating capacity, the following programs are to be developed:
      1. Increase the number of residents on community status by 10.
      2. Place approximately 20 residents in family care or in other residential domiciliary.
4. Year IV (1977)
a. The following programs are to be developed:
   1. Plan and develop a hostel in Macon County.
   2. Place approximately 20 residents in Family Care or other appropriate living arrangements.
   3. Plan and develop two therapeutic group homes in Macon and/or Curia Counties with approximately four residents in each home.

5. Year V (1978)
a. The following programs are to be developed:
   1. Place approximately 20 residents in Family Care or other appropriate community living facilities.
   2. Plan and develop two therapeutic group homes in Curia and/or Macon counties with four residents for each home.

F. Program Priorities. The following is a statement of program priorities to meet unmet needs or aimed at improving inadequate services in Curia, Macon and Thomas Counties. The program priorities not only cover those operated at or through Davies Developmental Center but also those which it is felt should be initiated by other State, local or private agencies within this service area. These priorities are viewed as essential elements in providing comprehensive services which ideally should be available to all retarded persons and children with developmental disabilities and their families in the three county area. As optimistic as one would like to be, at this point in time because of the complexities involved in providing or developing some of these services, it does not appear feasible that
full comprehensive services for all of these included in the target population can be achieved over the next five years. However, estimates of the volume of services that should be provided over the next five years have been made where possible. A prevention program. Estimating a birth rate of 15 per thousand in this service area and considering the rate of population growth, approximately 4,000 babies will be born each year in this service area. Of these 4,000 new births, approximately 700 may potentially be afflicted with mental retardation or some other developmental disability. Every known preventive technique and scientific finding should be applied in a concerted effort by all agencies and appropriate disciplines to extend this service to every prospective mother and particularly to those identified as being at "risk".

Information, casefinding, counseling and referral services. There are approximately 18,000 individuals in the target population. Over the next five years, increased and joint efforts by all agencies could conceivably provide these services to a majority of these individuals and their families.

Diagnosis, evaluation, individual programming and treatment. The more disabled individuals of the target population are in the greatest need and most require these services. If three comprehensive assessment teams are formed over the next five years, they could provide these services for approximately 500 individuals each year.
Home training programs together with parent education and homemaker services. These services should be available to approximately 150 to 200 children and their families each year over the next five years.

Day training centers for pre-school children. This service is directed at the physical, mental, emotional and cultural development to prepare approximately 50 youngsters each year for school and to be of aid to parents.

Day training centers. For 50 to 75 school-age children not able to attend special classes in the schools, to prepare them, if possible, for special class admission and at least to provide basic training and development and to aid parents.

Hostels. Over the next five years plan for the development of 50 to 75 accomodations in hostels.

Respite service. In various settings for approximately 50 to 60 individuals yearly.

Long-term care. The continued use of Davies Developmental Center for intensive or long-term care of approximately 300 residents.

Halfway Houses. The development of 40 to 50 accomodations in halfway house settings over the next five years.

Family care or boarding home family care. It appears possible that from 150 to 250 such placements may be beneficial in the next five years.
Placement in facilities such as health-related facilities, county homes, nursing homes, infirmaries. It seems feasible that 50 to 75 such placements are possible in this planning period.

Community workshops. It appears that approximately 450 to 500 placements for training or continued shelter employment may be necessary during the next five years.

Social, recreation and religious programs. Two hundred fifty to three hundred fifty individuals living at home or in family care or group situations during the next five years require these programs.

Transportation. The volume of this service is difficult to quantify over the next five years. However, the goal to be achieved over this period of time should be one in which no person suffers loss of service because of lack of transportation.

Planning and coordination efforts and public education in behalf of the target population. Some encouraging efforts are presently underway in this area. These efforts should continue and expand in the future. In order to be able to plan jointly for services required by the mentally retarded and for children with developmental disabilities, the Tri-County Planning Committee for the Handicapped has been established. A draft of this five-year plan was submitted to the Committee in advance and discussed at the regularly scheduled meetings.
A draft of this five-year plan was submitted to the Committee in advance and discussed at the regularly scheduled meetings. All views were taken into consideration and only then was the five-year plan finalized for presentation to the Department.

The Tri-County Planning Committee for the Handicapped consists of the following agencies from Curia, Macon and Thomas Counties:

- Community Workshop, Glendale
- Glendale Association for the Blind
- Division of Local Services - Department of Mental Hygiene
- New York State Department of Health
- Prospect Programs
- Thomas County BOCES
- Thomas County Chapter Association for Retarded Children
- Thomas County Citizens Committee
- Thomas County Mental Health Clinic
- United Cerebral Palsy Association of the Tri-Counties, Inc.
- Curia-Macon County Mental Health Association
- Curia-Macon County Mental Health Clinic
- Curia-Macon Counties Chapter
- N.Y.S. Association for Retarded Children
- Macon County Mental Health Clinic

Some examples of joint and cooperative efforts between Davies Developmental Center and member agencies of the Tri-County Planning Committee are: 1. Residents of Davies Developmental Center are afforded the opportunity to participate in special education classes within the community at the Thomas BOCES Educational Center. 2. In addition, we are also planning a joint program with the Thomas BOCES to provide vocational experiences and training for retarded individuals at the Davies Developmental Center and the Thomas BOCES facility. The classes
will be comprised of individuals from both the state facility and the community. 3. We also have a cooperative venture with the Curia, Thomas BOCES in which both their students and our residents participate in a work-study program which provides a half-day classroom experience and half-day meaningful work activities which can lead to salable vocational skills. This program is conducted at the Community Workshop in Glendale. 4. Under the auspices of United Cerebral Palsy Association, the services of an orthopedist are made available to residents of Davies Developmental Center both at the school and in the community. These consultations result in corrective surgery and medical supervision of physical rehabilitation programs at the school. 5. The growing cooraborative effort between the Davies Developmental Center Community Services Program and the Community Mental Health Boards is resulting in the processing of case referrals and the joint developing of community-based services for persons identified in the target population.
Appendix ii

E.S.P.

Emphasis Severely-Profoundly Retarded

The ultimate goal of the Intensive Program Unit - will be to develop those behaviors and skills that maximize the humanization of each resident regardless of his assigned developmental level.

The grouping in the Home Units and programs will be based on therapeutic individualized programming, to incorporate planned Home Unit activity and training with the availability of consultation with all specialized therapies as deemed necessary by the Therapeutic Teams.

An attempt will be made to develop a milieu of normalization as far as possible in the Home Units.

To achieve this goal under unitization, the team will represent or will be the prime organizational vehicle. The Team is composed primarily of those members of our staff who have direct contact with residents within their home unit environment. The team may also select individuals from various departments, services or the community as team members. The basic principle is the integrated effort of this multi-disciplinary team, who work on a coordinated principle designed to benefit the residents. In order to increase the effectiveness in delivering program services, five home units will be created in the infirmary building, with their own team coordinators. These will be
identified in the following fashion: a team coordinator for Little Steps, II-N, II-S, I-N, and I-S. Supervision will be provided from within these units.

The Team Coordinator for each Home Unit will act to reflect the team's assessment of residents and the programs they require. Each Home Unit has its own identity and, in conjunction with the Chief of Service through the Group Team Leader, will provide for the needs of the residents. The Team Coordinator, as an active member of the team, works directly with the Group Team Leader to provide the direction to be taken in meeting the needs of the residents.

I. ADMINISTRATIVE STRUCTURE OF INTENSIVE PROGRAM UNIT.

All departments will serve in a consultant capacity. Communications between consultants and the Units will be on the Coordinator and above level only. This is to insure proper channels of communications to be maintained.

II. TEAM GOALS FOR RESIDENTS.

Each team has the primary responsibility for the care and
development of programs for its residents. It is the Teams' assessment for the care and development of programs for its residents. It is the Teams' assessment of the abilities and limitations of a resident which determines the programs and services he will receive. For this purpose all available material concerning the resident should be utilized, all necessary assistance should be requested from the various disciplines whenever services are identified which are not provided by the personnel within the Home Unit. If not available within the school, the Team will work in conjunction with the Chief of Service to obtain these services from the community.

The broad goal of a Team assuming the development of those behaviors and skills that maximize the humanization of each resident may be divided into the following sub-goals:

A. Physical (medical, nursing, P.T., nutrition, dental)
B. Emotional, psychological
C. Self-help, eating, mobility, T.T., washing, dressing
D. Communication – SH Evaluation – gestural language
E. Socialization – Rec. – O.T., education – planned unit activity.
G. Family Contacts – the Team should foster good relations between the resident and his family; this will include good communications with the family and where practical; family participation in resident care and training. It is the Team's responsibility to communicate to the family all matters relating to the resident. Where this communication requires specialized information, as in the case of medicare matters, the team may ask the physician to make the contact. It is then the responsibility of this person to report back to the Team.
III TEAM GOALS FOR STAFF.

A. Since the Unit Team is the primary agent in providing for the programs and care for its residents, it is the first-line supervision for all staff assigned to the Unit.

B. In conjunction with the Group Team Leader, the Team should evaluate the necessity of staffing programs for its residents and justify these requests. The Group Team Leaders will forward these requests to the Chief of Service for further action.

C. When a Team makes arrangements with various departments for special services, the persons rendering these services become a part of the Unit Team during the length of time the services are being rendered. Arrangements to bring service to a particular Home Unit will be made between the Group Team Leader and the Department Heads.

The Group Team Leader represents the team coordinators and the teams. Each of the teams, under the leadership of their team coordinator, determines the special service needs they require from various departments and they develop individualized programs for the residents they are accountable for.

The Department Heads are responsible for seeing that high quality professional services required for residents are available to the Teams. The Department Heads, may therefore, exercise a degree of functional supervision in, and related to, their consultive role in seeing that these high quality professional services are delivered to residents.

D. The Team will suggest training required by the Staff. After the basic orientation of all new employees - it is the Teams' responsibility through the Group Team Leader to request training packages.

E. Within the guidelines of contract agreements, it is the Teams' responsibility to schedule its staff in the way best suited to its needs. This will include shift assignment, pass days, vacations, etc. This area includes responsibility for seeing that each shift has adequate coverage on a given day from within the Unit. If not possible, it is
The responsibility of the Shift Administrator, through the Team Coordinator of his alternate to make arrangements with other units, from within the Intensive Program Unit, for the loan of personnel. It is the Team's responsibility to correct any attendance problems.

F. The Group Team Leader shall assist the Teams in the development and coordination of all programs for the residents and shall be the staff liaison between the Teams and the Chief of Service, in relation to all resident programs and staff supervision and development.

IV. RELATIONSHIP OF TEAM TO TEAM COORDINATOR.

A. The appointment or selection of Team Coordinators will be made by the Group Team Leader and the Chief of Service with the concurrence of the Deputy Director, Clinical.

B. Each Team Coordinator will have an alternate on each shift in the person of the Home Unit Administrator who will act in behalf of the Team when the Team Coordinator cannot be present.

C. The Team Coordinator is chairman of all team meetings, and has a vote in all decisions. However, in the event of an impasse, the Team Coordinator has the authority to resolve the impasse. If necessary, he should consult the Group Team Leader.

D. The initiation and modification of the programs within Home Units will reflect the individual needs of residents.

E. An emergency situation requiring a prompt decision of any kind will be handled by the Team Coordinator with the understanding that the matter will be referred back to the Group Team Leader for final resolution. The Team Coordinator will discuss the resolution of emergency situations with the Team, in order to determine how these situations may be avoided in the future or better handled when they emerge.

V. THE RELATIONSHIP OF THE TEAM COORDINATOR TO THE GROUP TEAM LEADER.

A. The immediate Supervisor of the Team Coordinator is the Group Team Leader.
B. It is the responsibility of the Group Team Leader to see that the Team is meeting its responsibilities. If the Group Team Leader feels a team requires consultations of which it is unaware, he should bring this to their attention.

C. The Group Team Leader will permit the Team to make all decisions within its assigned authority. However, he is responsible and accountable for actions of the team.

VI THE RELATIONSHIP OF THE GROUP TEAM LEADER TO THE CHIEF OF SERVICE.

A. Immediate Supervisor of the Group Team Leader is the Chief of Service.

B. The ultimate responsibility for the organization and implementation of programs which allow each resident to develop to his greatest potential is that of the Chief of Service.

VII THE RELATION OF TEAMS TO DEPARTMENTS

A. Departments have available specialized services which teams can draw upon after consultation with the department. The department head will provide consultation services through arrangements with the team coordinator.

B. When a Team Coordinator and Department Head cannot agree on a particular working arrangement, the Chief of Service, through the Group Team Leader may be contacted.

VIII. THE TEAM RELATIONSHIP TO THE PLACEMENT AND DISCHARGE COMMITTEE: BY REFERRAL:

A. The Placement and Discharge Committee as the central coordinator unit whose responsibilities include processing referrals to the School, appropriations of admissions, seeking alternative placement for referrals from community, assisting transfers if necessary, community placements or discharge of residents, will refer new admissions to the Teams and act as agents, for the Teams in fulfilling their recommendations.
B. The Teams may look to the P.D.C. for assistance in carrying out program recommendations, evaluating legal implications of the Department of Mental Hygiene law and ensuring the human rights and legal rights of residents.

IX LIVING PROGRAM COORDINATORS' RELATIONSHIP TO THE GROUP TEAM LEADER AND HOME UNITS.

A. The Living Program Coordinator will work with and through the Group Team Leader and the Home Units to develop programs. Each Home Unit will identify one or more staff members who will be responsible for implementing programs on that unit. The staff will work closely with the living program coordinator, to see that an appropriate program is designed for each child or adult. In many cases, the living program will have to be articulated with other services the child or adult is receiving, such as: speech, O.T. and P.T., in order to achieve its maximum effectiveness.
The above planning chart was conceived and adhered to by the Director and Chief of Community Services at the Davies Developmental Center. The process of programmatic change in the existing program necessitates major modification of the traditional programs for the severely and profoundly retarded.

What has been attempted in this plan is to briefly present the goals, resources, and to present in a rudimentary way the planning, the process of programmatic change in the mental retardation state institution. For the mentally retarded, a truly human developmental center, it is necessary to establish a program that reflects the unique needs and capabilities of the individuals served.
APPENDIX iv

FAMILY CARE QUESTIONNAIRE

1. How many people do you currently care for in your home under family care?

- 1
- 2
- 3
- 4
- 5

2. If you have less than five (5) persons, would you be interested in having more residents placed with you?

Yes
No
Probably and would like more information
Not at this time.

3. In what age group and sex group is (are) your resident(s)? Also give the number of residents in each category.

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Male Number</th>
<th>Female Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>5-12 year old</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13-19</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20-30</td>
<td></td>
<td></td>
</tr>
<tr>
<td>31-50</td>
<td></td>
<td></td>
</tr>
<tr>
<td>51-65</td>
<td></td>
<td></td>
</tr>
<tr>
<td>over 65</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
4. Does your resident (s) have any physical handicaps?
   Yes
   No

5. Is your resident (s) required to attend any special therapy sessions?
   Yes
   No

6. What family members are currently living at home with you and the resident (s)?
   spouse
   son
   daughter
   mother
   father
   in-law
   companion

7. How often does the social worker visit your home?
   1 or 2 times a month
   3 or 4 times a month
   only when requested
   other (please specify)

8. How long has it been since the social worker's last visit?
   Less than 2 weeks
   About one month
   Two or more months
   Other (please specify.)
9. How often would you like the social worker to visit your home?

   Once a week
   Once a month
   Twice a month
   As often as requested
   As often as he is currently doing
   Other (please specify)

10. What are the most frequent problems you have with your resident(s)?

   - getting resident(s) to adjust to family schedules and routines
   - resident(s) causing disturbance in the family or community
   - teaching resident(s) how to use local services (i.e. bus, theater, etc.).
   - keeping the resident(s) interested in a hobby or other activities
   - getting resident(s) to make wise purchases with his money
   - providing companionship and counsel to the resident(s)
   - stays by himself too much
   - other (please specify)

11. What kind of emergencies have occurred with your residents(s)?

   - involved in an accident
   - became quite ill
   - accused of a crime
   - hurt another person or himself
11. (continued)

- absent from home for unusually long period
- fights or constantly argues with others
- would not comply with our family rules
- intentionally broke or damaged property
- other (please specify)

12. What types of problems in the Family Care Program do you discuss most often with the social worker?

- recreational activities for the resident(s)
- behavioral problems
- budgeting money for resident(s)
- personal hygiene of resident(s)
- teaching the resident how to be more independent
- reports and forms required by the State of New York
- other (please specify)

13. Would you be interested in joining a small, local group of family caretakers to discuss mutual problems and solutions, and to have social activities?

Yes

No

am currently involved in such a group

other (please specify)

14. Would it be useful if you knew techniques which helped your resident function better?

Yes

No

Possibly

Other (please specify)
15. What would you like the sessions to cover?
   - how to teach the resident a skill
   - how to help the resident adjust to community living
   - how to involve the resident in family life
   - how to help the resident maintain good personal hygiene
   - other (please specify)

16. Would you be interested sometime in talking with your social worker about specific training needs for family caretakers, residents, and even the staff that would help in better preparation for family care settings?
   Yes
   No
   Not sure

17. Do the people you care for have adequate activities during the day: for instance, if you have a child is he/she in a school program, or if an adult, is he/she in a sheltered workshop?
   Yes
   No
   Most of the time

18. How difficult is it for you to arrange recreational activities for your resident?
   Frequently difficult
   Occasionally difficult
   Seldom difficult
   Not at all difficult

19. If there is any difficulty in arranging recreational activities for your resident, what do you feel are the major reasons?
19. (continued)

-Limited local resources
-Inadequate transportation
-Unmotivated client
-Activities are available at inconvenient times
-Available activities are too expensive
-Other (please specify)

20. How did you originally learn about the Family Care Program?

-From a friend or acquaintance who is a family care parent.
-By radio announcement
-From your local community organization
-Through church
-In a newspaper ad
-On television
-Other (please specify)

21. Do the people you care for have needs (e.g. medical, counseling, etc.) which are not being met? If you feel their needs are not being met please list what these needs are. (If more space is needed use back of this page.)
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Miscellaneous


