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A TRAINING PROGRAM FOR FAMILIES OF THE  
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A TRAINING PROGRAM FOR FAMILIES  
OF THE MENTALLY IMPAIRED AGED  
AS LINKAGE MECHANISM IN A SYSTEM OF CARE

by

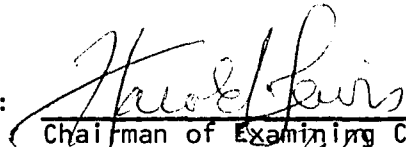
FLORENCE SAFFORD

A dissertation submitted to the Graduate  
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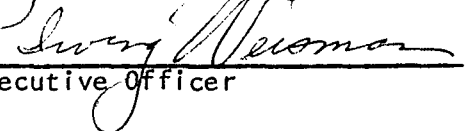
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This manuscript has been read and accepted for the Graduate Faculty  
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It is with profound personal sorrow that I record his sudden and untimely death on July 29, 1976, and herewith dedicate this project to his memory. It was a privilege to have benefitted from his wise counsel and advice. His professional commitment and integrity will serve as an inspiration in the development of future programs as unmet social needs are identified through sound administrative principles and practical research.

The only committee member not on the faculty of the Hunter College School of Social Work, Dr. Kurt Herz, Executive Director of Self-Help Community Services is especially appreciated for the vast experiences he shared, as an early innovator in programs for the aged. He has been a steadfast supporter in efforts to develop specialized care for the mentally impaired aged, and will continue to inspire working toward the eventual goal of better treatment of this vulnerable group.

Finally, my everlasting gratitude to Lawrence E. Larson, Executive Vice President of the Isabella Geriatric

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## Chapter I

### INTRODUCTION

The impetus for change derives from infinite sources in the social system--the inspiration for change is often personal. The project to be described is a training program for relatives of the mentally impaired aged, the goal of which is improved care for a vulnerable and neglected segment of our society. As a practitioner in the field of institutional services for the aged, the author became aware professionally, over the past decade, of the lack of appropriate services for this target population. As a member of a family whose sole surviving parent was becoming mentally impaired as he approached his eighties, the author was personally and intensely affect by the lack of appropriate services. The combination of professional and personal concern led to the development of the training program.

The relatives were selected as the focus for training primarily because they represent potentially the most responsible and caring element in the system to act on behalf of this defenseless, although numerous, group. The program was designed to include relatives of mentally impaired aged in the community, as well as those in long term care facilities, on the assumption that both groups could benefit from

the same curriculum, and that each group could be helped by the other through formal and informal interaction. Each group must cope with complex feelings in relating to their mentally impaired kin. Those whose kin are living in the community might learn from the experience of the group whose kin are institutionalized, which factors led to the decision to place their relatives in a nursing home, and what problems they can anticipate after placement. The relatives of the nursing home group might benefit simultaneously by a reminder of the nature of the problems for the mentally impaired in the community, and thereby reinforce their difficult decision.

An ultimate objective of the program was to help families with impaired kin in the community to function more effectively in the planning, assessment and choices of decision-making, and for those with relatives in long term care facilities, to deal more effectively with the institutional system. Toward this end, the immediate objective of the program design was to transmit, and have learned, essential knowledge and tasks, as well as attitude, associated with role assumption necessary to achieve a balance of shared function between the family and the formal organization in the care of the mentally impaired aged.

In order to design such a program it was necessary to study the current needs of the mentally impaired aged in the context of their families, against the background of the emergence of public concern for the problems of the aged,

and the development of the present service delivery system, or to put it more accurately, non-system. This will be described in the second chapter from the perspective of a social problem which is related to the many consequences of modern, industrialized society and scientific advances, including a value system which denigrates the aged.

The third chapter will discuss the nature of mental impairment in the aged, some conflicting interpretations of senility, and the pervasive negative professional and societal attitudes which add to the problem. Since one of the program objectives is to teach participants to recognize the level of mental impairment in their kin, in order to assume a degree of responsibility for their care, it is essential to have a thorough understanding of the physical, social and psychological components of the disorder.

Chapter IV will describe the theoretical framework for training the relatives of the mentally impaired to assume a significant role, along with formal organizations, for the optimal care of their kin. The specialized function of formal organizations and the family will be examined in relation to the specialized needs of the mentally impaired aged. Family theory will be discussed with reference to the crisis for the family caused by mental impairment of an older member. Role theory, and adult socialization will provide the training model to facilitate program participants in assuming the appropriate dependable role. Finally,

Andragogy will be discussed as the theory of adult education which was selected as the learning principle most applicable to the needs of the program participants on the assumption that they would be at least middle aged.

The design and evaluation of the training program will be described in Chapter V. The process and dynamics of the execution of the program will be fully discussed in Chapter VI. The concluding chapters will present the results of the data analysis, summarize the findings, and discuss their implications.

## Chapter II

### BACKGROUND OF THE PROBLEM AND PRESENT SERVICE DELIVERY MODELS

For the past twenty-five years, there has been a growing awareness of the elderly in our society, and the increasing problems related to aging. Throughout the world, modern industrialized nations have experienced an increase in the proportion of elderly in the population, with concomitant concerns for its impact on all other segments of society.

In the United States, the total population has increased threefold, since the turn of the century, while the number of persons over 65 has increased almost sevenfold, with an even higher percentage increase for those over 75. In 1900, 3 million of our 76 million population were over 65, approximately 4%, and now, with a total population of 203 million, the 20 million elderly comprise 10%.<sup>1</sup>

The growing number of aged persons is not in itself undesirable. On the contrary, longevity is prized universally. The lack of planning for the social, physical, psychological, and economic needs of this increasingly significant group, however, has led to numerous interrelated social problems. Although it is well known that the problems of aging are complex, and affect all of society's

institutions, there is as yet, no social policy on aging nor even a move toward social policy.<sup>2</sup> Ignoring the steadily growing body of knowledge about the needs of the aging, there is no comprehensive network of services, despite repeated recommendations from one White House Conference on Aging to another.

One of the most serious areas of needed services, and one which directly affects all other age groups across class lines, is the provision of health care for acute and chronic conditions. Although the aged represent only 10% of our total population, they account for more than 25% of the health care expenditures.<sup>3</sup> It is well known that the older a population is, the greater number of chronic conditions will be reported, which accounts for their disproportionate use of health services. These chronic conditions are also frequently disabling, and as families, although supportive, became smaller and more dispersed in response to the functionally changing needs of an urban and industrialized society, they were increasingly less able to care for their aged members. As a result, a variety of approaches toward care of the disabled aged has developed during the past century, particularly since 1935 when the Social Security Act was passed.<sup>4</sup> Among these are Homes for the Aged, Nursing Homes, Boarding Homes and very recently, Day Care Programs.

In the past decade, the greatest thrust has been in

developing nursing homes, or long term care facilities. The number of residents in nursing homes has doubled, from 554,000 in 1963 to over a million in 1973, with a current bed capacity of 1,200,000.<sup>5</sup>

These facilities are extremely variable in terms of the services offered, the kind of residents accepted, and the quality of care provided.<sup>6</sup> Although there have been periodic exposés of institutions for the aged for decades, they have not resulted in reform until very recently. The current investigations of nursing home care throughout the country, which has stirred considerable public outrage, has emerged from a concern, not for the lack of humane standards, but for the unanticipated high cost of care, following passage of Titles XVIII and XIX of the Social Security Act in 1965 (Medicare and Medicaid), with apparent lack of commensurate quality. It is obvious that the public pocket has more easily exposed nerve endings than the public conscience.

Within the nursing home population, the group which is most vulnerable to inadequate care and abuse, is the mentally impaired. They are unable to complain about the quality of care they receive, which often borders on neglect or indifference, and their relatives are reluctant to complain for them, either out of fear of retaliatory action from the staff, or from a sense of guilt for having placed their kin in a dehumanized environment.

It is known that the mentally impaired constitute

a large segment of the patients in nursing homes, although it is very difficult to obtain an accurate assessment of the degree of mental impairment of a population in any given institution, since there are no standard guidelines from one institution to another. Mental impairment is usually differentiated as mild, moderate or severe, and efforts have been made toward quantifying the degree of impairment, covering memory, orientation, judgement and general information. The most widely used test for mental status was developed by Kahn, Goldfarb, and others,<sup>7</sup> but although it has been revised and incorporated into other scales, there is no test which has been accepted generally for standard use.<sup>8</sup>

The classification of mental impairment, as currently used, represents a wide range of behavior, and different levels of functioning. Nevertheless, it is the category of disability most frequently found in nursing homes. Estimates of mental impairment in nursing homes, range from 50 to 87%,<sup>9</sup> but the most frequently quoted figure is over 50%.<sup>10</sup>

Adding to this large proportion of mentally impaired in nursing homes and intermediate care facilities has been a recent shift in state hospital policy, which has led to the rejection of most of the elderly referred for admission since 1968, referring them to long term care facilities instead, and transferring many other long term patients to nursing homes and other community facilities. Consequently,

by 1969, 75% of the aged who were diagnosed as mentally ill in long term care institutions, were in nursing homes, whereas a comparable proportion in 1963 was 53%, with 40% in state and county hospitals.<sup>11</sup>

This trend has not resulted in any improvement of treatment for these residents. They are still the recipients of predominantly custodial care. One study of the mentally impaired in nursing homes found extensive regression due to lack of stimulation, lack of adequate walking space, lack of recreation and occupational therapy, lack of space for socialization and activities and lack of dining facilities.<sup>12</sup>

In the past decade, there have been isolated attempts at developing therapeutic programs, such as specialized group activities,<sup>13</sup> sheltered workshops,<sup>14</sup> individualized interdisciplinary treatment,<sup>15</sup> therapeutic milieu,<sup>16</sup> reality orientation and remotivation.<sup>17</sup> These programs have been described in the literature, but with few attempts at replication, expansion, or evaluation, as to their impact on the total institutional program and their long term effects on individual residents.

Those facilities offering therapeutic programs usually follow a medical model, rather than a residential model for long term care, and one of the pioneering centers in geriatrics which has a special commitment to this population has developed a specialized facility following a hospital model.<sup>18</sup>

For the most part, the vast majority of facilities provide little more for the mentally impaired than room and board, assistance with personal care and supervision of medications. The personnel closest to these residents and most responsible for their care are nurse's aides and attendants who are poorly educated, untrained in geriatrics, and poorly supervised and motivated, resulting in a 75% rate of turnover annually.<sup>19</sup>

It can be seen from the foregoing that the institutionalized mentally impaired aged are a sub-group in society whose special needs are not being met adequately or appropriately. The fact that so little effort has been demonstrated on behalf of this disadvantaged population may be attributed in part to the frequent emphasis placed on the statistic that only 4% to 5% of the elderly are institutionalized. This can be used as an argument against allocating resources, in the competition for program funds. This is a misleading statistic, however, although cited internationally. Robert Kastenbaum, in an original analysis, "The 4% Fallacy," points out that 4% is the proportion of the aged which would be in long term care facilities at any point of time, representing a cross-section of the elderly population. However, if a cohort were analyzed longitudinally, there would be a probability that 44% over 65 eventually would require care in a long term facility or skilled nursing facility.<sup>20</sup> If this analysis is correct,

there should be as much public interest in the quality of nursing home care as the quality of life in the community, with both sectors requiring urgent attention.

Furthermore, from several studies of the aged in the community, it can be inferred that 15% suffer some degree of mental impairment, and constitute an "at risk" population.<sup>21</sup> Despite the widespread interest in "alternatives to institutional care," there are relatively few community alternatives to nursing homes for this "at risk" group.<sup>22</sup> Not only is there a lack of appropriate services in the community, but a failure to obtain care on the part of the elderly or their families, even where services do exist.<sup>23</sup>

The multiple and interrelated needs of the mentally impaired in the community have been described for years, from their need for protective services,<sup>24</sup> to their need for specialized day care centers.<sup>25</sup> A comprehensive analysis of the supports needed to sustain a vulnerable older person identifies the following: personal services (personal hygiene), supportive or extended medical services, maintenance services (housekeeping, food preparation), counseling and linkages that help connect the elderly to needed services.<sup>26</sup> However, what is available in practice lags far behind the theory.

A partial cause of this social neglect may lie in the fact that the aged, as a group, share a low status in our society. Little value is placed on the last stage of

life, which the younger members of society would like to postpone as long as possible. Among a group of major value clusterings identified in American culture are activity and work, achievement and success, efficiency and practicality, material comfort, progress and individual personality. Running through these complex orientations is an emphasis on the worth of active mastery, rather than a passive acceptance of events, and a high valuation of individual personality rather than collective identity and responsibility.<sup>27</sup> It is evident that these values would disfavor the aged, and weaken the influence of the family.

Since one of the basic values of our society is independence and self-reliance, with the respect and self-respect which people achieve in direct proportion to the degree of independence achieved and maintained, the low status of the elderly in our society can be understood partially in terms of dependency. It follows therefore, that the mentally impaired, or senile, will be among the least valued in society, being totally dependent, with little potential for achieving independence in the future, as would be the case for children, whose dependency is accepted as a normal and time limited stage of development or for other disabled groups for whom there is some hope for rehabilitation.

It can be seen from this retrospective view of the problem that the mentally impaired have multiple unmet needs,

which are being overlooked or inappropriately treated by many sectors of society. This training program which was developed for their relatives, was an attempt to test an innovative approach to meeting some of their immediate needs, with the least delay.

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### Chapter III

#### THE PROBLEM OF MENTAL IMPAIRMENT IN OLD AGE

##### Stereotypes of Old Age and the Inevitability of Senility

One of the pervasive myths about old age is that every one would become senile if they lived long enough. This myth is complementary to the stereotype of the elderly as set in their ways, forgetful, irritable, cantankerous, garrulous, or withdrawn and suspicious, a combination of attributes loosely associated with senility. The term "senility" also conjures up the image of a mindless, drooling, incontinent stage of vegetation which is dreaded by most older persons and their families.

In order to dispel the myth of the inevitable process of senility with increasing longevity, it is necessary to have at least a general understanding of the complex processes of normal aging and pathological aging. It must be stated from the outset of this chapter, that although the aged are discussed as a group, there is infinite variability in each individual aged person, which is reflective of his cultural, genetic, social and psychological heritage and life experience. Moreover, within a given individual, there is variation in the functional capacity of all of his interacting organ systems.

### Dysfunctional Attitudes Among Physicians

It is not surprising, when one contemplates the mystery of human physiology, and the awesome task of mastering the vast territory it encompasses, that physicians are invested by the public with a degree of supernatural qualities for their competence in this field of knowledge. It is unfortunate, however, that knowledge of the physiological process of human aging is not refined enough at present for many medical practitioners to overcome their attitudinal biases and recognize the difference between the normal and the pathological in elderly patients. Many symptoms of elderly patients which are presented to physicians are dismissed as "normal" with such comments as, "What do you expect for your age?" Conversely, symptoms which are normal reactions to external or emotional stresses may be misdiagnosed as chronic pathological processes and not amenable to treatment. Either bias can lead to irreversible damage to the elderly patient whose vulnerable state of balance requires an accurate diagnostic assessment and timely treatment.

### Normal Aging

It is difficult to define "normal aging" because it is so often accompanied by various degenerative processes which in themselves do not interfere with functional capacity. The major characteristic of the aged person is a general

slowing of all processes integrated by the central nervous system. The well preserved older person is able to do everything he did before but at a slower speed.<sup>1</sup>

Another characteristic of normal aging is that an aged person usually needs longer to adjust to new situations, and has lower resistance to random stresses.<sup>2</sup> However, a high level of mental and physical competence is found in many very aged persons, even into the upper nineties and in some exceptional centenarians.

#### Mental Impairment

For those who develop mental impairment in old age, it is a source of stress and consternation to the individuals, their families or neighbors, and the health professionals involved in their care. Although there are widely differing criteria for differentiating pathological symptoms from normal behavior in the aged, which holds for clinicians as well as the public at large, there are nevertheless relatively identifiable categories of mental impairment.

Mental disorders are traditionally classified as organic, when caused by brain damage (either directly from loss of brain cells and impaired function of cells, or indirectly due to interference with the normal blood supply to the brain), and functional or psychogenic when caused by psychic conflict or psychosocial factors.<sup>3</sup> In the aged, disorders are frequently related to both organic and

psychogenic factors, and accompanied very often by multiple physical ailments. This makes it extremely difficult to ascertain the cause, or etiology, of a mental disorder in an elderly patient.

Kral points out that although physiological cerebral aging may be a factor in the pathogenesis of organic brain syndrome, it is not the decisive factor. His studies indicate a relationship between the individual's genetic predisposition, his past capacity to endure emotional stress and his susceptibility to severe organic brain syndrome.<sup>4</sup> However, even where there is unquestioned organic cerebral pathology, there is no scientific agreement as to the nature of the degenerative process.<sup>5</sup>

#### Consequences of Etiological Dilemmas

This lack of agreement regarding etiology and diagnostic differentiation, as well as the extreme complexity of manifestations may be responsible in part for the lack of attention paid to careful diagnosis by physicians treating elderly patients. It may also be a reflection of the profession's negative attitude toward geriatrics as unrewarding, which in turn has led to a lack of knowledge or interest in the precise nature of impairment and appropriate prevention or treatment modalities. Organic brain syndrome, for example, is often associated with arteriosclerosis, but according to Dr. Joseph Foley, past president of the American

Neurological Association, "the frequently invoked diagnosis of 'cerebral arteriosclerosis' is usually wrong . . . . There is nothing mysterious about mental problems in the elderly. The physician mishandles them and the patient suffers needlessly only when the rules that govern all diagnosis are ignored."<sup>6</sup>

#### Role of Significant Others in Presenting Symptomatology

For this reason, it is particularly important for relatives of the mentally impaired aged, and other helping professions, to be knowledgeable about some of the manifestations of mental impairment, so that they may bring the symptoms to the attention of an interested physician. Sometimes an accurate description of symptoms is more useful for treatment selection and outcome prediction, than an attempt at diagnosis, according to Gurland, whose studies revealed extensive unreliability of diagnosis.<sup>7</sup>

#### Organic Brain Syndrome

One of the most common clinical disorders affecting the aged is labeled organic brain syndrome, and is usually described as mild, moderate or severe. It should be noted that although this is not a diagnosis, but a group of symptoms, it is the diagnosis most frequently used in institutionalizing the aged. Organic brain syndrome (OBS) is a disorder resulting from a diffuse impairment of brain tissue function. It should be differentiated as acute, when the

onset of symptoms is sudden, or of recent origin, or chronic when the symptoms have developed gradually, over a period of months or years.

#### Acute Brain Syndrome

An acute organic brain syndrome is usually related to a specific medical problem which is interfering with the normal supply of oxygen to the brain (via the vascular system) such as infection of any origin, heart or respiratory failure, brain tumors, uncontrolled diabetes, metastatic disease, drug reactions, kidney failure, metabolic imbalance, high temperature and physical injury, among many others. Sometimes acute brain syndrome is caused by a subdural hematoma (blood clot between the brain and skull) which resulted from a fall or injury. Since the aged have a high incidence of falls, this possibility should be explored if the old person who suffers an acute brain syndrome sustained a fairly recent fall or other accident.

If the acute physical disorder is identified quickly and treated, the accompanying brain syndrome usually is reversed. Often, the acute organic brain syndrome is superimposed on a mild or moderate chronic organic brain syndrome, which should also be treated, because if overlooked, it may progress more quickly as a result of the acute crisis.

Chronic brain syndrome

The term chronic brain syndrome (CBS) was adopted to avoid the stigma attached to the diagnosis of senile dementia, which was used for the same symptoms. It is assumed to be caused primarily by loss of brain cells, or cerebral arteriosclerosis which acts to slow down the flow of blood to the brain. It can also be related to any of the physical ailments which can cause acute brain syndrome, as well as such common problems as hypertension and nutritional deficiencies. Since emotional reactions to social and psychological stresses such as widowhood, retirement, separation from families, loss of income, physical ailments, etc., can indirectly cause self neglect leading to any of the previously mentioned disorders, these factors must also be assessed when an older person presents symptoms of mental impairment.

Symptoms presented in organic brain syndrome are affected not only by the organic disorder. How the individual reacts to the symptoms is related to his previous personality, constitutional traits, past patterns of adaptability and collateral systems. The environmental situation can greatly affect the kind and severity of symptoms. A known example is the person with moderate organic brain syndrome who is able to conceal the degree of impairment with a successful social facade carried over from a lifetime of competence with social skills. This is not to imply that the level of overt deterioration is determined by the past level

of social competence. There is ample evidence of profound disintegration caused by organic brain syndrome among persons of the highest intellectual and social levels, indicating that such advantages and the supports which accrue are not sufficient in themselves to stop the course of mental and physical deterioration, given a critical degree of brain impairment. In this physiological sense, chronic mental impairment is an impartial social leveler.

#### Significance of Memory Loss

Perhaps the most significant mental impairment of the organic brain syndrome is loss of memory, in the sense that it is essential not only for recall, but for the maintenance of skills and manipulation of symbols, that is, thinking.<sup>8</sup> It is the shared use of symbols in communication which differentiates man from all other animals. Descartes expressed this in the 17th century: "Cogito ergo sum--I think, therefore I am." It is the loss of ability to think and respond rationally which is probably most responsible for the widespread dread of the deteriorating mental processes of aging.

One type of memory loss may be mild and progress slowly. Unimportant aspects of an event may be forgotten, although the event can be recalled. The seemingly forgotten aspects may be available later, indicating impairment of immediate recall. If it doesn't cause excessive anxiety, it may

not be functionally disorganizing and therefore this type of memory loss has been called "benign forgetfulness."<sup>9</sup>

#### Symptoms of Organic Brain Syndrome

This contrasts with the malignant type of memory impairment known in England and Canada as senile amnesic syndrome, and is essentially severe impairment of immediate recall, shortened retention span, disorientation for time, place and person, loss of recent and remote memory, and sometimes confabulations. In addition, names and words are forgotten, comprehension and the capacity for simple calculations and abstract thinking is lost, judgement is severely impaired, and insight is absent. Signs of personal neglect, loosening of inhibitions, and incontinence may occur. Emotions may become labile, or flat, sometimes depressive or manic features are present, or delusions and hallucinations.

#### Problem Behavior

These last characteristics are most upsetting for relatives and other caregivers, as they present what are usually called "management problems." The impairment of judgement is often not recognized, and inappropriate behavior may be harshly judged by those concerned for the welfare of the impaired aged person. Emotional outburst may not be understood by the family, nor by presumed objective caregivers as manifestations of brain damage, and

instead may be resented as purposeful, difficult behavior, which causes either retaliatory or rejecting reactions. Delusions and hallucinations are also very difficult for non-professionals to deal with, even when understood as resulting from mental impairment due to the aging process.

#### Need to Recognize and Report Symptoms to Physician

There may be a sense of embarrassment at the unaccustomed, bizarre behavior presented, which would cause the family or friends of the disturbed older person to minimize the problem, or try to overlook it. The public in general has a fear of mental disorder, and it is usually easier for families to deal with these phenomena in their elderly kin if it is understood as resulting from physiological changes.<sup>10</sup> They must be educated to recognize these disturbed behaviors as symptoms, which must be reported in order to initiate a treatment plan.

#### Relationship of Depression and Anxiety

Another complicating feature of mental impairment in old age is the frequency with which symptoms of organic brain syndrome may be masked as depression or anxiety, both of which are often considered normal in old age, and left untreated. Conversely, symptoms of depression and anxiety, particularly when overshadowed by somatic complaints such as constipation, gastric upset, dizziness and palpitations, may mask an underlying organic brain syndrome.

### Call for Treatment

Depression and anxiety are common clinical problems of the aged, whose treatment should not be overlooked. These affective disorders are among the mental impairments classified as functional or psychogenic, but this is an arbitrary and unuseful category, since all of the disorders have functional and organic components.<sup>11</sup> In many, these are normal but disabling reactions to the many losses associated with old age. Depression and anxiety, if not treated quickly, will lead to behaviors which will perpetuate the conditions.

### Behavioral Consequences of Depression and Anxiety

The depressed person tends to lose interest in activities he once enjoyed, and the anxious person tends to avoid situations which may increase his anxiety. The resulting social isolation and inactivity can lead to decreased skills in using the abilities which remain. This type of vicious cycle can lead to chronic and severe depression which in turn can be the cause of many organic disorders.

### Interlocking Vicious Cycles

Another example of a causal chain reaction of pathology is the direct consequence of physical disability and pain leading to decreased mobility, which might lead to inability to shop for food, leading to malnutrition, which

can in turn cause physiological depression, or organic brain syndrome.

Malnutrition can also be caused by economic factors (insufficient income), social factors (loss of interest in food when socially isolated), other physical factors (ill-fitting dentures possibly due to weight loss, and therefore inability to chew, leading unbalanced diet) or diminishing eyesight or strength, making it too difficult to prepare an adequate diet. It can also be caused by loss of appetite which is a common reaction to depression.

Still another type of interlocking vicious cycle is started by an excessive consumption of alcohol, which might be a response to the depression or anxiety induced by innumerable social, economic and psychological causes. Alcoholism can be linked directly to brain damage, or to other physical disorders such as liver disease which then can lead to brain damage. Excessive drinking can also be a factor in malnutrition, with the ensuing chain reaction previously described.

Malnutrition is a condition which has many causes and many effects, in people of all ages, and which is given short shrift by most medical practitioners. It is not part of a routine physical examination for a patient to be asked for a detailed account of his dietary intake. However, even such a common deficiency as calcium, which frequently is present when adults cut down on milk consumption, with its symptoms of fatigue, nervousness, and leg cramps is often

undetected in medical examinations. The same is often true for many vitamin and mineral deficiencies, which can particularly be etiological factors in complaints of older persons, whose metabolic capacity to utilize nutrients also changes with age. These symptoms are then attributed to depression or organic brain syndrome, sometimes treated and sometimes not.

As families and others are sensitized to these chain reactions of multiple causes, there will be more attention paid to them by the medical profession. Some of the common symptoms of depression, in addition to the obvious mood of sadness and dejection are feelings of helplessness, loss of appetite, insomnia, guilt, lack of vitality, constipation, or less frequently diarrhea, and total negativism which can turn away those who would like to help. These symptoms have been described and interpreted by Goldfarb as a "search for aid," an attempt at adaptation to unfavorable circumstances.<sup>12</sup>

#### Treatment for Depression and Anxiety

A first line of treatment for depression and anxiety is to enlist the aid of the nearest and dearest in providing a more supportive and emotionally satisfying social environment. Community resources must be explored, such as day centers, to provide substitute relationships, roles, additional income, household help, adequate diet in a satisfactory

social milieu. Family members must be encouraged to offer the opportunity for more intimate and affectionate contacts. Individual therapy and group therapy can be helpful.

A second line of treatment, which might be used simultaneously with "people treatment," is appropriate use of medications. Anti-depressants can be very effective, to enable the older person to make use of the social interventions. The use of medication is very complicated in older people, however, because of the precarious balance of their increasingly fragile physiology. The use of tranquilizers for anxiety is even more risky, since some tranquilizers act as central nervous system depressants and can cause depression, or increased organic brain syndrome, if there is a mild degree already present. There should be careful monitoring of all medication for possible side effects, and timely adjustments of dosages.

Again, a key element in successful treatment may be found in the watchdog role of relatives or surrogate families, in their collaboration with the medical practitioner as advocate and informant.

#### Problem of Paranoia

A frequent problem which may emerge in old age is paranoid behavior. Although the specific causes are unknown, it is often associated with sensory losses, and a rigid, obsessive personality type. The use of projection is

a primitive defense, which may be used by the suspicious older person in restructuring an environment which is becoming threatening, due to failing vision, hearing, or memory. The older person resorting to this mechanism frequently blames persons close to them for real or imagined problems. This is one of the most difficult problems for relatives to cope with, whether or not the paranoid ideation is directed toward them.

Immediate treatment of paranoid patients is similar to that for depression and anxiety, that is, first to reduce the anxiety which leads to paranoid reactions, through psychotherapy and by improving the environment (including seeing to it that visual and auditory problems are corrected, if possible). Equally important is the use of appropriate medication, but this can sometimes be an impossible goal, if the suspicious older person refuses medications, or resists monitoring.

Family members often need counselling and guidance in dealing with their own reactions to the paranoid behavior of a close older relative.

#### General Treatment Approaches in Mental Impairment

There is a growing group of geriatric practitioners who have been advocating a treatment model for the mentally impaired aged which parallels the public health approach of screening, prevention, diagnosing, treatment, and rehabilitation. Such innovators as Robert Butler and Elaine Brody

in this country, and Anderson, Macmillan, and Whitehead in England have pioneered efforts toward a comprehensive program of care for the mentally impaired aged, emphasizing thorough physical examination to ascertain possible physiological causes, or medical problems in addition to the mental impairment, thorough social and psychological assessment, and supports to help them at home (such as home visits by a medical-social team, household help, meals on wheels, day care programs, day hospital programs, intermittent in-hospital care).<sup>13</sup> For those whose care is beyond the capacity of the family and the community, congregate care facilities are recommended, with a specialized range of treatment programs, individualized to the needs of each patient.<sup>14</sup>

Some enthusiastic practitioners have claimed that an optimistic treatment program, utilizing remotivation techniques and reality orientation can reverse the course of senility.<sup>15</sup> On the basis of other evidence, however, it seems more likely that those patients responded to increased stimuli for a limited time, and may also have regressed when the treatment was terminated. Another plausible explanation might be that they were not suffering from severe organic brain syndrome, but depression masked as organic brain syndrome, which responded to the therapeutic intervention.

Although it has been demonstrated that the benefits of intensive treatment for the severely mentally impaired aged may not extend past the duration of the program, treatment is nevertheless recommended on the value assumption that even the most deteriorated patient deserves the opportunity to utilize whatever human capacities remain. A secondary gain from a therapeutic milieu is improved morale for the staff working with these helpless patients, and for their relatives who suffer deeply from the ineluctable decline of their loved ones.

Whitehead's approach is that treatment should be given, even when the prognosis is poor. Because of the complexity of overlapping and masking conditions, treatment of one problem may result serendipitously in improvement in other unanticipated areas.

Anderson suggests that senility can be prevented through identifying the high risk groups in the community, such as the recently widowed, those living alone, and those showing signs of mental impairment. He describes senility as an illness, and seeks methods to prevent it by placing the high risk elderly under social surveillance and providing medical and social services.

Macmillan identifies the locus of senile breakdown as in the inadequacy of family resources and the community to deal with the needs of the older person. He too suggests that most senile breakdown is preventable, and even reversible

through home visits and hospital care.

#### Other Treatment Approaches

Other new treatment approaches offer hope to a group which until now could look forward only to progressive deterioration. DeBakey, the renowned heart surgeon, has had remarkable success (better than 70%) with over 3,000 cases of surgical intervention in the treatment of cerebrovascular insufficiency. With improved surgical techniques and sophisticated intensive post-operative care, geriatric patients can benefit from this major procedure.<sup>16</sup> This treatment, for the present, is probably limited to the very wealthy, and since so many of the aged are poor, this modality can only serve a very small proportion of those who might be helped.

Eisdorfer recently has offered hope through judicious use of cognitive acting drugs.<sup>17</sup> Although there is no conclusive evidence regarding the effectiveness of a variety of drugs which have been used experimentally throughout the world to improve the cognitive capacity of the elderly, drugs which affect the circulatory system, and cerebral vasodilators such as Hydergine, appear to be of value.

#### Segregated or Specialized Care?

An important treatment issue has been, and remains, for those who must be institutionalized, whether it is better to care for the mentally impaired aged in separate sections

of institutions, or integrated throughout the facility with the mentally alert.<sup>18</sup> Those who favor integration argue that it preserves the mental ability which remains, and provides a more normal environment.

Meacher did an extensive study of specialized facilities for the mentally impaired aged in England, Separatist Homes, which he found to be far inferior to the Ordinary Homes. His main objection was the lack of humane care, the amount of constraints employed, the use of ridicule as a means of control and their locations which made it difficult for relatives to visit. Meacher did not feel the behavior of the mentally impaired aged would upset alert residents in the ordinary homes. He found their tangential speech "artificially contrived defensive sallies," and interprets organic brain syndrome not as pathology, but as "attempted adaptation, executed with varying degrees of ingenuity."<sup>19</sup> Since the creation of separate quasi-medical facilities did not lead to improved care, Meacher views the social policy which established them as a means of concealed social control, easing the problem of social disposal of a group for whom relief appeared unavailing.

Those facilities which favor separating the mentally impaired aged, argue that better care can be provided by specially trained personnel, and that it protects the mentally alert who are very threatened by the proximity of the mentally impaired aged.

From review of the evidence, as well as from personal experience, I am convinced that the severely mentally impaired aged require separate, specialized facilities, with appropriate treatment programs. Since most facilities at present do not provide appropriate treatment, the major function of separation is the protection and comfort of the alert residents. Inasmuch as there is no evidence that integrating the mentally impaired aged with the alert benefits the mentally impaired aged in any measurable way, it is more likely that this is a rationalization used to justify a policy which was developed for fiscal expediency. It is easier to maintain full occupancy by filling vacant beds with the first patient who is available, than to have to wait for patients of a particular mental status.

Those facilities which offer the best models of care for the mentally impaired aged, do so on a specialized, segregated basis, according to degree of impairment.

#### Human Warehouse Controversy

Recent investigations of Nursing Homes in the United States, based on concern for financial abuses, exposed horrible circumstances for many patients, lacking proper treatment and care. One result has been a current interest in the plight of the institutionalized aged and an outcry for improved care.

Some years ago, Baizerman addressed this problem

through an analysis of the label "senility" as a means of social control. He argued that senility is a social role, with shared rights, responsibilities, and expectations of behavior. Since the advent of Medicare and Medicaid, with greater numbers of nursing home beds and public funds available for payment, families of stress-producing impaired older persons have more often used the nursing home as an acceptable alternative for their care. Baizerman posits that the social role of senility provides a linkage between the family and the bureaucratic organization, by enabling the family to put away a surplus family member.<sup>20</sup>

Although there is a validity to the analysis of senility as a social role, the interpretation of its use to store away dysfunctional family members is a perpetuation of the myth of a dumping syndrome, that is, that families discard their elders once they are placed in a nursing home. This myth, for which there is no empirical evidence, causes unnecessary guilt for relatives who must place an impaired old family member. Existing evidence shows instead that placement is generally arranged as a last resort, only after many other alternatives have been tried and the family can no longer manage the increasing needs of their relative.<sup>21</sup>

Those who share responsibility for the care and protection of the mentally impaired aged in our society, have a formidable and sometimes overwhelming task. They must sort out fact from fiction in the emotionally charged area of

decision making, usually at a time of crisis, in order to balance the rights of the older people with their needs. Decisions made at this time have profound consequences for the mentally impaired aged for the remainder of their lives. This task calls for awareness of the widespread negative attitudes which are held toward the mentally impaired aged, in ourselves and in society generally. At the same time, a rational decision calls for the broadest knowledge of the interacting physical, social, economic and psychological influences impinging on the needs and wishes of the individual and his family. Planning for this group calls for a realistic appraisal of the total problem, an acceptance of conditions which cannot be improved, and a determination to alleviate whatever can be changed. This chapter has attempted to highlight those aspects of mental impairment which are most important for the relatives and significant others in the lives of the mentally impaired aged.

It is evident that although a great deal of knowledge has been accumulating about the multiple problems in assessing and treating mental impairment in the aged, there is a great deal still to be learned. Programs and services which are known to be effective in preventing or decelerating some types of impairment, and treatment modalities which are known to be helpful in rehabilitating or decelerating the rate of deterioration in some types of mental impairment are not available at this time for the most part in this country.

As relatives of the mentally impaired aged become more knowledgeable about the nature of the disease, and the kinds of supports and services which are needed to care appropriately for those afflicted, they may prove to be a powerful influence in the competition for social programs, leading to a wider range of services and options in the future.

Footnotes to Chapter III

<sup>1</sup>V. A. Kral, "Senile Dementia and Normal Aging," Canadian Psychiatric Association Journal, 1972, 17, 11, p. 26.

<sup>2</sup>Ibid., p. 27.

<sup>3</sup>All statements about mental impairment in this chapter are derived from the following sources:

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<sup>4</sup>V. A. Kral, p. 283.

<sup>5</sup>G. Blessed, B. E. Tomlinson and M. Roth, "The Association Between Quatitative Measures of Dementia and Senile Change in the Cerebral Grey Matter of Elderly Subjects," Journal of Psychiatry, 1968, 114: pp. 797-811.

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<sup>6</sup> Joseph Foley, "Pinpointing Mental Disorders," Geriatrics, Medical World News, 1973.

<sup>7</sup> Barry Gurland, p. 352.

<sup>8</sup> Felix Post, "Disturbances of Memory and Thinking," Gerontologist, 1970, 10 (1) II: pp. 5-8.

<sup>9</sup> V. A. Kral, p. 26.

<sup>10</sup> M. Fisch et al., "CBS in the Community Aged," Archives of General Psychiatry, 1968, 18: pp. 739-745.

<sup>11</sup> Edward Busse and E. Pfeiffer, p. 109.

<sup>12</sup> National Institute of Mental Health, Aged Patients in Long-Term Care Facilities: A Staff Manual; based on staff seminars at the Hebrew Home for the Aged in Riverdale conducted by Dr. Alvin Goldfarb (Washington, D.C.: U.S. Government Printing Office, 1973).

<sup>13</sup> Ferguson Anderson.

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J. A. Whitehead.

<sup>14</sup> Elaine Brody, "Congregate Care Facilities and the Elderly," Aging and Human Development, 1970, 1 (4), pp. 279-321.

<sup>15</sup> Muriel Oberleder, "Crisis Therapy in Mental Break-down of the Aging," Gerontologist, 1968, 8 (3): 35.

<sup>16</sup> Michael E. DeBakey, "Surgical Treatment of Atherosclerosis and Cerebro-Vascular Insufficiency in the Elderly," in Abstracts of Proceedings, International Gerontological Conference, Vol. 2 (Kiev, 1972), pp. 172-174.

<sup>17</sup> Carl Eisdorfer, "Observations on the Psychopharmacology of the Aged," Journal of American Geriatrics Society, Vol. XXIII No. 2, February, 1975.

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<sup>19</sup> Michael Meacher, Taken for a Ride; Special Residential Homes for Confused Old People: A Study of Separation in Social Policy (Great Longman, 1972).

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## Chapter IV

### FRAMES OF REFERENCE AND METHODOLOGY

From the perspective of systems theory<sup>1</sup> we assume that the mentally impaired aged as a group are one part of the social system, whose care is the function of other interrelated elements of the system, such as the family, significant members of the community, social agencies, the staffs of nursing homes, and governmental institutions. The nursing home seen as an open system, is affected by its own organizational structure, the staff and patient systems, and the interaction of elements in the outside environment, such as other community organizations and families and friends of the patients, and conversely affects the other parts of the system which are interdependent. Therefore, any program which is introduced with the purpose of affecting one part of the system, as for example, the family, will potentially influence all other parts of the system.

#### Family Structure

The family is viewed as a universal institution, whose form and functions vary according to the culture of a given society.<sup>2</sup> It can be broadly defined as consisting of individuals related by blood, marriage, or adoption, whose reciprocal roles and behavior originate in the norms

of their culture or subculture.

The family in earlier agrarian societies was a productive unit, in which all members had defined economic and social roles. It insured its own continuity and identity through the transmission of traditions, shared beliefs, and practical career knowledge. Change occurred gradually, and older generations trained the young to succeed them and carry on the same traditions. The family form could generally be described as an extended family, where relatives of several generations included not only parents, children and grandchildren under one household, but possibly uncles, aunts and cousins as well. The extended family did not invariably live under one roof, but relatives usually lived near one another.

The modern American family has been rapidly changing, demographically and functionally, affected by, and in turn affecting, the course of industrialization and urbanization. The rate of change (which varies according to subculture) has been accelerated by the advances of technology, with its effect on communication, transportation, means of production, and transmission of information, as well as by the destructive force of technology through the development of the means of nuclear annihilation.

The changing structure of the modern family has accompanied the changing structure of society. Efficient production as a goal of industrialization led to a

differentiation of function for the family, and to the development of formal organizations as the rational means of carrying out their specific tasks. Formerly tasks of the family, economic production, education, health care, religious instruction, recreation and entertainment, all became functions of large organizations.

The family became more specialized in its differential function as the socializing agent of society, indoctrinating the young with the cultural norms and values of society, providing affectional bonds, management of tensions, and sexual and reproductive functions. The tempo of social change, however, and the dynamics of changes in fundamental values and attitudes, has led to major problems for the family of role strain, identity confusion and generational conflicts.

There has been controversy among sociologists over the past three decades in describing and analyzing the changes which have taken place in the modern family.

First, of special significance to this study, was the fact that the aged were not treated as part of the family, as indicated by their absence in most texts on the family.<sup>3</sup> Where they were mentioned, they were generally treated as liabilities or problems, the responsibility for which should not be borne by the family.

It had been assumed that the nuclear family, consisting of only two generations in one household, developed as

the form most congenial to the requirements of industrial society, but that the strains caused by rapidity of changing values was leading to the breakdown or dissolution of the American family.

More recent studies have concluded that the nuclear family as the modal family organization, is a myth, and that most individuals are part of an extensive kinship network, sharing in a system of reciprocal aid and affection, and are not isolated in their family of procreation. The family form most typical of modern society has been termed the "modified extended family" by Eugene Litwak. The modified extended family consists of a coalition of related, nuclear families, not bound economically or geographically, maintaining autonomy but partially dependent in terms of exchanging significant services.<sup>4</sup>

The assumption of this family form as most common in modern society was the frame of reference for our program with relatives of the mentally impaired aged.<sup>5</sup>

#### Theory of Shared Function and Balance Theory

A related theoretical model which we are following as a rationale for the usefulness of our program is Litwak's theory of shared function. According to this theory, in a technological society the family and bureaucratic organizations share functions in all areas of life. The family does not specialize in one function, and the organization in another.

Primary groups and formal organizations both play a role in most major areas in our society, achieving maximal social goals through this shared functioning, because these two systems bring together different but complementary means for reaching these goals.

However, in order for each of these systems to function maximally, it is necessary for a balance to be found through linkages between systems which will permit kinship structures to exist along with bureaucratic organizations, in a coordinated manner.

Litwak posits that a mid-point of social distance should be found as an ideal balance point, since extreme distance and extreme closeness both tend to disrupt goal achievement.

This balance is particularly relevant in understanding the conflicts which emerge in family groups when they must deal with the problem of protective care for their mentally impaired elders. The members of a modified extended family, usually separated geographically, find it very difficult to assume the total responsibility which may be required by their impaired kin. The nursing home, in our current society, is the organization apparently most suited to offer physical protection to this group. However, the nursing home, as a large organization is not able to meet the emotional needs of these elderly, who despite mental impairment still have needs for affection.

As a bureaucratic structure, the institution is run by formal rules, impersonally administered. There is a systematic division of labor, based on specialized competence which leads to fragmentation of services, and often to inadequate care, if the patient is not known and treated as a whole person. The family, by maintaining contact with the nursing home staff, can reinforce the identity of the patient as a whole person, and his or her significance in the system. By continuing to provide the affectional ties for the family member, even when institutionalized, the relatives maintain their specialized function.

From this point of view, a program which will enable the family and the organization to find a balance in their shared function of caring for the impaired elderly, will provide an important link in the system.

#### Filial Crisis and Filial Maturity

I have observed from years of practice in a geriatric center, and it has been noted in the literature, that middle-aged and aging families of the mentally impaired aged experience great stress and personal anguish when facing the crisis of decision making concerning institutionalization, or in coping with their care at home.<sup>6</sup> Family members coming from different socio-economic levels, of varying ethnic backgrounds, from a wide range of occupations, exhibit a similar lack of awareness about the general problems of the aged in our society, and total ignorance about

the nature of mental impairment in the aged. Even those skilled members of the helping professions, such as physicians and social workers, are at a loss when confronted by the complex problems in dealing with the moderate to severely confused elderly in their own families.

The adult children of the mentally impaired aged usually experience a filial crisis when confronted by the need to assume new role behaviors in their interaction with their totally dependent parent. These relatives are often themselves in the aging phase of the life cycle, and confronted by personal anxieties about their future. Their primary task during this family crisis is to move toward the developmental stage of filial maturity characterized by Blenkner as the capacity to be depended upon.<sup>7</sup> In addition to the difficulties in succeeding in this task which result from previously unresolved interpersonal relationships, is the culturally induced strain from the egalitarian ideology of a democratic society which interferes with the need to take control.

Families facing the unexpected problems of planning for their parents characteristically grope for cues, lacking experience and knowledge about the last stage of life. They need professional guidance in the task of assessing realistic alternatives, which is often unavailable.

Those who have placed their parents in an institution usually exhibit a wide range of behavior, from overly

critical attitudes toward the nursing home staff, stemming from their feelings of guilt, to silent acceptance of mistreatment and neglect of parents, resulting from feelings of powerlessness in the face of a dehumanizing bureaucratic environment. These dysfunctional reactions interfere with the exercise of dependable behavior with respect to the mentally impaired kin.

Rational attempts at planning for the impaired group residing in the community which is the protective task of the responsible relatives, requires a broad knowledge base of the social and psychological aspects of aging, knowledge about the functioning of the older person in his social setting, his individual strengths and weaknesses, the dynamics of relationships within his family, the attitudes and values they share, or which may be in conflict, their economic resources, as well as a thorough familiarity with the community resources which may be available. This requires the insightful cooperation of the family with a professional involved in the planning process, since the aged person involved, by virtue of his mental impairment, is not capable of rational input.

There are very few professionals trained in gerontology and qualified to offer appropriate help to these troubled families. Those institutions and agencies which have qualified staff, allocate very little time to counseling families. Some of the progressive nursing homes have

orientation meetings for relatives of new residents, offer individual counseling by social workers, and in some facilities, group therapy. The vast majority of geriatric facilities, however, have no programs for relatives, and for those whose elderly are in the community, guidance is hard to find, even for those sophisticated enough to negotiate the information and referral network.

The training program for the families of the mentally impaired aged, therefore, was developed with the purpose of overcoming to some extent, a significant gap in services for these inter-generational aging families in crisis. From the framework of crisis theory, this intervention is introduced to stimulate the mobilization of dormant strengths and capacities. The crisis may be viewed not only as a threat to family stability, but as an opportunity for growth and adaptation, leading to better methods for dealing with their situation.<sup>8</sup>

#### Methodological Implications of Role Theory and Adult Socialization

Role theory postulates that an individual's role behavior in society is related to his and society's expectations of the norms of behavior for a particular status, fitted into a framework of social values, and that since an individual occupies multiple statuses simultaneously, there should be congruence in the role-set, or role repertoire of a normal, integrated adult. Lack of congruence, as well as

lack of role-clarity, leads to role-strain and role-conflict. This is seen as a major source of stress for the relatives of the mentally aged, when the role demands as kin to a dependent old person, interferes excessively with their other roles as spouse, parent, employee, etc. In contemporary society there is a general "overload" of role responsibilities, adding to the stress experienced by the family members, who must allocate priorities according to unclear norms in their ordering from mandatory to discretionary components.<sup>9</sup>

Furthermore, we accept the premise that role behavior is acquired through socialization, the process of learning socially relevant behavior at various stages of the life cycle.<sup>10</sup>

Socialization is understood to be continuous throughout life, since the internalization of socially prescribed norms in childhood is not comprehensive enough to meet the demands of later years. This is especially true in modern, technological society with its rapid changes in behavioral norms and values, where the role requirements learned for a particular status may be inappropriate by the time the status is reached.

Many familiar social institutions have developed to aid the adult in socialization, such as citizenship classes for new immigrants, programs to retrain employees in a new technology, family life education and parent-education programs for newlyweds and new parents. In addition, there

are many informal ways in which socialization is aided, such as the seeking out of people with similar experiences, from whom an adult may learn.<sup>11</sup>

Despite this, very little is known about the socialization of adults. As Chillman puts it, "There seems to be an implicit assumption that a full fledged adult ought to know how to handle his various life tasks and that society owes him no help in this matter."<sup>12</sup>

Such an assumption might have validity in a static society, where social positions are relatively fixed and traditional family roles are learned within the cultural context of the family. Role models are readily available in the extended family, which is the norm for such societies. In a rapidly changing culture, however, there is no adequate preparation for new roles which must be assumed within the framework of the developmental tasks of the individual and the family.

Part of the problem with respect to the mentally impaired aged, which can be expressed as a case of "cultural lag," may be related to the lack of consensus surrounding the social value issues affecting familial norms of behavior. Since there are no clear value orientations concerning the mentally impaired aged, those roles impinging on them will be unclear. Moreover, role models are unavailable in the modified extended family, from whom the adult children and other kin of the mentally impaired aged can model their behavior,

and there are no reference groups with similar experiences whose norms they can adopt.

Since adult relatives of the impaired aged in our society are not socialized for the new, and usually unexpected role of protector of their parent or kin, the training program was an attempt to induct them into their unfamiliar role by providing a learning experience to compensate for this gap.

#### Educational Method

The learning principle chosen for the training program was the theory of adult education articulated by Knowles as most effective with adults.<sup>11</sup> Following the principles of Andragogy (the art and science of adult learning) the program attempted to establish a climate of informality, mutual respect, and collaboration. The curriculum was based on the principle of mutual planning, and self-directed learning, accomplished by a problem centered educational model. It was assumed that these adult learners came into an educational activity because of experiencing some inadequacy in coping with current life problems and want to apply what they are learning immediately. They are ready to learn those things they need because of the developmental tasks they are confronted with in their various roles. Therefore, the curriculum was organized around problems encountered by the participants in their family relationships as affected by their mentally impaired kin, with participants identifying

the theoretical and practical knowledge necessary to deal with these problems.

Another principle of Andragogy, that of the role of experience as a resource in learning, was particularly relevant for the training program. Since a major problem for the participants has been identified as lack of role clarity and congruence, one focus of the program was on experiential learning, by means of role play, discussion of case material, simulation and group discussions. Material was organized so that by the end of the program, participants should have learned their new roles by experiencing them, along with a general knowledge base of the nature and meaning of mental impairment in our society.

#### Summary

From these theoretical frames of reference, the program aimed to help families recognize the universal elements in their unique situations, while attempting to help them work through developmental tasks. Through the acquisition of knowledge and self awareness it was hoped that they can reach the stage of filial maturity in which they can accept being depended upon by their parent or kin. In this stage, the family can more readily behave dependably, by assuming a balanced share of the protective function along with the appropriate formal organizations, not interfering excessively with other legitimate, competing role demands.

Footnotes to Chapter IV

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<sup>2</sup>Raymond Smith, "Family: Comparative Studies," in David L. Sills (ed.), International Encyclopedia of the Social Sciences, Vol. 5. (Macmillan Company and The Free Press, 1968), p. 301.

<sup>3</sup>Belle Beard, "Are the Aged Ex-Family," Social Forces, 27, 1949, pp. 274-279.

<sup>4</sup>Eugene Litwak, "Extended Kin Relations in an Industrial Democratic Society," in E. Shanas and G. Streib (eds.), Social Structure and the Family (New Jersey: Prentice-Hall, 1965).

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<sup>6</sup>Margaret Blenkner, "Social Work and Family Relationships in Later Life with some Thoughts on Filial Maturity," in E. Shanas and G. Streib (eds.), Social Structure and the Family (New Jersey: Prentice-Hall, 1965).

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<sup>7</sup> Margaret Blenkner, p. 57.

<sup>8</sup> Howard J. Parad and Gerald Caplan, "A Framework for Studying Families in Crisis," in Crisis Intervention (New York: FSSA, 1965).

<sup>9</sup> William Goode, "A Theory of Role Strain," American Sociological Review, 25, August 1960, pp. 246-258.

<sup>10</sup> Bruce Biddle and Edward J. Thomas (eds.) Role Theory Concepts and Research (New York: John Wiley and Sons, 1966).

<sup>11</sup> John Clausen (ed.), Socialization and Society (Boston: Little, Brown, and Company, 1968).

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## Chapter V

### DESIGN AND EVALUATION OF THE TRAINING PROGRAM

On the assumption that the distinctive role requirements of kin to the mentally impaired aged can be learned in a relatively short, intensive training experience, a six week program was planned, to be offered at the Isabella Geriatric Center on Saturdays, in two hour sessions.

The first hour of each session consisted of lecture and participant discussion. The second hour was to be devoted to laboratory experiences of role playing, simulation, group discussion of case material presented by participants, and a summing up of the session's lessons.

The program was offered jointly to two large groups, one consisting of relatives of the mentally impaired residents at the Isabella Geriatric Center, and other Nursing Homes in the area, where there has been no other opportunity for family group meetings, and the other a group of families whose mentally impaired relatives reside in the community.

An announcement of the course was mailed to appropriate relatives of the residents at Isabella Geriatric Center living in the greater New York area, and to a select group of relatives known to community agencies serving the aged in Manhattan, Bronx, Brooklyn and Queens. (Appendix 1.)

A press release was sent to the local neighborhood newspaper, which reached other relatives, not known to the community agencies. (Appendix 2.) The program was offered from the first week of January to mid-February, as a potentially favorable time for this target group.

The program was carried out under the auspice of the Isabella Geriatric Center. This non-profit, voluntary agency, established as a nonsectarian, charitable Home for the Aged, exactly 101 years ago, enjoys the reputation of providing the highest level of quality care. It is unique in having developed three levels of care in one facility: an apartment house providing a wide range of services to facilitate the independence of the relatively healthy older person, an intermediate care facility for the older person in need of more services, such as closer medical and personal supervision, and a nursing home for the older person who requires full time nursing supervision. The Board of Managers has demonstrated complete confidence in the Executive Vice President, an administrator who is also a trained social worker, by giving him great freedom in developing programs which reflect the most modern philosophy of care for the aged.

One area of service which the Home has not developed until now is the extension of programs to the aged still in the community, nor are there any special services for family members, with the exception of limited individual counselling. As a consequence, in recognition of a need to be more

responsible to the community, the proposed program was welcomed by the Executive Vice President, who enlisted the cooperation of all other sectors of the agency. As part of the organizational structure of the Isabella Geriatric Center, I was able to carry out this training program, with administrative approval, on the premises, without having to seek funds, or levy a charge to the program participants.

#### Program Content

The curriculum developed in the first session a non-technical knowledge base about mental impairment, and its effect on family relations in modern society as a necessary tool for the work of the participants. To stimulate maximum interest and retention of the didactic material, it was presented with personal references to the emotional impact of these conditions. Reinforcing the knowledge component, the participants translated these generalized conditions into problems which they were experiencing, which were then identified as needs from the program. (Appendix 3.) For the balance of the sessions, as individual problems were discussed which required an understanding of the basic physical, psychological and social aspects, the factual material from the first session was reviewed, clarifying for all participants the relationship between the knowledge component and the problem solving skills being developed in the program.

In the second session, practical management problems were presented for those in the community, and dealing with visits and staff relations for those in the nursing home. The second hour was devoted to a role play problem of family members discussing placement of a relative in an institution.

Session three dealt with practical management problems confronting both groups of relatives, followed by a role play involving family conflict over visiting, and dealing with the institutional staff. Discussion underlined the significance and applicability of the range of problem situations for both groups of relatives.

It was assumed that the nursing home relatives would be helpful to the community group, through sharing their techniques in handling similar problems before placing their kin in the nursing home as well as demonstrating that all problems for the family are not solved in the institution. Conversely, it was assumed that they would be helped in accepting the necessity for their decision to institutionalize their family member, by identification with the community relatives, struggling with similar problems which they had experienced in the past.

Session four dealt with the clinical problems of depression, paranoia, and sexual acting out and the special implications for family members. Case examples were examined, presenting alternative methods of management.

Session five examined the role of religion and other

ethical belief systems, and identified the value issues causing conflictual feelings for the participants.

The sixth and final session discussed the problems of the participants in the context of Litwak's balance theory of shared function. The theoretical analysis of the limitations of bureaucratic organizations with reference to the very emotionally laden problems experienced by the program participants had practical relevance and was designed to evoke an action orientation on the part of the participants. A simulation of a Community Board hearing involving an application to open a model day center for the mentally impaired aged was designed to close the program with an emphasis on the need for involvement of the relatives in the process of active social intervention on behalf of their kin.

#### Evaluative Design

The effectiveness of the program is evaluated by means of a pre-test, post-test, self-administered questionnaire. Since there are no existing questionnaires to measure the behavior and attitudes relevant to this study, an instrument was developed by the project director. The questionnaire covers such items as family relationships and interaction, role perception, frequency of visits to aged family member, frequency and quality of interaction with nursing home staff, amount and kind of concrete services given, effects of aged relative on other aspects of respondent's life, expressed feelings of guilt, confusion, conflict,

feelings about own old age and own children, knowledge about aging in our society, knowledge about mental impairment in the aging, recognition of value issues. (Appendix 4.)

The responses provide a profile of the respondent's knowledge and attitudes about aging and mental impairment, as well as a profile of interaction with other family members and institutional staff. These are the variables which reflect whether the participants have increased their knowledge of aging and developed any skills in role behaviors which have resulted in improved care for their aged relatives.

The post-test questionnaire repeated all questions except those which provided background information. An open ended question was added to seek the participants' own evaluation of the training program, and whether they found it helpful in dealing with the problems of their mentally impaired relatives.

Inasmuch as this group would be able to experience an improved level of functioning immediately upon completion of the program, if it was successful, the questionnaire was repeated 6 weeks after the program ended, to measure the duration of any effects.

As a check on the validity of using self-administered questionnaires to measure the relevant changes, an extensive personal interview was conducted with a selected 15% sub-sample. The sub-sample was chosen to include community and institutional relatives whose questionnaires represented

a wide range of responses, on the assumption that this would reveal the strength or weakness of the instrument in tapping the true reactions of the participants in the program. It was expected that the personal interview might uncover dimensions of the study which was not revealed by means of the questionnaire alone.

The criterion of success or lack of success of the program is whether it had the outcome of helping the families of the mentally impaired aged to function more effectively as outlined in the statement of the purpose of the program. "More effective functioning" is operationalized as the achievement of role congruence as demonstrated by change in role behavior and self-expressed satisfactions and dissatisfactions with their role performance vis a vis their aged relative and larger family, and in achieving a balance of responsibility shared with appropriate social agencies.

Since part of the program focused on the identification of value issues underlying the role conflicts experienced by the participants, the Rokeach Value Survey was given to each participant at the beginning of the program, and six weeks after the last session, to measure if there were any shifts in value orientations. (Appendix 5.) Since this standardized instrument has proven validity and high reliability, if any significant shifts occur in major value orientations, it may be inferred that it is related to the training program.<sup>1</sup>

Because of the practical constraints of time and money in finding a comparable control group, and the difficulty with this type of program in controlling for antecedent and extraneous variables, the evaluation design of the program is non-experimental. It concerns itself with a project limited to before and after measures of one group receiving one program. Careful attention was paid to the dynamics of the program by recording all sessions on cassettes, and any changes observed are analyzed descriptively. This design is compatible with Lewis Coser's view of the analysis of sociological statistics. "Qualitative observations on a small universe can provide theoretical leads that may at a later stage be amenable to more refined statistical treatment. To refrain from using descriptive data because they may lend themselves only to tabular presentation will not only diminish our theoretical powers but will retard the refinement of statistical analysis as well."<sup>2</sup>

Tests of significance were to be applied when appropriate, however the small number of participants did not lend itself to that degree of statistical analysis. Accordingly, data was treated descriptively.

Change in behavior is measured by self-reporting in the questionnaire, and cross-validated through reports by professionals who have referred the participants in the program.

Behavioral changes are rated by the project director,

by a predetermined scale. A panel of three experts in the field of institutionalization rated the same changes, to establish reliability and validity.

The training program can be considered successful if there is improvement noted, six weeks after the final session, in a balance of responsibility shared with their family members and relevant social organizations, in accordance with the individual needs of their impaired kin, by the majority of the participants who have attended at least half of the sessions.

Footnotes to Chapter V

<sup>1</sup>Milton Rokeach, The Nature of Human Values (New York: The Free Press, 1973).

<sup>2</sup>Lewis Coser, "Presidential Address: Two Methods in Search of a Substance," American Sociological Review, December, 1975, p. 693.

## Chapter VI

### DYNAMICS OF THE PROGRAM

#### Registration Criteria

Because of the enthusiastic interest expressed in the program, enrollment was opened to as many participants as wanted to come, the only prerequisite being that they had to be the relatives of a mentally impaired older person. The project director, noting that two registrants were professionals with considerable experience with the aging, called them to explain that the program would be geared to relatives with no knowledge of mental impairment and the problems of aging in our society. They said that they registered because of experiencing problems in relation to their mentally impaired parents and felt the program might be helpful. One was a Minister with over ten years of experience as Pastor to nursing home patients, and the other was a Professor of Gerontology, a former director of an association of Homes for the Aged. With misgivings, they were allowed to attend, since the project director felt that their vast experience in the field would interfere with their fitting into the group. These fears were unfounded, as it was obvious that substantive knowledge and professional experience were of no value in coping with their own

reactions to their relative's mental deterioration and consequent behavioral changes.

These participants were as emotionally disturbed by their problems with their parents as any of the less experienced participants, and each expressed great satisfaction and help by the end of the program.

#### Establishing a Climate of Informality

There had been 64 registrants, of whom 48, or 75% showed up at the first session. In keeping with Knowles' principles of Andragogy, careful attention was paid to the learning environment, and a multipurpose activity room was selected which was large enough for comfort, but not so large that the participants would lose a sense of intimacy. One wall was decorated with a floral drape, and the other walls and furniture were bright yellow, creating a warm and inviting atmosphere. The chairs were arranged in three concentric semi-circles, filling the room but not overcrowding it.

A large number of participants arrived one half hour early, sat quietly, looking tense and not talking to one another. When a huge urn of coffee and platters of pastries were brought in, conversation started. The session started twenty minutes late to put the participants more at ease by allowing them to become acquainted over a cup of coffee. After the first hour, during the break there was much

animated interaction among the participants. The first session ended one half hour later than scheduled, and many participants remained to have more coffee and conversation with their newly found peer group.

#### Content Session One

From the outset, the program was presented as a problem solving model with the goal of providing the tools necessary for more rational, satisfactory family relations and institutional relations with respect to the mentally impaired aged. It was assumed and demonstrated that the participants were motivated to acquire a body of knowledge about mental impairment and aging in our society which might help them to deal better with the emotional conflicts which they were experiencing.

The heightened emotional level of the group was evidenced frequently by the urgency and tone with which problems were presented for discussion, or tears with which experiences were shared. The project director described the development of her interest in this field which grew from a personal confrontation with mental impairment in her father, and the course of his deteriorating condition, with the intention of establishing an empathic relationship with the group. Although the program format was educational, it turned out to be at least as much a therapeutic experience.

As the knowledge component was developed, the participants were invited to raise questions or make comments

based on their personal experiences, which were then used to reinforce the more abstract learning. The following case example will illustrate the process.

The project director indentified a source of difficulties for the relatives of the mentally impaired aged as the need to acquire new role behaviors for which they have no prior experience and without benefit of role models from whom they can learn. One participant, a married daughter in her fifties, commented that when she brought her parents for their initial interview to Isabella Home, she recalled having the same feelings as when she registered her children for kindergarten and realized that her role had completely turned around. She also recalled her feelings as her mother's mental impairment advanced, so that she was not always able to dress herself. As the daughter helped her to dress, she was painfully aware of the difference in her emotions from when she helped her own daughter dress. She said with tears in her eyes, "I didn't want to be her mother--she had been a wonderful mother."

The rest of the group nodded in agreement as the incident was recounted, most having experienced similar emotions at what seemed to be the strain of role reversals. The project director pointed out that it is not role reversal which takes place, but the assumption of a new role, that of protective kin, or helper. The psychological relationship between adult child and impaired parent does

not turn around, although the incorrect concept of role reversal and second childhood is widely held.

The group then was introduced to the concept of filial maturity as the developmental task which confronted them. This was explicated as the need to assume dependable role behavior, appropriate to the level of their kin's impairment. The specific, practical problems which were raised as a result of this discussion formed the basis for further theoretical and practical explication.

The most frequent problems expressed by the relatives centered around their difficulty in relating to their kin during visits, and their frustrations in seeking help from the staff of institutions. To deal with the first set of problems, the necessity to understand the nature of mental impairment, and the meaning of their kin's behavior was emphasized. This was followed up with a factual presentation using a blackboard as a visual aid.

To deal with the second set of problems, the project director suggested that the group might form the nucleus of a family council which could bring their shared concerns as relatives to the administration of the institution. This was discussed as a practical means of fulfilling a balance of shared function between the primary group and the institution in a nursing home setting, and explicated in the context of bureaucratic theory and systems theory. There was immediate interest in the idea of a family council, and

the project director undertook to discuss the mechanics of establishing such an organization with administration and report back at the second session.

Since it was apparent during the first session that many participants have internalized the myth that families abandon their relatives when they are placed in nursing homes, the concrete task of organizing and serving on a family council to counteract this guilt-producing myth, emerged as an unanticipated goal for the program.

Other significant principles and problems presented in the first session are summarized in Appendix 6. One of the most common themes was a need to try to change the behavior of the mentally impaired, revealing lack of knowledge of the physiological disorder, and/or a denial of the extent of the relative's impairment.

Because the litany of heartbreaking problems was "beginning to should like a soap opera," as observed by one participant in an audible aside, the project director made conscious use of humor to release some of the mounting emotion. Several amusing true anecdotes about the interaction of mentally impaired residents revealed that institutional life is not necessarily tragic, and provided welcome comic relief.

By the end of the first session, it was evident from their comments that many participants experienced a sense of exhilaration and expectancy that the program would be helpful

to them. Among the comments overheard was, "I wish this had been available three years ago when my mother first entered the Home. It would have saved me a lot of heartache."

The first questionnaire and value survey was disturbed at the end of the first session with an explanation of the evaluative task of the project director, and with a request for cooperation in returning them by the second session.

#### Groundwork for Family Council

Before the second session, the project director conferred with administration on the interest of the relatives in establishing a family council. Although the creation of similar organizations had been suggested in the past, and rejected as being too meddlesome to management, the climate was now favorable because recent bad publicity about nursing homes has led to a demand for making institutions more open to public scrutiny. As a result, the suggested plan was welcomed by administration as a means of demonstrating a responsive stance to criticisms and an openness to suggestions. An active family council was also viewed at this time as a potential ally to the institution, in the current budget crisis which is threatening existing services.

It was decided that the family council should be self-starting and self-directed, but some guidance would be available if requested. Communication was to be established directly with administration through elected representatives

of the council.

### Content Session Two

The difference in mood at the start of the second session was dramatic. There was already a sense of group cohesion, and animated discussion took place over coffee and cake before the formal start of the session.

Picking up the common desire to change the behavior of their relatives, expressed during the first session, the project director suggested borrowing the philosophical motto adapted from theological sources by Alcoholics Anonymous: "Grant me the serenity to accept what cannot be changed, the courage to change what can be changed, and the wisdom to know the difference." It was anticipated that this slogan would be a psychological aid as the participants worked at the task of learning the nature of their relative's condition, and at identifying under which circumstances the condition might be ameliorated, and when they had to accept an irreversible decline.

Many management problems were discussed using the participant's examples as a springboard for clarification. An example of the dilemma facing the relative of the older person who, no longer oriented to reality, insists on doing something inappropriate, will illustrate another common problem for the participants. Several members of the program had experienced the problem posed when their relative would pack their belongings and insist they were leaving to visit

another member of the family--often someone long deceased. They were unable to accept a realistic reminder of their current situation, and reacted with frustration and hostility to the relative who had to restrain them. One way to deal with this type of situation is to accept the new reality of the impaired older person, and to make some excuse as to why their wishes couldn't be met, calling for ingenuity in devising individual excuses which might be accepted. The relatives of the mentally impaired in the nursing home were particularly helpful to those still in the community in sharing techniques which they had found effective.

The major difficulty for the relatives is the necessity to create fictions in order to avoid agitated reactions from their kin. This is viewed as deceptive behavior and evokes an array of emotional reactions, with which the participants were confronted in the program.

The principle was stressed that if conditions of mental impairment could not be changed, its consequences had to be accepted, and part of that acceptance meant that it was no longer possible to relate in the same manner, based on the expectation of shared values and norms of behavior. In this context, having to distort the truth, or lying, with the purpose of protecting a defenseless impaired older person, should not have the ethical approbation usually associated with untruthfulness. Where the cultural value of honesty is a primary principle in relationships, this

management technique is viewed at first with abhorrence, and only gradually accepted as a practical solution.

The second half of the session was devoted to role playing, in which several participants were to enact the problem of the family whose impaired older relative could no longer be maintained safely in the community, and who refused to go into a nursing home. The goal of the role play was to give the participants the opportunity to try out the new skills which had been discussed, and to experience a more effective role in the assumption of responsibility and decision-making with regard to the needs of their relative.

It was found that the technique of role playing was a fiasco with this population, as they were unable to transcend their current roles, and could not handle the carefully detailed problem situation. The project director was forced to drop the role play, using the situation for teaching directly, which the participants seemed to prefer.

The report about administration's cooperation in founding a family council was received enthusiastically. Some participants stayed after the session to work out plans to implement their new goal.

### Content Session Three

The program outline (Appendix 3) was followed for this session, including another attempt at role playing. However, the situation of a relative of a nursing home resident, coming to the nurse with a long list of legitimate

complaints of neglect, met with the same failure as the previous week. When the nurse responded to the relative's complaints with the comment, "These things happen because your mother is so confused," the relative immediately retreated saying, "I'm sorry I bothered you," and ended the role play. Another relative commented empathically, when the project director tried to encourage other responses, "That's because nurses are so authoritarian that we're all intimidated by them."

This led to a fruitful discussion of the guilt-provoking behavior of many members of the staff in nursing homes, and to the concrete methods for relatives to use in presenting legitimate complaints. However, it was decided to drop the other experiential learning technique of a simulation planned for the sixth session, since it was clear that this group was in need of more direct sources of information. Furthermore, it was evident that they were developing their new skills through interaction with their newly found reference group.

#### Content Sessions Four - Six

The remainder of the sessions conformed to the program outline, with the exception of the planned simulation for the last session, involving social action for the mentally impaired aged in the community. The most emotionally charged session was the fourth, when the problem of

sexuality was discussed. There was absolute silence in the room as the project director discussed normal sexuality in old age, and the special problem of sexual acting out in the mentally impaired. Case examples were presented of behavior resulting from damage to the part of the brain which controls sexual impulses. Dramatic examples were selected of problems in the nursing home, as well as in the community, which elicited examples of personal experiences which had been too painful for some of the participants to discuss up until that point. The embarrassment and outrage which they had suppressed was released with evident relief, based on the newly acquired knowledge that unexpected sexual behavior can be part of the normal process of deterioration caused by organic brain syndrome.

Session five seemed to be particularly stimulating to the participants in the discussion of the value issues related to their conflicts. Analyzing situations in order to uncover the underlying values which operate to dictate choices in everyday behavior, was a new experience for most of the participants, and one in which they expressed great interest. They had been sensitized for the first time when filling out the Rokeach value survey after the first session, but during the fifth session were able to learn how these value choices related to their conflicts with respect to their relatives. The values of independence, egalitarianism, and responsibility, and family security and self-actualization,

were discussed at great length, revealing at an analytical level of abstraction how these values might conflict, leading to anger and then guilt. These were then related to the earlier discussion of the developmental task of filial maturity and the need to find a balance of shared function with the large organizations equipped to care for the mentally impaired aged in modern society.

The final session could be characterized as dealing with problems of separation. Most of the participants expressed the wish that the program would continue. One participant stated, almost angrily, "I'm sure you said the program was going to last ten weeks!" One brought a bouquet of flowers. One community relative gave a contribution to the Isabella Home. One brought a camera to take a picture of the group. One participant, who had to be hospitalized for a critical problem, had his wife phone their regrets, saying that he was more upset about missing the last session than about his hospitalization. He had been so moved by the program that he wanted to bring a corsage of orchids to the final session. The project director had to submerge a powerful impulse to continue the program in response to the enthusiasm of the participants and their unhappiness at its ending.

The participants most actively interested in establishing a family council proposed that they meet during the break to discuss following up with its organization. After

the break he reported that the group decided to hold their first meeting the very next Saturday after the end of the program, in order not to lose their group identity and the impetus of their meetings. A donation was spontaneously given for stamps to send out an announcement to all relatives at the Isabella Geriatric Center.

One participant from another nursing home announced that he would try to organize a family council at his nursing home. The session ended with a spirit of activism and optimism that they would as a group, continue to manifest concern not only for their own mentally impaired relatives, but for all the residents of the home and for the aged in general.

## CHAPTER VII

### DATA ANALYSIS AND EVALUATION OF PROGRAM RESULTS

#### Introduction

The program is first assessed in terms of the number of registrants and sessions attended, in order to establish the need for such a program, and the continuing interest of the participants to its conclusion.

The results of the program are analyzed from the data collected in the questionnaires completed by the participants before and after the program. Demographic characteristics of the participants as well as their impaired kin are examined to determine whether the study group is similar to or different from the general population.

Physical and mental characteristics of the impaired kin as perceived by the participants, are reviewed in order to identify any possible relationship to the problems expressed.

Selected family characteristics are obtained in order to learn whether the participants had any role models from whom they could have learned the skills needed for coping with mental impairment, as well as to explore any possible relationship between past family patterns and current behavior.

Since it is commonly held that relatives feel guilty when their kin are placed in Nursing Homes, one direct item on the questionnaire seeks the recognition of guilt, which is then cross analyzed with other behavior.

Frequency of visits as reported by the participants is a key variable which is studied as an indicator of change which might have taken place as a result of the program. This is cross analyzed with several other variables to ascertain any possible relationships to the pattern of visiting which was reported.

For the mentally impaired who are unable to deal with the institutional staff on their own behalf, one of the most important services provided by their relatives is to maintain direct contact with the providers of care. These contacts were reported in the questionnaires in terms of frequency and satisfaction, and are reviewed for possible changes which might be attributable to the program.

Selected attitudes of the participants are identified, related to family and societal responsibility for the care of the aged since these might influence their ability to assume a balanced responsibility with appropriate social institutions. Selected role conflicts, as reported by the participants, are reviewed, to determine whether the problems experienced in relation to their impaired kin were interfering with other significant aspects of their lives, and whether any change occurred in this respect during the course of the program.

Selected value orientations are identified by the completion of the Rokeach Value Survey, and examined for possible shifts, since part of the program aimed at increased self-awareness, in part through recognition of the basic values which influence social behavior.

Results of a test of substantive knowledge of aging and mental impairment which was incorporated into the questionnaire are reviewed in order to measure if there is any gain in the course of the program.

Finally, the results of follow-up interviews held with a sample of five participants are summarized as case vignettes, and provide additional insight into the data collected by means of the questionnaires.

Although percentages are used frequently in analyzing the data, these figures must be read with caution because of the small samples which served as the target population. Percentages are convenient for comparative purposes, but can be misleading if the reader attaches more importance to them than is intended. Extreme caution is urged in assessing the data for the community population, which only totaled seven cases.

#### Program Registration and Attendance

There were 64 registrants for the program, of whom 54 actually came.

TABLE 1  
Enrollment by residence of impaired kin

Number enrolled		Dropped out before first session	Attendance some sessions	Attendance first session
Nursing Home ..	47	6	41	36
Community .....	17	4	13	12
Total .....	64	10	54	48

The reasons given most often for dropping out before the beginning of the program were transportation problems, and illness of the registrants.

Of those who attended the first session, 74 percent completed three or more sessions.

TABLE 2  
Total attendance

Total sessions attended	Nursing Home	Community	Total	Percent
6	11	3	14	26
5	11	2	13	24
4	5	1	6	11
3	5	2	7	13
2	5	0	5	9
1	4	5	9	17
	41	13	54	100

The average weekly attendance was 4.9 sessions. The average attendance for each session was 35.5, as shown as follows:

Weekly attendance

<u>Session</u>	<u>Number of participants</u>
1	48
2	42
3	24 (Severe snowstorm)
4	36
5	33
6	30

Most of the 14 people who dropped out after the first two sessions gave no explanation, but one dropped out because of the death of her mother, and another because of personal illness.

Of the 40 participants who attended at least half of the sessions, 32 completed questionnaires before and after the program. Of the 8 who did not complete questionnaires, 1 was from the community group, and dropped out because of transportation problems. Of the 7 from the nursing home group, 1 was hospitalized for a long period of time, 3 gave no explanation for not completing questionnaires, 1 dropped out with no explanation, 1 was not sent a second questionnaire because a severe family upheaval precluded reliable responses, and 1 was constantly very late because of other commitments, and therefore did not qualify as having completed at least half of the sessions.

For the analysis of program results, the population basis will be the 32 participants who attended at least half the sessions and completed two questionnaires. There was a

loss of 4 nursing home participants and 1 community participant, who did not return their third questionnaires, bringing the population down to 27 at T3.

Demographic Characteristics of Participants

In planning programs for any population, it is important to identify the age, sex, educational level, etc., of the target group. Most references to family members having problems related to the aged, assume that these relatives are the middle aged children of the aged. From Table 3, it can be seen that 69% of the participants are children of the mentally impaired aged. However, the 31% of the involved relatives who are not the children comprise a substantial proportion, indicating that their needs and characteristics must also be taken into account when planning services or programs for the aged and their relatives.

TABLE 3

Distribution of relationships by residence of impaired kin

	Nursing Home	Community	Total	Percent (N=32)
<b>Children:</b>				
Sons*	8	0	8	
Daughters*	9	5	14	
Total	17	5	22	69
<b>Others:</b>				
Spouse	1	1	2	
Sibling*	6	1	7	
Nephew	1	0	1	
Total	8	2	10	31

\*Includes In-Laws

It can also be seen from this table that although there is almost an equal distribution of sons and daughters of Nursing Home residents who are involved in their relatives care, there are no sons of community residents involved. Although the community sample is small, this is suggestive that daughters may be more likely to assume, or be expected to assume the role of caregiver to the aged in the community.

It is also of interested to note that the siblings involved are all sisters, most of whom are over 60 years of age:

Distribution of participants  
according to sex

	Children	Spouse	Others Sibling	Other	Total
Male .....	8	1	0	1	10
Female ...	14	1	7	0	22
Total ..	22	2	7	1	32

Distribution of participants  
according to age

	Children	Spouse	Others Sibling	Other	Total
30-39.....	1	0	0	0	1
40-49.....	4	0	0	0	4
50-59.....	9	0	2	0	11
60-69.....	8	0	3	1	12
70+ .....	0	2	2	0	4
Total..	22	2	7	1	32
Median	50-59		Median	60-69	

A review of the educational level of the participants reveals that 87 percent completed high school or better.

Education of relatives of the impaired kin

Level completed	Number	Percent
Less than 8 years schooling .....	0	0
Some High School .....	4	12.5
High School graduates .....	12	37.5
Some College .....	8	25.
College Graduates .....	3	9.4
Advanced Degree .....	5	15.6

This is a more highly educated sample than the general population in which the current median educational level is high school graduate.<sup>1</sup>

The distribution of participants by religion paralleled that of their impaired kin.

Religion of participants

	Number	Percent
Jewish .....	13	41
Catholic .....	9	28
Protestant .....	7	22
No preference .....	2	6
Other .....	1	3

Of this population, 37% expressed the attitude that religion was a source of solace during this period, as derived from item 45 P in the questionnaire.

"My religious belief sustains me  
through this difficult period"

	Yes	Percent (N=12)	No	Percent (N=20)
Catholic	7	58	2	10
Protestant .....	2	17	5	25
Jewish .....	2	17	11	55
Other .....	1	8	2	10
Total .....	<u>12</u>	<u>38</u>	<u>20</u>	<u>62</u>

From this table it is clear that religion is experienced as a source of comfort by the great majority of the Catholic participants, with respect to problems with their impaired kin.

The distribution of participants by race paralleled that of their impaired kin, as well as the general nursing home population. Since there was only one non-white participant, as shown below, race will not be cross analyzed with any other variables.

Participants by race

White .....	31
Black .....	1

The income and occupational level of the participants is in the range to be expected for the predominantly middle class group represented by this population.

Occupation of participants

	Number	Percent
Housewife .....	5	16
White Collar .....	9	28
Blue Collar .....	0	0
Managerial .....	0	0
Technician .....	8	25
Professional .....	7	22
Retired .....	3	9
Total .....	<u>32</u>	<u>100</u>

Income of participants according to marital status

Annual	Number		Total	Percent
	Single	Married		
6,000 and under ...	4	2	6	19
6,000-12,000 .....	4	6	10	31
12,000-18,000 .....	2	6	8	25
18,000-24,000 .....	1	2	3	9.5
24,000 and over ...	0	3	3	9.5
No answer .....	0	2	2	6
Total	<u>11</u>	<u>21</u>	<u>32</u>	<u>100</u>

Demographic Characteristics of the Impaired Kin

The median age range of the impaired kin in the community was 75-79, as contrasted with a median range of 80-85 in the nursing home group, which can be seen in the following table.

Age of impaired kin by residence

Age	Nursing Home	Community	Percent (N=29)
70-74	4	0	13.5
75-79	5	4	31
80-85	4	2	21
86-89	6	0	21
90-95	3	1	13.5
Total	<u>22*</u>	<u>7</u>	<u>100</u>

\* Impaired kin total 3 less than relatives because 6 relatives cared for the same 3 residents (two married couples, 1 pair of sisters). This total of Nursing Home residents will be reflected in all tables describing the impaired kin.

This supports the assumption that the institution is the place of treatment for the oldest and most impaired segment of the elderly.

The following table shows the sex distribution in the nursing home and the community impaired kin. The ratio of mentally impaired males to females in the nursing home is similar to the ratio of healthy males and females in the institution, which is 1:5. However, the ratio of mentally impaired males to females in the community is much lower than the expected ratio of healthy males to females of this age group, which would be 2:3.<sup>1</sup> Since the sample is so small, it is pure speculation to discuss the possible causes for this variation. Two alternative explanations could be the following.

1. Men who survive into advanced old age are more likely to be married than women. Those who

become mentally impaired may have an alert wife to care for them, proving to be less of a responsibility to other relatives.

2. Men are culturally more conditioned to maintain their independence, and therefore more resistant to accepting help from other relatives.

Impaired kin by sex and residence

	Nursing Home	Percent	Community	Percent
Male .....	5	23	1	14
Female .....	17	77	6	86
Total .....	22	100	7	100

The median length of residence in the Nursing Home for this group of impaired kin was 1-2 years, as follows:

Length of residence in Nursing Home

	Number	Percent
Less than 3 months .....	2	9
3-6 months .....	2	9
6-12 months .....	3	13
1-2 years .....	6	27
2-5 years .....	8	36
More than 5 years .....	1	4
Total .....	22	100

This parallels the current median length of stay of all residents in the Nursing Home.

The following table shows the distribution of the impaired kin according to their former occupations. Since there were only 6 males in the sample, their distribution is not computed in percentages.

Former occupation of impaired kin

	Male	Female	Percent
Housewife .....	0	7	30
White Collar ...	2	5	22
Blue Collar ....	3	2	9
Managerial.....	0	3	13
Technician .....	1	4	17
Professional ...	0	1	4.5
No answer .....	0	1	4.5
Total .....	<u>6</u>	<u>23</u>	<u>100</u>

It is generally assumed that most elderly women have no occupational experience other than as housewives. This population seems to be at variance with this assumption, inasmuch as only 30% have been identified as housewives, and more than twice as many have had other occupations. Whether this population is non-representative in this regard, or whether the popular assumption is faulty would require further investigation.

Physical and Mental Characteristics of the Impaired Kin

The physical and mental characteristics of the impaired kin as perceived by the participants in response to item 9 in the questionnaire were reviewed in order to identify any possible relationship to the problems expressed by the participants.

TABLE 4  
Physical functioning of impaired kin

	T1				T2			
	Nursing Home	Com- mun- ity	Total	Per- cent	Nursing Home	Com- mun- ity	Total	Per- cent
Good	8	4	12	41	6	3	9	31
Fair	7	2	9	31	7	2	9	31
Poor	7	1	8	28	9	2	11	38
	<u>22</u>	<u>7</u>	<u>29</u>	<u>100</u>	<u>22</u>	<u>7</u>	<u>29</u>	<u>100</u>

Time 3 is not analyzed for physical function since there was only one change indicated for the Nursing Home group and one for the community.

Since sensory function sometimes affects mental status in the aged, it was also reviewed as perceived by the participants. There was no change reported in vision or hearing from T1 nor was any relationship observed with any other variable. It is therefore omitted from any further discussion.

At T1 most impaired kin were reportedly in good physical condition (41%), but within the six weeks of the program, the proportion dropped to 31%, and those reportedly in poor condition increased by 10%.

There are many emotional and behavioral changes which take place in the impaired older person which are related to mental impairment. The participants were asked to select those characteristics which applied to their kin, since these represent some of the most difficult problems for the

family. Only T1 and T3 are compared since there was minimal change at T2.

TABLE 5  
Selected mental and behavioral characteristics  
of impaired kin

At least sometimes:	T1			T3		
	Nurs- ing Home (N=22)	Com- mun- ity (N=7)	Total	Nurs- ing Home (N=18)	Com- mun- ity (N=6)	Total
Confused .....	21	5	26	16	6	22
Cooperative .....	17	7	24	12	6	18
Hostile .....	12	6	18	8	5	13
Argumentative ...	13	5	18	9	5	14
Suspicious .....	12	3	15	8	5	13
Irritable .....	16	6	22	9	6	14
Hallucinates ....	7	2	9	6	4	10

Almost every participant described their kin as confused (95%) which is expected, since this is the most common symptom of mental impairment in the aged. Almost three quarters of the Nursing Home participants consistently describe their kin as cooperative, in contrast to the 100% in the community. All other characteristics described are the negative behaviors which cause problems for the participants. The one cited most often is irritability (73% at T1 and 50% at T3) which of course makes visits and relationships very difficult.

All negative characteristics are cited less frequently by T3, but it is impossible to identify any causal relationship,

since there are innumerable possible explanations. One plausible possibility is that the participants became more tolerant of their relatives behavior during the course of the program through knowledge of the condition, or through their sharing of experiences in the group. Another possibility could have been that the condition of the impaired kin improved since mental impairment fluctuates according to the state of the primary condition which may cause the mental impairment. However, Table 4 showed a pattern of deterioration, giving credence to the first explanation.

Almost all impaired kin had suffered a mental decline gradually, which was now of long duration, as shown as follows.

Pattern of mental decline over period of time

	Nursing Home	Community
Recent and sudden .....	0	0
Gradual, over past few months	1	0
Sudden, but of long duration	2	0
Gradual, but of long duration	19	6
Intermittent .....	0	1

The few exceptions form subgroups which are too small to seek any relationship to other variables.

Family Characteristics

Participants were asked whether they knew their grandparents, and if so whether they were mentally impaired, and lived with their families or in an institution. (Item 1,

Questionnaire, Appendix 4). The purpose of this item on the questionnaire was to ascertain whether there were any role models available to them with reference to the care of the relative for whom they are now concerned.

Did you know your grandparent(s)

	Nursing Home	Community	Total	Percent
Yes .....	17	5	22	69
No .....	8	2	10	31
Total ....	25	7	32	100

Mental status of grandparent(s)

	Nursing Home	Community	Total	Percent
Normal .....	15	5	20	90
Impaired ...	2	0	2	10
Total ....	17	5	22	100

As shown, only 2 of the participants (both in the Nursing Home group), knew grandparents who were mentally impaired, both of whom lived with their families. No one had grandparents in a nursing home. Therefore, none of the participants had role models in their families from whom they could learn appropriate behavior toward their mentally impaired kin.

Relationships within the family were examined in terms of whether there were any family favorites, and whether most visiting was based on affection, or based on a sense of obligation, since these past patterns could influence current modes of behavior.

TABLE 6  
Relationship with family members

		Nurs- ing Home	Com- mun- ity	Total	Per- cent
Favorites in family?	Yes .....	3	1	4	12
	No .....	22	6	28	88
	Total	25	7	32	100
Most visiting based on affection		24	7	31	97
Most visiting based on obligation		1	0	1	3
Total		25	7	32	100

As shown in Table 6, almost all families are described as affectionate, with very few designated as showing favoritism.

Participants were asked to identify past patterns of their relationship to their mentally impaired kin, and of their personality characteristics. The results are shown in Table 7, which reveals that most participants describe their past relationship with their kin positively.

An analysis of data from Table 7, provides a profile of those mentally impaired kin who have had a characteristically positive or negative relationship with the participants. Those relationships which are based primarily on duty and obligation, and those kin who are described as authoritarian, controlling and self-centered are viewed as negative relationships in our culture.

TABLE 7

Past relationship and selected personality and behavioral characteristics of impaired kin by residence

	Nursing Home	Community	Total	Percent
Past relationship with impaired kin:				
Based on affection	19	5	24	77
Based on Duty and Responsibility	6	1	7	23
Total	25	6*	31*	100
Personality of impaired kin as authoritarian and/or controlling:				
Yes	7	3	10	31
No	18	4	22	69
Total	25	7	32	100
Behavior of impaired kin as self-centered:				
Yes	4	1	5	16
No	21	6	27	84
Total	25	7	32	100

\* 1 participant missing from community total omitted these variables, describing past relationship as "mutually dependent"

TABLE 7A

Profile of past relationship

	Nursing Home	Community	Total	Percent
Positive characteristics*	13	4	17	53
Negative characteristics*	12	3	15	47
Total	25	7	32	100

\* Includes more than one characteristic per person.

It can be seen from the foregoing that the profile of past relationships is divided almost equally as positive or negative.

### Recognition of Guilt

Practitioners in the field of institutional care for the aged often observe emotional behavior by the families of the residents, which is commonly attributed to guilt over placement in the institution. One item on the questionnaire asked directly whether they felt guilty that their relative was in a Nursing Home.

In answer to the direct question, most participants did not acknowledge feelings of guilt, or failed to recognize it as a problem, with only 24% expressing guilt, in contrast to the majority which was expected. By T2, of the 6 participants who had expressed guilt, 3 stated they were unsure, and 1 moved to no guilt. By T3, only 10% expressed guilt, as shown in Table 8.

TABLE 8

#### Expressed guilt by Nursing Home participants

	T1 (N=25)	Percent	T2 (N=25)	Percent	T3 (N=21)	Percent
Yes .....	6	24	3	12	2	10
No .....	19	76	19	76	18	85
Unsure ...	0	0	3	12	1	5

None of the community group expressed guilt at any time in answer to the direct questions on the questionnaire.

An interesting pattern emerges when comparing the degree of change on the variable of guilt between the group expressing guilt, and the group expressing no guilt. While most of the participants who expressed guilt initially changed in the direction of reduced guilt, of the 19 participants who did not express guilt, there was practically no change. Only one participant changed in the direction of expressed guilt.

This difference is significant by inspection. It would seem that for most of those participants who recognized guilt as a problem, the program was of help in reducing it.

#### Perceived Problems of Participants in Relation to Impaired Kin

The participants were asked at the beginning of the program which problems were most difficult for them in relation to their impaired kin, and again at T2 and T3. The open ended responses fell roughly into the categories listed in Table 9.

It is apparent from Table 9 that there were progressively fewer problems expressed by T2 and T3, with the exception of "inadequate supervision." The most common problem expressed was "dealing with mental impairment." Since the program specifically taught this skill, as well as understanding of the other conditions cited as problems, it seems reasonable to infer that the decrease in number of problems expressed

may reflect increased skills obtained from the program in dealing with these problems.

TABLE 9  
Most difficult problems of participants  
in relation to impaired kin

Responses*	T1 (N=32)	T2 (N=32)	T3 (N=27)
Dealing with mental impairment .....	9	4	3
Kin's physical condition .....	5	6	3
Kin's emotional condition .....	7	5	6
Emotions replacement .....	3	2	1
Visits conflict with other responsibilities .....	3	1	0
Physical care of kin .....	1	1	0
Inadequate supervision .....	1	1	3
No problems .....	1	4	4
No response .....	4	7	4

\* Includes more than one response per person

Unmet Needs of the Impaired Kin

The participants were also asked at the beginning of the program to identify needs of their impaired kin which were unmet, in order to establish a baseline profile of needs and problems as perceived by the participants. There are no community kin represented in this table, since no one identified any unmet needs. This was an open ended question whose responses were categorized in Table 10.

TABLE 10

Unmet needs of impaired kin in Nursing Homes

Responses*	T1 (N=25)	T2 (N=25)	T3 (N=21)
Adequate care .....	6	5	5
Socialization .....	4	4	2
Activities and/or therapy ....	4	3	2
Emotional fulfillment .....	1	2	0
No unmet needs .....	6	6	5
No response .....	5	6	6

\* Includes more than one response per person

There are clearly no great changes in the perceived needs of the impaired kin during or after the program. These needs will be cross analyzed with other relevant variables as they are discussed.

#### Visiting Characteristics

Various care orientations of the participants toward their impaired kin were sought in the questionnaire. It had been hypothesized that one area of difficulty for the participants might be in the amount of time allotted to visiting their impaired kin. From experience it seemed that relatives who are upset by their kin's condition might either visit too seldom to provide the emotional contact needed, or more often than needed, causing conflicts with their other role responsibilities. The visiting behavior reported by the program participants did not support this hypothesis.

TABLE 11

Total visits per month to Nursing Home kin

	T1	T2	T3
Less than 1 .....	0	0	1
2-3 .....	1	1	1
4-5 .....	11	11	5
10-15 .....	8	8	7
20-25 .....	4	5	7
30 or more .....	<u>1</u>	<u>0</u>	<u>0</u>
Total	25	25	21

The median number of visits per month was 10-15, which did not change during the program or at T3.

Although there is no comparative data available on the average number of visits received by an average Nursing Home resident, from the experience of the project director, this is more than a normal amount of visiting, representing about 2 visits per week, whereas a more frequent pattern is once a week.

Examination of the Summary of Data (Table A, Appendix 7) shows that within these categories of visits, 7 participants increased and 3 participants decreased their visiting during the program. For the remaining 15 participants, there was no change, as shown as follows.

Visiting pattern to Nursing Home kin

	Number	Percent
No change .....	15	60
Increased .....	7	28
Decreased .....	<u>3</u>	<u>12</u>
Total .....	25	100

Item 16 in the questionnaire asked whether the participants felt their visits were frequent enough to meet the needs of their kin. It was inferred that those who were unsure, or answered negatively, experience conflict about their visiting.

TABLE 12  
Conflict over visits to Nursing Home kin

Often enough?	T1	Percent	T2	Percent	T3	Percent
Yes	14	56	16	64	13	62
No .....	7	44	7	36	5	38
Unsure ....	4		2		3	
	<u>25</u>	<u>100</u>	<u>25</u>	<u>100</u>	<u>21</u>	<u>100</u>

From Table 12 we see that 44% of the participants expressed conflict over the frequency of their visits at T1, 36% at T2, and 38% at T3. This was unexpected, since almost all the participants visit at least once a week.

During the program, 14 participants, or 56% expressed conflict as shown as follows.

Often enough?	T1	T2	T3
Yes .....	3	5	3
No .....	7	7	5
Unsure .....	4	2	3
Total .....	<u>14</u>	<u>14</u>	<u>11</u>

See Table A, Appendix 7 for the variation of change.

Cross analysis of this variable with the length of residency of the impaired kin shows that conflict does not

decrease with a longer period of association with the Nursing Home, since 57% of the conflict group had residents in the Nursing Home for more than 2 years.

TABLE 13

Conflict over visits by length of residency of impaired kin

Length of residency	Expressed conflict		No conflict	
	Number	Percent	Number	Percent
Less than 3 months .....	1	7.2	2	18.2
3-6 months .....	2	14.4	0	0.0
6-12 months .....	1	7.2	2	18.2
1-2 years .....	2	14.0	4	36.4
2-5 years .....	7	50.0	3	27.2
more than 5 years .....	1	7.2	0	0.0
Total .....	14	100.0	11	100.0

Analysis of this variable with other characteristics of the participants provides some interesting patterns. When comparing the group expressing conflict over visits with those who increased the number of visits during the program (Table A, Appendix 7) it is seen that 50% of the group increased their number of visits. This is a sharp contrast to the 9% increase in visits of the no conflict group.

Further analysis of the group which increased their visits reveals that of the 6 who expressed conflict, 2 resolved this conflict by the end of the program, expressing satisfaction with the frequency of the visits. (Table A, Appendix 7).

TABLE 14

Conflict over visits by increased total visits

	<u>Expressed conflict</u>		<u>No conflict</u>	
	Number	Percent	Number	Percent
Increased visits .....	6	43	1	9
Did not increase visits ...	8	57	10	91
Total .....	<u>14</u>	<u>100</u>	<u>11</u>	<u>100</u>

It is also of interest to note that 72% of the group expressing conflict, visited at least twice a week, in contrast to the no conflict group, in which 54% visited with that frequency.

TABLE 15

Conflict over visits by frequency of visits

Monthly visits	<u>Expressed conflict</u>		<u>No conflict</u>	
	Number	Percent	Number	Percent
20-25 .....	5	36	3	27
10-15 .....	5	36	3	27
4-5 .....	2		4	46
2-3 .....	1	28	0	0
1 or less .....	1		0	0
Total	<u>14</u>	<u>100</u>	<u>11</u>	<u>100</u>

This would indicate that the absolute quantity of visits per participant does not substantially help these participants deal with their feelings of conflict.

When the variable "expressed conflict about frequency

of visits" is cross analyzed with the "selected mental and behavioral characteristics of the mentally impaired aged," another interesting relationship emerges.

TABLE 16

Conflict over visits by mental and behavioral characteristics of kin

Kin at least sometimes	Expressed conflict (N=14)		No conflict (N=11)	
	Number	Percent	Number	Percent
Hostile .....	9	64	3	27
Argumentative ..	8	57	5	45
Suspicious .....	7	50	5	45
Irritable .....	11	79	5	45
Hallucinates ...	5	36	2	18
Cooperative ....	11	79	8	73
Confused .....	13	93	11	100

The consistently higher percentages of impaired kin who have difficult characteristics, in the group of participants who express conflict over visits clearly suggests a relationship between these variables. From this table it appears that irritability is the behavioral characteristic most related to conflicts over visits, with hostility the second most frequently designated negative characteristic.

A cross analysis of conflict over visits and profile of past relationship (Table 7A) shows an apparently different relationship from the one just described.

TABLE 17

Conflict over visits by  
profile of past relationship

	<u>Expressed conflict</u>		<u>No conflict</u>	
	Number	Percent	Number	Percent
Positive characteristics	9	64	4	36
Negative characteristics	5	36	7	64
Total .....	14	100	11	100

This cross analysis suggests a positive relationship between the expression of conflict over visiting and a past positive relationship. This finding seems to contradict the previous one, from which one might infer that negative behavioral characteristics will keep the relatives from visiting as often as they feel they should, therefore causing conflict. From Table 17, one might infer that more relatives who have had a positive relationship experience conflict over not visiting their impaired kin often enough. Although these findings seem contradictory, both inferences are plausible, possibly explaining why there is such an unexpected high percentage of participants expressing conflict over visiting, despite the reality of adequate visiting behavior.

Another variable cross analyzed with conflict over visits was religious sustenance, to determine whether religious faith was effective in eliminating some of the conflict experienced by the participants. As seen in Table 18, it

seems to have neither a positive or negative association with the expressed conflict over visits, the percentage being almost the same distribution as the total population.

TABLE 18

Conflict over visits by religious faith

	<u>Expressed conflict</u>		<u>No conflict</u>	
	Number	Percent	Number	Percent
Religion sustains .....	5	36	4	36
Religion does not sustain	<u>9</u>	<u>64</u>	<u>7</u>	<u>64</u>
Total .....	<u>14</u>	<u>100</u>	<u>11</u>	<u>100</u>

Still another factor possibly related to conflict over visits is the perceived satisfaction of the mentally impaired relative with the frequency of visits. The following data show an apparent relationship.

TABLE 19

Conflict over visits by perceived satisfaction of mentally impaired kin

	<u>Conflict</u>	<u>No conflict</u>	Total
	Number	Number	
Kin dissatisfied ....	6	3	9
Kin satisfied .....	7	4	11
Kin unaware .....	<u>1</u>	<u>4</u>	<u>5</u>
Total .....	<u>14</u>	<u>11</u>	<u>25</u>

A much higher proportion of the no conflict group perceive their kin as unaware of their visits than of the

conflicted group. If their relatives are objectively more "unaware," this may explain why they have less conflict than the other group. However, 50% of the conflicted group report that their relatives are satisfied with the amount of visiting, but still are conflicted. This is a clear indicator of inappropriate responses on the part of these participants, which did not change at T2 or T3.

The visiting pattern of the community participants is not analyzed, since almost all the mentally impaired aged live with members of their families, who see them on a daily basis.

#### Services Provided by Participants

Since all but one of the community kin lived with their relatives, most had all services they required provided by their family members, such as provision of meals, help with personal care, and supervision of medications and finances. The one person who lived alone, and for whom the relative was unable to provide appropriate services, was mugged and hospitalized during the course of the program. The relative was able to have her placed in a nursing home after hospitalization, which solved the problem of providing the basic services she needed.

For the kin residing in nursing homes, most services are provided by the institution. The most important service relatives can provide is emotional support and continuity

with their past lives through visiting, which has been discussed. Other services provided by participants include maintaining contact by telephone, bringing favorite foods, and keeping in contact with the nursing home staff on behalf of their kin.

It has been observed that relatives sometimes tip the staff to insure better service, although this is against regulations. In answer to a direct question about tipping practice, no one answered affirmatively that they tipped, perhaps because they felt it would jeopardize the employment of those who accepted tips if they were identified. Although it would appear from the questionnaire that tipping does not take place in the nursing home, it is in fact a problem, and was therefore part of the program content, with the intent of exposing the problem created for residents whose families don't or can't tip, or for those who have no families nearby.

Familiar foods are not always served in institutions, and are often an important link to the outside world, as well as to a sense of identity. Participants were therefore asked whether they bring favorite foods to their relatives.

As can be seen in Table 20, most participants bring favorite foods to their relatives, with very little change during the program of those who often provided this service, and a suggestive decrease of those who never provided this service.

TABLE 20  
Favorite foods for kin

	T1 (N=25)		T2 (N=25)		T3 (N=21)	
	Number	Percent	Number	Percent	Number	Percent
Often	11	44	11	44	9	43
Sometimes	8	32	6	24	8	38
Never	6	24	8	32	4	19

One of the most important services which a relative can provide is to maintain contact with the staff on behalf of their kin, but relatives are often timid or naive in dealing with defensive and authoritative institutional staff. These skills were a prime target during the training program.

TABLE 21  
Number of participants\* having contact\*\* with institutions' staff

	T1	Percent	T2	Percent	T3	Percent
	(N=25)		(N=25)		(N=21)	
Doctor	16	64	12	48	9	43
Nurse	21	84	21	84	17	81
Aide or Attendant	21	84	23	92	19	90
Social Worker	21	84	21	84	16	76
Dietary Personnel	5	20	4	16	1	4
Activities Worker	8	32	7	28	5	24
Administrator	10	40	9	36	5	24
Other	2	8	4	16	2	10

\* Includes more than one staff contact per participant

\*\* Includes "often" and "sometimes"

TABLE 22

Distribution of participants' \*  
satisfaction with contacts\*\*

	T1		T2		T3	
	Number Satisfied	Percent Satisfied	Number Satisfied	Percent Satisfied	Number Satisfied	Percent Satisfied
Doctor	3	19	2	17	2	22
Nurse	10	48	11	52	7	41
Aide or Attendant	6	29	8	35	6	32
Social Worker	15	71	7	33	6	37
Dietary Personnel	0	0	0	0	0	0
Activities Worker	1	12	1	14	2	40
Administrator	2	20	2	22	3	60
Other	2	20	2	20	2	20

\* Includes more than one staff contact per participant

\*\* Includes "often" and "sometimes"

From the foregoing tables it can be seen that the participants have the greatest amount of contact with the nurses, aides, and social workers at T1, and with the aides at T2 and T3. There was a marked decrease in contacts with the doctors, administration, dietary and activities workers from T1 to T3.

The most consistent satisfaction was with the nursing contacts, with at least 41 percent expressing satisfaction with contacts at all times. Although the amount of contacts with the aides was highest, satisfaction was much lower, averaging only 32%. The least amount of expressed satisfaction was with contacts with the doctors, dietary personnel,

activities and administration.

Lack of satisfaction with the doctors was most outstanding, in that only 19% of the 16 participants who had contact at T1 expressed satisfaction, perhaps accounting for the steady decrease in contacts at T2 and T3, with only 9 contacts by T3. An alternate explanation is that doctors provide the least amount of service in a nursing home (in terms of staff hours) and are least available for contact.

There was no satisfaction expressed at all in contacts with the dietary personnel, but there were fewest contacts with this department from T1. There was a low degree of satisfaction with activities workers with whom there was a moderate amount of initial contact. There was also a low degree of satisfaction with administration initially, but although the amount of contact decreased markedly by T3, the degree of satisfaction with these contacts increased.

The most unexpected finding was the drastic change in contacts with the social workers. While there was the highest expression of satisfaction at T1 with the greatest number of contacts (71% of 21 contacts), satisfaction dropped by half at T2 and T3. Cross analysis of this variable with any other variables provides no clue to an explanation for this dramatic change. Nor were there any changes in personnel, or agency practice during this period which might account for this.

It must be noted that lack of satisfaction with

contacts is interpreted from the responses "no" or "unsure" to the question, "Do you feel that speaking with the staff on behalf of your relative results in better care?" The proportion of these responses is "unsure" to "no," by a ratio of three to one. This indicates that the source of dissatisfaction may be a lack of feedback to the participants, and not necessarily the non-performance of service to their kin.

Furthermore, nursing home relatives often see the social worker about problems their kin are having as a result of lack of care from other departments. The social worker tries to verify whether the problems are real or based on misunderstanding or misinformation, and then tries to clarify for the relative how they should appropriately pursue their complaint. When indicated, the social worker becomes a liaison between the family and the staff, but is not always successful in getting the results desired by the family. Since one of the prime goals of the program was to train the relatives to negotiate the institutional system, it is possible that as they became more aware of how to pursue their legitimate grievances they became less satisfied with how their social worker had dealt with these problems.

A review of all other possibly relevant variables uncovered no relationship to the number of contacts with the staff, with the exception of the identification of unmet needs

of the impaired kin (Table 10).

In order to simplify comparisons, all contacts were counted as equal, whether they were designated as "often" or "sometimes" on the questionnaire. Those participants who had identified unmet needs had more than the 3.8 average number of contacts with the staff (Table B, Appendix 7), while the participants who identified no unmet needs had fewer than average contacts.

TABLE 23

Needs of kin by average number contacts

	Unmet Needs (N=16)	No Unmet Needs (N=9)	Total Nursing Home Participants (N=25)
Average number contacts with staff	4.2	3	3.8

This is an expected relationship, and indicates appropriate role behavior on the part of the participants, if their perception of unmet needs is correct, and not the displacement of other emotions. Assuming that the increased contact with the staff is appropriate, the low degree of satisfaction with the contacts, even at the end of the program, suggests the need to find better means of interacting with the staff, which might lead to improved satisfaction.

Attitudes and Role Characteristics of Participants

Selected attitudes and role characteristics of the participants were identified by the selection of statements on the questionnaire with which the participant "tended to agree."

Role attributes were summarized and categorized with the following results.

TABLE 24

Role conflicts expressed by seventeen participants\*

Kin's Problems interfere with:	T1	T2	T3
1. Other Important Aspects of my life	6	9	2
2. My health	4	3	1
3. My job	4	2	2
4. My leisure	6	6	3
5. Community activities	3	4	4
6. "I do more than I should because others in family don't do as much as they should"	6	7	4

\* More than one conflict reported by some participants

Inspection of Tables 24 and 25 shows that significantly more participants (N=31) express lack of role conflict than those who expressed conflict (N=17). Of the conflicts identified, only the first, concerning interference in

other important aspects of the participants life, changed noticeably during the course of the program. By T2 nine participants recognized that their responsible behavior toward their impaired kin was interfering with other role responsibilities. Examination of Table C, Appendix 7, will show that by T3, ten different participants had expressed this conflict, including the four who did not return questionnaires at T3. If we assume that these four participants did not resolve this conflict, by T3 four of the total of ten resolved the conflict. This conservative analysis of 40% improvement indicates a considerable degree of change which may be related to the program.

TABLE 25

Lack of role conflict expressed by 31 participants\*

I do as much as I can:	T1	T2	T3
1. Because no one else can/ should take responsibility	12	15	12
2. Without interfering with needs of others in family	17	18	18
3. Without resentment	22	22	21
4. I don't resent what I do because my relative deserves it	23	25	25

\* More than one reported by some participants

It is interesting but not surprising to note that 100 percent of the Nursing Home participants who had indicated this role conflict (N=7) were among the group which was conflicted about visiting.

The two items indicating lack of role conflict which changed most from T1 to T3 were those dealing with resentment. The movement from 71% indicating item 4 in Table 25 at T1 to 92% at T3 is highly suggestive of increased sensitivity to the nature of mental impairment, and therefore to a lessening of the resentment which is a common and normal reaction to the emotional burden experienced by the participants. An analysis of item 2 in Table 25 by individual participants suggests another indication of increased skill. (See Table C, Appendix 7).

At T1, seventeen participants indicated they "do as much as they can without interfering with the needs of others in their family." All were from the Nursing Home group. At T2, five of these participants did not select this statement on the questionnaire, indicating a possible increase in awareness that their responsibilities were in conflict. In addition, four community participants selected this statement at T2 who had not selected it at T1, which is highly suggestive of the acquisition of skill in balancing the needs of others in the family.

The attitudes which were examined in the questionnaire related to the priority of needs of parents versus children,

the responsibility of the family versus society for the care of the aged, and toward the involvement of family with the institution's staff in care of the aged. Selected results are shown in the following table.

TABLE 26  
Selected attitudes of participants

	T1 (N=32)	Per- cent	T2 (N=32)	Per- cent	T3 (N=27)	Per- cent
1. Priority of duty:						
to Parents .....	4	12.5	4	12.5	5	18.5
to Children .....	5	16	4	12.5	2	7
2. Family has basic responsibility for care .....	19	59	18	56	14	51
3. When family can't, society should take responsibility ....	22	68	23	71	23	85
4. Nursing Home should encourage family to participate in care	22	68	28	87.5	22	81
5. If participant needs care in future:						
Prefers Nursing Home	22	68	22	68	18	66
Prefers care by own children .....	4	12.5	3	9	5	18.5

It is apparent from the first item on Table 26 that when forced to choose in a conflict of duty between parents and children, most participants would not commit themselves to a preference without having more facts on which to base a decision, which is an appropriate position.

It is also clear that most participants feel that the family has the basic responsibility for care of its members, but when it cannot provide the care needed, a still larger percentage believes that it is society's responsibility to provide the care. (85% by T3). Although 68% shared this belief at T1, the increase to as much as 85% suggests that the principles stressed during the program may have influenced this change of attitude.

When the response to item 4 are examined by Nursing Home participants only, we find that 17 (68%) expressed this attitude at T1, 22 (88%) at T2, and 17 (81%) at T3. The increase from 68% at T1 to 81% at T3 suggests a marked improvement in a significant attitude for the Nursing Home relative in order to achieve a balance of function with the institution in the care of their kin.

One last attitude which was changed considerably is shown in item 5 in Table 26. When this item is examined by location of kin, we find that of the Nursing Home participants, 19 (76%) at T1 and T2 expressed a preference for Nursing Home for their own care if needed in the future, and 14 (67%) at T3. In the community group, 3 out of 7 participants expressed this preference at T1, 4 out of 7 at T2, and 4 out of 6 by T3.

While most of the Nursing Home participants show a preference for institutional care for themselves if needed, by T3 the percentage is reduced indicating a reappraisal of

the necessity for Nursing Home care, and a possible shift toward a shared balance of responsibility. Conversely, although the group of community participants is very small, it is interesting to note that they changed even more in this attitude, which suggests the influence of the program toward recognition of the need for shared function between the family and institutions when specialized care is required, or the influence of the Nursing Home participants as a reference group from whom new attitudes and skills were learned.

#### Value Orientations

Since all attitudes and role behaviors are based upon internalized values, the participants were asked to complete the Rokeach value survey at T1 for a base line measure of their value preferences, and at T3 to see if there was any noticeable shift in value orientations which might be attributable to the influence of the program. The complete value data are listed in Appendix 8.

For the purpose of this program, only those values were selected for comparison which might enhance the protective function of the participant, or which might cause conflicts with respect to their need for role congruence. The median ranking of the following terminal values are examined for their relevance to the program: a comfortable life; a world of beauty; family security; freedom; happiness; inner harmony; pleasure; salvation; self-respect. The

following instrumental values are examined: capable; cheerful; forgiving; helpful; honest; independent; loving; obedient; responsible.

Since the Rokeach value survey has established validity, the results obtained from a very large national sample are compared with the results of the program participants.

TABLE 27  
Selected terminal value medians

Values	T1	T2	National Median <sup>2</sup>
A comfortable life	11	12	7.8
World of beauty	12.5	12	13.6
Family security	5	4	3.8
Freedom	7	7.5	4.9
Happiness	8.5	5.5	7.9
Inner Harmony	4.5	4	11.1
Pleasure	15	16	14.1
Salvation	18	18	9.9
Self respect	4	6	8.2

TABLE 28  
Selected Instrumental Value Medians

	T1	T2	National Median
Capable	9	9	8.9
Cheerful	11	8.5	10.4
Forgiving	7.5	7.5	8.2
Helpful	10	7.5	8.3
Honest	3	3	3.4
Independent	6	7	10.2
Loving	8	5	10.9
Obedient	16	17	13.5
Responsible	4.5	4	6.6

It can be seen from these tables that the value rankings of the participants is quite different from the national sample. They rank the following values higher: inner harmony; self respect; independence; loving; and responsible.

The following values are ranked lower than the national average: a comfortable life; family security; freedom; happiness; pleasure; salvation and obedient.

This is consistent with the behavior of the participants as a group, which reflects submerging personal pleasure in the interest of responsible, loving deeds which would lead to self respect and inner harmony.

A comparison of the result of T1 and T2 shows a somewhat higher ranking of family security, and a much higher ranking of happiness, cheerful, helpful, and loving.

There is a somewhat lower ranking at T2 of self respect, pleasure, independent, and obedient.

Although basic values change very slightly in a life span, change does take place when a person becomes aware of contradictions in his total belief system and of a sense of self-dissatisfaction.<sup>3</sup>

The program attempted to help participants recognize contradictions between their stated beliefs and their behaviors. Since they were highly motivated to find ways of dealing better with their family problems, it is possible that the change in orientation toward higher ranking of

happiness, cheerfulness, helpfulness, love, and the concomitant lower ranking of pleasure, and independence may be related to the effect of the program.

Knowledge of Aging and Mental Impairment

The following tables will show the distribution of scores received on the 25 item test of substantive knowledge of aging and mental impairment which was incorporated in the questionnaire.

TABLE 29

Distribution of scores on test of knowledge of aging and mental impairment

Number correct	T1 (N=32)	T2 (N=32)	T3 (N=27)
less than 10 .....	4	8	3
10-14 .....	13	5	6
15-18 .....	12	16	6
19-22 .....	2	3	12
no response .....	1	0	0
Total .....	<u>32</u>	<u>32</u>	<u>27</u>

Median score T1=13, T2=15, T3=17 (Table B, Appendix 7)

TABLE 30

Distribution of final scores by sessions attended

Number correct	Total sessions attended			
	3	4	5	6
less than 10 .....	0	1	1	2
10-14 .....	2	1	1	2
15-18 .....	1	1	2	5
19-22 .....	0	2	7	4

It can be seen that the scores do not follow the expected distribution, but the trend was for higher scores to be obtained by participants who attended the greatest number of sessions.

A preliminary analysis of scores at T2 revealed much lower scores than expected by the project director. Several questions dealing with statistics were reworded, tapping the same information, on the assumption that this population might be unaccustomed to learning through statistics, but might have grasped the concepts with which the statistics were concerned. The median score was highest at T3 (17 correct), having increased from a median of 13 at T1.

The final median score was compared with the median score achieved by a group of social work students upon completion of a graduate level course on aging, given by the same instructor. The graduate students (N=13) had a median score of 22, or twenty percent higher. Although the participants did not demonstrate the achievement level of the graduate students on the substantive questions, when the difference of education and length of course is taken into account, the majority of the participants were able to master a substantial amount of the substantive material.

Satisfaction with the Program

It was apparent throughout the program that the participants were very satisfied by the experience, as they expressed their feelings very openly.

In answer to an open ended question about how the program helped, the responses fell roughly into the following categories.\*

		<u>Percent</u>
Increased knowledge about mental impairment	21	66
Less guilt and more self understanding ....	12	38
Group experience helpful .....	11	34
Learned to cope better .....	6	19
Better understanding of institutional system	3	9

\* Includes multiple responses .

In answer to the direct question about whether the program was helpful personally, most felt it was helpful.

TABLE 31

Was training program helpful

	T2	Percent	T3	Percent
Yes	30	93	22	82
No	0		2)	
Unsure	2	7	3)	18
Total	32	100	27	100

In answer to whether they were doing anything different as a result of the program, only eight participants answered affirmatively.

TABLE 32  
Different behavior resulting from program

	Nursing Home	Community	Total	Percent
Yes	4	4	8	30
No	13	1	14	52
Unsure	4	1	5	18
Total	<u>21</u>	<u>6</u>	<u>27</u>	<u>100</u>

However, of the seventeen participants from Isabella Home, eleven became active members of the newly formed Relatives' Council. This includes three of the participants who answered "Yes" in Table 32. Adjusting Table 32 for this correction, it should indicate changed behavior as follows.

TABLE 32 (Adjusted)  
Different behavior resulting from program

	Nursing Home	Community	Total	Percent
Yes	13	4	17	63
No	6	1	7	26
Unsure	2	1	3	11
Total	<u>21</u>	<u>6</u>	<u>27</u>	<u>100</u>

It can be seen therefore, that although 82% of the participants stated that the program was helpful, only 63% were behaving differently as a result of the program.

Effectiveness of Program

The effectiveness of the program is evaluated by the proportion of participants who have achieved a more balanced share of caring for the mentally impaired aged, an increase in knowledge of mental impairment and aging in society, and a lessening of role conflict.

A simple scale was devised, in which a plus is assigned to categories in which the participants showed definite improvement, a minus for categories in which the participants need improvement, and no value is assigned to categories in which there was no need for change. The pluses and minuses were given equal weight, and then tabulated, with the result for each participant designated as the balance function.

This rough scale was designed without attempting to develop weights appropriate to each category, because of the non-experimental nature of the study. Dealing with innumerable variables, even in a small sample, would make it presumptuous to attempt a more precise method to assess the interaction of the participants with their impaired relatives, their larger families, and the institutions involved.

A vivid example of the rival explanations for any presumed causal relationship is "the intervening banana variable" of which the project director learned at the beginning of the last session. One of the participants had

never spoken during the program, although she had attended every session with evident interest. From the first questionnaire I knew that she lived with her parents, and was troubled about her mother who is mentally impaired. We met before the start of the sixth session, and I asked how she and her father were getting along and dealing with their problems. "Much better," she replied brightly. "She's much more manageable." I asked how long that had been, thinking that the program was probably effective in helping the daughter learn how to cope with the mother's behavior. "For three weeks now," she said. I was starting to feel proud. "The mother of a friend of mine was having the same problem--very anxious and irritable, and her doctor told her to eat a banana a day, which made her less difficult. So I decided to give my mother a banana a day too, and now she's much more manageable."

Since bananas are a rich source of potassium, they are often suggested as a supplement to the diet when someone has a potassium deficiency, which frequently results from taking diuretics. One of the common symptoms of potassium deficiency (as well as calcium and magnesium deficiency) is the behavioral manifestation of anxiety and irritability. Since the participant's mother improved after eating her daily banana, she probably had had a potassium deficiency, causing her irritability, in addition to the organic brain syndrome which caused her forgetfulness and confusion.

If the effectiveness of the program is judged solely from the measurements obtained through the questionnaire, many false conclusions could be drawn. In answer to the question on whether any changes had taken place, the participant noted yes, more manageable. This might have been interpreted as an indicator of improvement during the course of the program which was possibly related to program content. This case example underscores the necessity for extreme caution in any conclusions drawn which infer possible relationships. Despite this cautionary tale, the project director scrupulously followed the evaluative design of the program, and developed a scale to measure the designated changes, by which the effectiveness of the program is assessed.

The scale which was adopted provides an approximate measure, through which the participants are compared with one another, affording a practical tool for assessment. The rating scale was discussed with a panel of three experts in the field of institutional care for the aged,<sup>4</sup> who made some helpful suggestions, and then concurred that it is a valid instrument. They then rated the participants by the same scale, with 100 percent agreement. See Table D, Appendix 7, for complete rated categories for each participant.

The following is the scale summarized.

TABLE 33

Rating of increased skills and improved function of participants\*

	Better	Per- cent	Needs improve- ment	Per- cent	No change	Per- cent
Test of knowledge/at least median level..	18	56	11	34	3	9
Conflict/roles.....	16	50	5	16		
Dysfunctional attitudes .....	14	44	8	25		
Contact with staff of institution .....	7	28	2	8***		
Joined Relatives Council .....	13	72**	2	6		
Conflict/visiting ...	3	9	9	28		
Experienced guilt ...	4	16	3	12***		
Family involved in care .....	2	6	4	16		
Appropriate care (Community only) ...	3	43			4	16
Feels program helped	27	84	3	9	2	6
Balance function ....	26	81	4	16	2	6

\* Multiple categories for each participant.

\*\* N=17 Participants from Isabella Home plus 1 Community participant whose relative was admitted to Isabella Home between T2 and T3.

\*\*\* N=25 (Institutional participants only).

From this summary, it is clear that the majority of the participants acquired an adequate amount of knowledge about mental impairment and aging, although this did not seem to be related to other variables when cross analyzed. The program was, therefore, effective in transmitting, and having learned, a specialized area of knowledge.

Half of the participants indicated some improvement

in at least one area of role conflict, and 44% indicated fewer dysfunctional attitudes. For a group with many serious emotional problems, this seems to be a respectable degree of improvement, and another area in which the program seems to have been effective.

Of the institutional group, 28% improved in making satisfactory contacts with the staff, and 72% joined the Relatives Council which was formed as a direct result of the program. This is undoubtedly the most significant indicator of the program's effectiveness.

One of the most difficult problem areas for the institutional participants was conflict around visiting, which seemed to be more related to the quality of the visits than the quantity. Only 3 participants indicated any improvement in this area, while 9 clearly needed improvement. It is apparent that the program was not an effective means to relieve the participants of this conflict. In the related area of expressed guilt, while only 4 participants improved, they represent a large proportion of the small group which expressed this as a problem.

The principle of involving more family members in the care of the mentally impaired aged, was apparently not realizable through the intervention of the program, as reflected in the smallest degree of improvement shown in Table 33.

The 3 community participants whose kin were no longer appropriately kept at home, seemed to make quick use of their new skills, in arranging for admission to Nursing Homes. The program seemed very effective in transmitting the values, attitudes and skills needed to actuate these transfers to institutions.

In terms of eliciting expressed feelings of being helped, the program was remarkably effective, with 84% of the participants stating that the program was helpful to them.

Finally, in tabulating the individual plus and minus scores, there is an improved balance function for 81% of the participants, as indicated by this very approximate measure.

The plan to check on the effectiveness of the program with reports from the professionals who had referred the participants to the program was not realizable, with two exceptions. Those who had referred clients to the program were not actively involved with them. For example, the social worker from JASA who had referred a client never saw him again because he had been dissatisfied with her other attempts at intervention. The social workers who referred most of those relatives from other nursing homes, stated that they rarely see them, because they don't usually visit during the week from 9-5 when the social workers are there. One exception was the case of a program participant

who contacted his social worker in order to try to organize a Relatives Council, which certainly can be judged as an example of program effectiveness. The other exception was a participant who had been referred by the social worker in a senior citizen center who had been counselling her since her relative, a member of the center, started to deteriorate mentally. This social worker confirmed the marked improvement which was measured by the questionnaire. Other participants were self-referred through the mailed announcement or the local newspaper item.

This extreme lack of contact with professionals who could help them is a clear justification for the need for other such interventions as the training program.

#### Validating Interviews with Subsample

One last technique in analyzing the results of the program, was a follow-up interview with a sample of 5 participants, after receiving their T3 questionnaires. The purpose of these interviews was to check the validity and reliability of the responses, and to ascertain whether there were significant problems which had not been identified by means of a self administered instrument.

Three Nursing Home and two Community participants were selected, several of whom had expressed lack of help from the program, representing a range of relationships: spouse, daughter, sisters and nephew. They also were in

the upper range of participants, although not by design, with an average age of 64.

The interviews were rewarding, in that each added a new degree of insight into the complexity of the problems.

All five interviews verified the reliability and validity of responses, as far as they went. Some participants found it too tiresome to consider all of the items in the very long questions in which they only selected statements with which they agreed. But every item selected was truthfully identified. They also demonstrated some weaknesses in the instrument which sought to obtain a picture of the available modified extended family for each resident, and by that means, identify which family members might be available to share the tasks of visits, outings, etc.

A summary of the family contellation of some participants will serve to illustrate.

Case 1. Mr. S., age 75, came to the program to learn how to deal with the difficulties posed by his 80 year old mentally impaired wife, with whom he still lives. Through the questionnaire, we know that he has married sons, and that he is upset that "all who should be involved are not." This did not change from T1 through T3, and we could conclude that the program was not successful in helping Mr. S. learn how to involve his sons and their families more in their share of caring for Mrs. S.

In the interview it was learned that Mr. S. has two sons. The wife of one has a terminal illness which totally occupies this son, leaving him emotionally unable to assume any additional responsibilities. The other son is in charge of a big project in Denver, which necessitates his travelling back and forth to New York frequently. His wife is a devoted daughter-in-law, who helps occasionally by having Mrs. S. spend the day with her. However, she also has a father who

also is beginning to deteriorate, and she is often torn by her responsibilities and not available to Mr. S. as often as he needs her help. Although he understands the problems of both his sons, he still feels somewhat abandoned.

Case 2. Mrs. G. is the 63 year old, married daughter of Mrs. Gn., age 90, who suffers from mental impairment, but lives at home with her 90 year old husband, who is frail, but mentally alert. Mrs. G. is the only one of three siblings who lives in N.Y., and therefore near enough to help with shopping, supervision and emergencies. Her brother and sister live in New Jersey and Connecticut, but help often, as they are a close knit family. When asked about her children's involvement with their grandparents, Mrs. G. said she has one daughter who lives in Chicago, and twin sons, one of whom lives in Los Angeles, and the other in Ithaca. None are therefore available.

Case 3. Mrs. H. is a 63 year old widow whose 70 year old sister, Mrs. S. has been a resident of Isabella Home for two years. She and a married sister, Mrs. G., have an extremely close and symbiotic relationship, each reinforcing the other's neurotic denial of their older sister's mental status. Through the interview it was learned that they had felt very close to their oldest sister, who had served as a model for them, and who was described as brilliant and competent when young, knowing "every word in the dictionary." Mrs. G. is particularly upset by Mrs. S.'s mental impairment, because when she suffered a "nervous breakdown" following the birth of twin sons, Mrs. S. took over all responsibility and cared for them until Mrs. G. recovered.

Mrs. H. is also unable to recognize the extent of her oldest sister's problem. She recounted that Mrs. S.'s husband's brother was widowed when very young, and left with an infant to raise. Dr. and Mrs. S. had the brother and his infant move in with them, and Mrs. S. raised this child as her own son, never having any children of her own. When this son was an adolescent, Mrs. S. developed symptoms of mental illness, becoming reclusive, neglecting the house and herself, and not allowing any visitors except her family. The sisters do not know the origin of this problem which lasted for years, with Dr. S. and his brother also denying the problem to the extent that they refused to get psychiatric help for her. Their solution to the problem of the house becoming totally neglected was to move after 10 years

into another house.

When Dr. S. died 6 years ago, Mrs. S. became alcoholic, and was looked after by her brother-in-law, who remained in their home. By the time he died suddenly, four years later, Mrs. S. had become so deteriorated mentally that she had to be institutionalized. Her sisters still deny the extent of her mental impairment, which is now diagnosed as organic brain syndrome, secondary to alcoholism.

In the questionnaire, Mrs. H. had only listed her sister, Mrs. G. During the interview it was learned they have three other siblings, in Syracuse, Maryland, and Florida, who of course are not available to help. It was noted that Mrs. S's nephew, who they call her stepson, was not listed as a family member who might be available. Mrs. H. said that he only visits once a month, and she's very angry with him, and therefore did not list him.

Mrs. H. was one of the two participants who stated in the questionnaire that the program was not helpful to her personally. Without benefit of the interview, this case history would not have been available, and it could have been assumed that there was something lacking in the program which might have helped Mrs. H. With this detailed history, it is clear that Mrs. H. would need extensive counseling to possibly counteract the extensive, long term family pattern of denial, rather than the experience of the training program alone. However, the project director feels that the program was indeed effective in helping Mrs. H., although she did not acknowledge it in the questionnaire. Mrs. H. became one of the most active members in forming the Relatives Council, and was elected Treasurer. This is a very constructive outlet for her ongoing, exaggerated complaints about the institution, and she is very happy with her new role.

Case 4. Mrs. J. is another widow, age 59, whose 72 year old sister, Mrs. H., is a resident at Isabella Home for several months. Mrs. J. is one of the two residents who still expressed guilt at the end of the program that her relative is in a Nursing Home, and although she stated in the questionnaire that she enjoyed the sessions, and the group experience, she was not sure that the program was helpful to her. Through the interview it was learned that Mrs. H. was the oldest sibling, who came North to work. She worked hard, saved all her money, and brought up her whole family, one by one, including her parents. Mrs. J. was the first of the family to be brought to New York from South Carolina, at age 14, by Mrs. H.

She said, "She raised me like a mother." Mrs. J.'s husband died 12 years ago. When Mrs. H.'s husband died, 8 years ago, Mrs. J. wanted her sister to live with her, but she refused. As Mrs. H.'s mental condition deteriorated, she was no longer able to live alone, and Mrs. J. moved her in with her, 2 years ago. As the process continued its downward course, Mrs. H. needed to be institutionalized, as she required 24 hour supervision, and Mrs. J. works to support herself. When asked about other family members who could help, it was learned that there is a brother and sister-in-law living nearby, but the brother is disabled since a recent heart attack, and the sister-in-law is incapacitated by severe, chronic asthma. Mrs. J. is upset because her two sons don't visit, and cannot accept that they are disturbed by the Nursing Home environment and the fact that their aunt doesn't recognize them, or know them even when they identify themselves. Mrs. J. also needs counselling, and was referred to her Social Worker.

Case 5. Mr. Z. is the 62 year old nephew of Mrs. G., a 92 year old resident of Isabella Home for the past year and a half. She was supposed to move into the Home with Mr. Z.'s mother, her sister with whom she lived, but Mrs. Z. died before they could move in. Since Mrs. G., who was mentally impaired, had been dependent upon her sister, she had to be immediately placed in another Nursing Home, since there was no vacancy at Isabella Home. Mr. Z. was very conscientious about pursuing a transfer to the Isabella Home, which he felt was a better facility for his aunt. As a participant in the training program, he was very involved, attended every session, and has since become an active member of the Relatives Council. From the questionnaire it was learned that he is Mrs. Z.'s only relative. When asked in the interview why he is as involved as he is, visiting frequently, often interceding on her behalf with the staff, when he is "only a nephew," Mr. Z. said she was more like a mother to him. Mrs. G. had been his Godmother, and ran a small business, at their home, while his own mother went out to work. She was closer to him, therefore, in many ways than his mother, and more responsible for his upbringing.

This provides an important insight for better understanding the complex relationships which affect the reactions

of the relatives of the mentally impaired aged in their ability to accept and deal with the changes which take place in their close kin. It is often assumed that the adult children are most affected by problems of their parents. From these few case examples it is apparent that in many instances other relatives assume the filial role reciprocally because their kin have assumed a parental role in earlier years. Professionals working with these relatives must not presume a particular set of role behaviors for a given family relationship because of the great variation in family roles.

It is also apparent that in addition to the adult children and surrogate children who need help with these problems, the spouses, siblings, and in-laws of the mentally impaired also are in need of help.

### Summary

Forty participants attended at least half of the sessions, with an average of 35.5 at each session.

Demographic data revealed that 69% of the relatives of the mentally impaired aged who participated in the program were middle aged children, but that the remaining 31% of kin who were involved also comprise a substantial group, with special problems and needs. The median age range of these other kin was 10 years older than the children.

The participants were of a middle class income level,

but of a higher educational level than the general population.

The median age range of the impaired kin in the community was 5 years younger than the kin in the nursing homes.

The median length of residence in the nursing home was 1-2 years.

The emotional condition most frequently cited as characteristic of the impaired kin was irritability. Hostility, argumentativeness, and suspiciousness were also cited by more than 50% of the participants at T3. These characteristics are cited less frequently than at T1.

Examination of selected family characteristics revealed that 69% of the participants had known their grandparents, but only 2 members of this sample describe them as mentally impaired.

Past relationships with their impaired kin were basically positive for half the participants and negative for the other half.

Although it is commonly assumed by professionals in institutions for the aged that relatives feel guilty when their kin enter an institution, only 6 of the nursing home group expressed feelings of guilt on the questionnaire. The program was helpful in reducing guilt for 4 of the 6.

Problems expressed as most difficult for the participants, such as understanding mental impairment, were reduced by the end of the program.

Frequency of visits was assumed to be an indicator

of appropriate or inappropriate behavior of the nursing home group, which would be a measurable criterion of change during the program. It was found that only 2 participants visited less than once a week, and yet 38% of the participants expressed conflict over not visiting often enough, by T3. This conflict did not decrease when cross analyzed with length of residency, nor was there a decrease of conflict when the frequency of visits increased.

Half of the group expressing conflict also indicated that their kin are unaware of their visits.

A relationship was found between conflict over visits, and difficult behavior of impaired kin.

A relationship was also found between conflict over visits and a positive past relationship with kin.

A significant area of training was to help participants learn to negotiate the institutional system in order to achieve adequate, satisfactory contacts with the staff. Only 28% improved in direct contacts with staff. However, an unanticipated goal of the program became the formation of a relatives council, as the most effective means for the participants to deal with the system.

In analyzing a selected group of role conflicts and attitudes, it was found that far fewer experience role conflict in relation to their impaired kin than those who express lack of role conflict. Of the 6 conflicts analyzed, only one, concerning interference in other important aspects

of life changed remarkably during the course of the program, changing from 19% at T1 to 7% at T3.

Examination of selected attitudes which concern family or societal responsibility for the care of the aged showed an increase in the belief that society should provide the care when the family cannot.

There was a marked increase among the nursing home group in the attitude that the institution should encourage the family to participate in care.

Among the community group, there was an increase in the attitude expressing preference for nursing home care for self if needed in the future.

Analysis of 18 values of Rokeach's survey which might be relevant to this program showed that the population had different median rankings than a national sample. They ranked the following lower as guiding principles in their lives: a comfortable life, family security, freedom, happiness, pleasure, salvation, and obedient. The following were ranked higher: inner harmony, self-respect, independence, loving and responsible. The value which differed most dramatically was salvation, with the participants' median ranking twice as low as the national sample. In the follow-up survey there was a higher ranking of family security, happiness, cheerful, helpful and loving, and a lower ranking of self-respect, pleasure, independent and obedient.

The test of substantive knowledge of aging showed that most participants could increase their skills through this type of program. However, cross analysis with other variables showed that increased knowledge of aging and mental impairment was not related to change in other relevant skills.

An analysis of expressed satisfaction with the program showed that 66% of the participants felt that the program increased their knowledge of mental impairment. Thirty-eight percent felt less guilt and more self-understanding, and 34% expressed that the group experience was helpful.

Eighty-two percent felt the program helped them, and 63% were behaving differently as a result of the program.

Follow-up interviews with a sample of 5 participants indicated that the responses to the questionnaires were reliable and valid, but that the questionnaire did not elicit sufficient data for a full understanding of the complexity of relationships involved, and for an assessment of the individual's need for counselling in addition to the program.

Footnotes to Chapter VII

<sup>1</sup>Herman Brotman, "Who Are the Aging," in Mental Illness in Later Life, ed. E. W. Busse, and E. Pfeiffer (Washington, D.C: APA, 1973), p. 32.

<sup>2</sup>Milton Rokeach, The Nature of Human Values (New York: The Free Press, 1973), p. 57.

<sup>3</sup>Ibid., p. 286.

<sup>4</sup>Expert panel of judged:

Millie Felder, Resource Consultant, N.Y.C.  
Department for the Aging, Former Administrator  
Menorah Home for the Aged, Brooklyn, N.Y.

Lawrence E. Larson, Executive Vice President  
Isabella Geriatric Center, N.Y.C.  
Former President, N.Y. Assn. Homes for the Aged

Sarah Olstein, Director, Social Services,  
Jewish Geriatric Center of Long Island

## Chapter VIII

### CONCLUSIONS AND IMPLICATIONS

#### Need For Program

From the initial response to the project and from the record of participation of those involved, it was demonstrated that the assumed need for training programs designed to help the relatives of the mentally impaired aged was correct.

The finding that 40 participants attended at least half of the sessions, with an average of 35.5 at each session supports this inference.

There was also an indication that there is a need for, and interest in similar training programs designed for other professionals, to help them work more effectively with this segment of the aged. This was evident in the many requests from professionals who sought permission to join the group, or requested any printed material which might come from the program.

The design of a short, intensive program available on Saturdays appealed to many participants who might otherwise have had difficulties in committing themselves to a longer period of time. The format of a training program with

a planned, time-limited curriculum was well received by this group, who might have been fearful to join if it had been announced as an opportunity for group therapy. These participants were in need of the knowledge and skills which were taught during the sessions, as well as the opportunity to ventilate their feelings in a group which could share them.

The intensity of emotions at the close of the sessions suggest that the participants could have benefited from a longer program, and would have continued to come. Future programs should plan to run ten to twelve weeks, rather than six, since the demonstration revealed substantive areas of ignorance and personal confusion and conflict which a longer program could attend to with benefit to those involved.

In addition, time should be planned for individual counselling and referrals, since many participants sought counselling before and after each session.

#### Characteristics of Participants

From the data analysis it was seen that the participants were a middle class, predominantly white sample, of higher than average education. This was expected, since it parallels the background of their kin, when the generational difference in average educational levels is taken into account. Since this is not the socioeconomic level characteristic of all groups of relatives of the mentally impaired

aged, this is viewed as a limitation inherent in the setting which must be weighed in the assessment of the program.

Although it is generally assumed in the literature on institutionalization of the aged that it is the middle aged children who are the relatives concerned with their care, the findings of the program revealed a range of interested relatives of varying age groups, most of whom had many personal problems with their own aging, and with relationships in their extended families. This was immediately apparent to the project director with the very first applicant to the program. This applicant was the 75 year old daughter of a resident at Isabella Home who was due to celebrate her 100th birthday shortly before the beginning of the program. The fact that a 75 year old was interested in investing her time and energy to learn to deal better with problems related to her 100 year old mother was in itself noteworthy. The week before the birthday party, however, the daughter's 54 year old son died suddenly of a heart attack, leaving a wife and five children. The applicant obviously did not attend the program, but after a period of mourning sent a note expressing regrets at being unable to attend.

This example emphasizes the upper age range of participants which might be anticipated in future programs designed for children of the aged, (who comprised 69% of the program participants) as well as the multiple problems and

crises with which this group must cope at this developmental stage of the life cycle.

The demographic tables, and the case histories described in Chapter VII reveal a wide range of ages, a diversity of relationships, and an intensity of problems not necessarily associated with the normative behavior expected for kin other than children. It is apparent that such diversity should be anticipated in planning future programs.

In view of the substantial number of spouses and siblings (31% of program participants) involved with problems of their mentally impaired kin, future programs can assume an increasing number of these older relatives as the proportion of the aged in the population continues to increase.

From the finding that daughters and sisters are the predominant caregivers in the community, it is apparent that future programs should be planned with the needs of these caregivers in mind.

It was also learned from the program that the areas of choices are more limited for these relatives than is generally assumed. While a hypothesis of the program was that it was important to help participants involve more family members to share responsibility, few available relatives were found, because of the age and health condition of the relatives, and their geographic location.

On the other hand, there are sometimes relatives available as resources who are not included for inappropriate reasons or because they were not informed about the need for their involvement. One son-in-law of an Isabella Home resident serendipitously received an announcement of the program. His wife, who has a history of depression, had not involved him in her problems concerning her mother, although her mother's condition disturbed her greatly. Upon review of the announcement, he decided to enroll with his wife for the program. Both attended every session, claiming they were very helpful. The outcome of the supportive help offered by the husband through his attendance at the programs was to enable the daughter to overcome some of the problems related to her mother more easily.

Furthermore, programs should attempt to reach the younger kin of this population who often avoid visiting nursing homes with large proportions of mentally impaired aged. They are often protected by their parents from the upsetting experience of the nursing home world, but they could add great joy to the environment with their presence. Some progressive facilities offer special activity functions on special occasions to encourage participation by the grandchildren. The inclusion of younger kin in training programs following our model could enable them to participate with more understanding and fewer conflicts.

Based upon the program's findings, the assumption of the modified extended family as the family structure most common in our society was supported. However, it is clear that the aging urban family tends to consist of widely dispersed nuclear units, with very few members, mainly upper middle aged and older, available to their mentally impaired kin.

#### Mix of Community and Nursing Home Relatives

The decision to offer the same program content experimentally to a mix of participants with kin in the community as well as in the nursing home proved to be fortuitous. Both groups benefitted from the same knowledge base, and the groups were mutually helpful through formal and informal interaction. The nursing home participants became a reference group for the community participants. The nursing home participants were also reinforced in their decision to institutionalize by reminders of the community problems and frustration which they had already resolved.

In addition, both of these populations, which demonstrably have problems of conflict, anxiety, and guilt, urgently need the intervention of a social work oriented service, which is not presently available. Offering the same program from a nursing home base, to participants in the community as well, is an effective means to quickly reach large numbers of clients in need of services.

Characteristics of Impaired Kin

The median age of the impaired kin in the community (75-79) was 5 years younger than the kin in the nursing homes. From this fact it can be inferred that their relatives can anticipate a long period during which they will be dealing with the kinds of problems which were the target of the program. This suggests the need to schedule future programs so that a larger proportion of community relatives will be able to attend.

Although the median age of the nursing home group was 80-85 years, their median length of residency was found to be 1-2 years. It would appear that there is need for programs which are addressed to the long duration of problems which can be anticipated for the relatives.

In the course of the 6 week program, the physical condition of 25% of the impaired kin worsened, as perceived by the participants. This suggests that program content should be designed to help participants learn to expect a progressive physical decline in their kin. From the frame of reference of the nature of mental impairment discussed in Chapter III, this would parallel a progressive decline in mental capacity, which the participants must also learn to anticipate and accept, if it has been diagnosed that their kin are suffering from chronic brain syndrome.

From the finding that the negative emotional conditions, such as irritability and hostility, with which the

participants described their kin were cited less frequently at T3 than T1, it can be inferred that the participants gained in tolerance during the program. Since there was no physical improvement during the same period, it is probable that this improvement in emotional characteristics as perceived by the participants is based on their acceptance of the expected behavior through increased knowledge and awareness, as well as through sharing of experiences with the group. This would support the andragogical assumption that adult learners want to apply what they are learning immediately, and that the program provided them with a learning experience which helped them to work toward acceptance of those negative conditions which could not be changed.

#### Family Characteristics

From the data it was shown that 69% of the participants had known their grandparents, but only 2 participants described their grandparents as mentally impaired. Since the trend is for more old people to survive into very advanced old age, it can be anticipated that a greater percentage will suffer mental impairment. The relatives of these older people will need help in dealing with their problems, having few role models from whom they can learn appropriate means of coping.

Past relationships with impaired kin were basically positive for half the participants and negative for the other half. Efforts to identify explanatory associations between past relationships with present behavior was unproductive. Knowledge of past relationships did not appear helpful in predicting how individual family members will react to problems of mental impairment in their kin.

#### Major Problems for Participants

It had been assumed that a major problem for relatives of mentally impaired aged is dealing with guilt for having placed their kin in an institution. Only 6 of the nursing home participants expressed guilt on the questionnaire. Apparently most relatives have worked through these feelings at a conscious level, since the realistic needs of the mentally impaired aged are clearly beyond the capacity of an average family. However, they are still very conflicted at an unconscious level which was manifested by the nature of the problems raised during the training sessions. Although there was definite evidence of improved behavior and a decrease in expressions of guilt by the end of the program for 4 of the 6, it is still an apparent problem for many. Active participation in the Relatives Council which resulted from the program may prove to be a constructive outlet for the unresolved conflicts which trouble this group.

The findings indicate that problems described as most difficult by the participants, such as dealing with mental impairment, were reduced by the end of the program, suggesting increased skills obtained from the program.

Another major problem is the inability to accept the inevitable deterioration which occurs in their kin, with whom there is often strong identification. By identification with a new reference group which was available through the program, these identity problems were lessened. As one participant put it, "The program was a great help to me by getting to know others with the same problems. I guess misery loves company." This supports the initial assumption in the design of the program that reference groups are an aid in adult socialization.

Visiting is another major problem area for this group. Although it was hypothesized that the problem for the participant would be related to visiting too seldom to meet the needs of their impaired kin, or visiting more often than needed, thereby interfering with other role demands, this proved to be incorrect. Most participants visited often enough, with one third visiting more than needed, and only 2 participants visiting less than once a week. The problem was not the quantity of visits, but rather the quality of these visits, dominated by the painful feelings caused by their kin's condition. This was reflected in the 44% of the group at T1 which expressed conflict over the

amount of visits, when in fact they visited frequently enough. Thirty eight percent still expressed conflict at T3, despite objectively sufficient visits. This expressed conflict was equally associated with length of residency and increased frequency of visits. The program did not help in reduction of conflict in this area.

From participants comments during the sessions, the program seemed to be helpful in providing concrete suggestions for making the visits more positive experiences, but not enough to appreciably reduce the degree of conflict expressed.

Half of the group expressing conflict also described their kin as unaware of their visits, with no improvement by T3. The program was not successful in reducing this inappropriate conflict.

Based upon the finding of a positive relationship between conflict over visits and difficult behavior of impaired kin, it can be inferred that relatives don't visit their difficult kin as often as they feel they should.

Based upon the finding of a positive relationship between conflict over visits and a past positive relationship with kin, it can be inferred that relatives feel they should visit more often when they have had a good relationship in the past.

Since both inferences are plausible, this may account for the high proportion of conflict over visiting,

despite the more than adequate pattern of visits.

The degree of role strain and role conflict which was assumed to be a major source of stress for the participants was not evident from the data collected. This may reflect a weakness in the instrument design, since the problems raised by the participants during the program revealed considerable conflict and role confusion.

Based on the analysis of a selected group of role conflicts and attitudes, it was found that far fewer experience role conflict in relation to their impaired kin than those who express lack of role conflict. Of the 6 conflicts analyzed, the one related to interference of the problems with impaired kin in other important aspects of the participants' life changed considerably during the program, from 19% at T1 to 7% at T3.

It was hypothesized that the participants could be helped to function more effectively in regard to their kin's problems through increased awareness of those attitudes and values which were relevant. The data showed an increase in the belief that society should be responsible for the care of the aged when the family cannot provide the care needed. A marked increase was found in the nursing home group in the attitude that the institution should encourage the family to participate in care, indicating gain of an important attitude in assumption of more balanced function, which was a major goal of the program. In the community group, there

was an increase in the attitude expressing preference for nursing home care for self if needed in the future, suggesting growth in recognition of the need for shared function between family and institutions when specialized care is required.

Analysis of 18 values of Rokeach's survey which might be relevant to this program showed that the population had different median rankings than a national sample. They ranked the following lower as guiding principles in their lives: a comfortable life, family security, freedom, happiness, pleasure, salvation and obedience. The following were ranked higher: inner harmony, self-respect, independence, loving and responsible. The value which differed most dramatically was salvation, with the participants' median ranking twice as low as the national sample. The low ranking of this value would indicate that this group is more demanding of self than the average. This is consistent with their motivation to participate in the program, to seek the skills needed in dealing with the complex feelings related to mental impairment. In the follow-up survey there was a higher ranking of family security, happiness, cheerful, helpful and loving, and a lower ranking of self-respect, pleasure, independent and obedient. This suggests that the program may have been effective in helping participants recognize contradictions between their stated beliefs and their behaviors, and would support Rokeach's finding that

change in values takes place when awareness of contradictions in the total belief system leads to a sense of self-dissatisfaction. These changes in value ranking indicate a trend toward balance in role congruence for this target population.

Because of the small sample of community participants, it is not useful to categorize their major problems. Most needed the information which was taught during the program to enable them to make appropriate decisions concerning the care of their kin. Half of the group succeeded in working through the complex mechanics of admissions in nursing homes, and the other half were prepared for future need by learning about their options and sources of help in the future. However, when the project director asked one participant during the follow-up interview whether he would know where to seek guidance if he found he could not cope with his wife's problems in the future, he responded, "Why, I take it for granted that I can come to you."

This clearly indicates that future programs should build in the opportunity for counselling, not only for the duration of the program, but after the close of the program as well.

Follow-up interviews with a sample of 5 participants indicated that the responses to the questionnaires were reliable and valid, but that the questionnaires did not elicit sufficient data for a full understanding of the complexity

of relationships involved, and for an assessment of the individual's need for counselling in addition to the program. This suggests that both questionnaires and personal interviews are necessary to obtain the range of data necessary for an adequate assessment of the needs and capacities of the participants and their families.

The problems experienced by the community participants pointed up the need for better service from information and referral sources, and for revision of current nursing home admission policies and procedures. Although many nursing homes are admitting the mentally impaired aged which previously did not, their procedures for entry are more applicable to the mentally intact, cooperative aged person, who is part of the decision-making process. In actuality, the mentally impaired applicant does not usually have the judgment needed to participate in decision making, and the institutions need to have more flexible procedures, helping the relatives in their task of assuming responsibility and control. The mentally impaired older person and his/her family need the most individualized admission plan, calling for the management of a skillful social worker, knowledgeable about the problems of mental impairment. Such a service is all too often not available.

The experience of the program substantiated the assumption that most relatives of the mentally impaired aged experience a "filial crisis" as described by Blenkner,

resulting from their need for new role behaviors. This should be expanded to include the concept "familial crisis" for those closely involved relatives who are not the adult children of the aged. The frame of reference of family structure and role theory developed in Chapter IV was reinforced by the participants in their need to work out new behavioral norms to satisfactorily resolve the conflict of competing claims of kin and other role responsibilities. Interventions during these crises can have positive results, not only for the relatives and impaired kin, but for the inter-personal functioning of these relatives in general.

Furthermore, as the field of aging has identified the need for a range of options in programs and services to meet the individual needs of the aged, the findings of this training program indicate the need for a range of options in programs and services for their relatives as well.

During a period of financial crisis in the field of institutional care, there is little hope in calling for the increased services of social workers, since the trend is to cut out these services as much as possible. For this reason, the training program, offering an inexpensive model for large numbers of clients may prove even more timely than anticipated, in providing an alternate solution to this gap in services.

Outcome of Program

The test of substantive knowledge of aging supported the assumption that participants could increase their skills through this type of program, since 56% showed improvement. However, cross analysis with other variables showed that increased knowledge of aging and mental impairment was not related to change in other relevant skills.

An analysis of expressed satisfaction with the program showed that 66% of the participants felt that the program increased their knowledge of mental impairment. Thirty-eight percent felt less guilt and more self-understanding, and 34% expressed that the group experience was helpful.

Eighty-two percent felt the program helped them, and 63% were behaving differently as a result of the program.

A significant area of training was to help participants learn to negotiate the institutional system in order to achieve adequate, satisfactory contacts with the staff. Only 28% improved in direct contacts with staff which led to increased satisfaction. However, an unanticipated goal of the program following the needs identified during the first session, was the formation of a relatives council, as the most effective means for the participants to deal with the system. The most important outcome of the training program was the creation of the Relatives Council,

immediately after the close of the training program. The Relatives Council represents the ideal mid-point of social distance between family and staff, as formulated by Eugene Litwak, which may lead to the maximum goal achievement of optimal care for the nursing home residents. Furthermore, it is a most constructive and satisfactory method for the nursing home participants to assume and fulfill their protective role.

The participants took full responsibility for organizing their new group independently, with results far exceeding all expectations. After two months, the nucleus of 13 members from the training program grew to over 100 paid members, including relatives of residents throughout the Isabella Geriatric Center, both impaired and well.

The participants took on the task of organizing the Council with great zeal, and were very skillful. They perform their tasks with evangelical commitment, the constructive and creative use of the emotional energy activated through the training program. The level of commitment is illustrated by an appeal made at the first meeting by the prime organizer, that all members pledge to continue their membership and involvement in the Council even after the death of their relatives who reside at the Center.

In the few months since the end of the training program, the Relatives Council has formed very active committees which are providing the residents with an enriched

program through obtaining volunteer entertainment of high quality, additional parties and gifts on special occasions, and added protection through the formation of a committee of "residents representatives" who act as ombudsmen. They are a group with many skills and contacts as resources, and have already had a successful fund raising party, and are publishing a very professional monthly newsletter, entitled "Good Relations."

The project director was asked to speak to their first large meeting, and was credited with having inspired their formation. The Council has the support and cooperation of Administration, and it is expected that the Council will provide an ongoing opportunity for the relatives to fulfill a meaningful and formalized role in the institutional system. Whether its value as an integral part of the organization will continue to be recognized despite anticipated financial crises, will be a test of the competence of management to utilize this available resource effectively.

The families of the mentally impaired, as members of the Relatives Council, are now visiting other residents who are mentally intact, offering a release for those relatives needing to relate to an alert parent figure. While some relatives have always included other residents in their visits, this is now a formal, structured possibility for those who were unable to do so previously. This serves the

double purpose of enriching the lives of the other residents as well as the relatives of the mentally impaired.

One member of the Relatives Council, a program participant who is retired, volunteered to serve as a discussion group leader for a small group of residents. This has given him a new purpose in life, which he views as an extension of his devotion to his mother. Shortly after he started this new role, his mother died, but he has continued to come to the Home, and meet with his discussion group, in keeping with the pledge taken by all members of the Council.

Less direct outcomes of the program are related to problem areas which were identified as a result of the evaluative design. In examining the possible causes for decreased satisfaction of the participants with their contacts with Social Service it became evident that social work skills were often being inappropriately used. Having accepted the role of liaison between relatives and staff, much time was spent dealing with problems which really should have been handled by other departments, and therefore leaving less time for direct counselling. With the formation of the Relatives Council, most of these grievances will be handled directly by the relatives with the appropriate department, freeing the social workers to fulfill their more specialized function. This finding has implications for other large organization, suggesting that more efficient use of staff time can be accomplished by clarification, and

opening of inter-departmental lines of communication to include direct communication with the consumers of services.

Another unplanned outcome of the program was a heightened sensitivity of the staff to the needs of the program participants and their kin. Through the questionnaires, many problems were identified which were not known previously by the staff, and which then received attention. One impaired resident was identified as being in need of volunteer visitors, since she was alert enough to want conversation, but had such a negative personality that she rejected all contacts. Special efforts were made successfully to find two special volunteers. Another resident was found who could empathize with her, and provide the companionship she craved. Ironically, just as this neglected resident started to benefit from this contact, she died very suddenly, leaving not only a bereaved family, but a bereaved volunteer resident. The family was comforted by the fact that the last days of their kin were made more bearable, and in gratitude have maintained contact with the volunteer resident, who has found in them a surrogate family.

Perhaps the most important long term result of the program is that it will become an ongoing service at the sponsoring agency, in response to the enthusiasm of the participants. This is the most concrete indicator that the hypothesized need for the training program was correct. The

project director will offer an extended program to a new group, on a twelve week basis, in the Fall of 1976.

In accordance with the evaluative design, the program was demonstrably effective since 81% of the participants improved in balance of shared function. The program proved to be a linkage-mechanism in a system of care which led to a greater balance of shared function between primary group and formal organization, posited by Litwak as necessitated by the structure of modern society.

In summation, the need for the training program has been clearly demonstrated. The auspice of a sponsoring geriatric center as a favorable location is substantiated by the favorable consequences for the participants as well as the institution. The program content was appropriate to the needs of the participants, and can be used by other sponsors, inasmuch as it is based on a flexible design, which can be used for other populations.

The planning and execution of the training program taught the project director that there is an urgent need for a book covering the same substantive content. Consequently, a publisher has been contacted who is interested in the topic, as a guide for families of the aged. This book will be completed as quickly as possible, as another direct outcome of the program.

In recognition of the need to share the results of this demonstration project with a wide audience of

practitioners in the field of aging, the project director will read a paper summarizing the training experience at the Gerontological Conference in New York, in October 1976.

In conclusion, the execution of the training program in accordance with the goals of its evaluative design, was a rewarding personal and professional experience. It fulfilled a personal commitment to work toward better care for the mentally impaired aged, adding immeasurably to professional growth and awareness of the needs of their families as well.

APPENDIX 1

WOULD YOU SPEND 12 HOURS LEARNING HOW TO DEAL MORE EFFECTIVELY WITH THE  
PROBLEMS OF YOUR ELDERLY RELATIVE?

Old age can be a time of peace and comfort, or it can be a time of pain and turmoil. It depends so much on whether one is blessed with good health...both physical and mental. Those of you who have a relative suffering from mental impairment in their old age know what anguish this affliction can cause an older person, as well as his or her family.

Like most adults in our society, you probably have no experience in dealing with the problems presented by your mentally impaired elderly relative. Mental impairment may be evidenced by periodic or constant confusion, emotional outburst, overly suspicious tendencies, hallucinations, or poor judgement. You are upset and confused by this behavior, so different from when they were well and normal, caring for themselves as well as others.

Whether or not they are in a nursing home, they need your help and care. The challenge to you is how to help appropriately. How can you resolve the conflicts you are now experiencing?

For the first time anywhere, a training program has been developed to teach adults how to cope with the difficulties presented by mental impairment in their elderly relatives. Florence Safford, Director of Social Service of the Isabella Geriatric Center, is offering a six week program, on Saturdays from 1 to 3 P.M., at the Isabella Geriatric Center, beginning January 10, 1976. There will be no charge for this pioneer program. Its primary goal is to help you deal more effectively with the problems experienced as a result of mental impairment in your elderly family member. The program is being offered to those of you whose relatives are living at Isabella Home, as well as residents in the community.

Work with us toward understanding these complex problems.

To register, send in the attached form. Remember, there will be no charge for this program. For further information, Telephone 781-9800, extension 327.

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Registration Form: Please enroll me for the 6 week Training Program for Relatives of the Mentally Impaired Aged, January 10 to February 14, 1976.

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone No. \_\_\_\_\_

To: Florence Safford, Director of Social Service  
Isabella Geriatric Center, 515 Audubon Avenue, New York, N.Y. 10040

APPENDIX 2

**8—HEIGHTS·INWOOD—Thursday, December 18, 1975**

## **Geriatric Center Offers Course**

A six-week training program for relatives of the mentally impaired aged will be offered, free of charge, at the Isabella Geriatric Center, 515 Audubon Ave., on six consecutive Saturdays, from Jan. 10 through Feb. 14, from 1 p.m. to 3 p.m.

The program will be conducted by Florence Safford, director of Social Services at the Center, and is designed to teach adults how to understand and cope with the difficulties presented by mental impairment in their elderly relatives.

The course is open to people whose relatives live at Isabella Home as well as to residents of the community.

Anyone wishing to enroll in the training program for relatives of the mentally impaired aged, should write to Florence Safford, Isabella Geriatric Center, 515 Audubon Ave., New York, N.Y. 10040, or telephone (212) 781-9800, extension 327.

TRAINING PROGRAM FOR FAMILIES OF MENTALLY IMPAIRED AGED

SESSION I.

Part A. The problems of mental impairment in the aged.

1. Physiological and psychological aspects.
2. The effect on family relations in modern society.

Part B. Identification of the problems experienced by participants, and needs from the program.

SESSION II.

Part A. Practical management problems.

1. For those in community: physical frailty; denial of need for help; nutrition; personal hygiene.
2. For those in institutions: complaints of infrequent visits; inability to follow normal conversation; relations with staff.

Part B. Role play of 3 members of a family discussing placing relative in institution.

SESSION III.

Part A. Further management problems: handling of finances; cost of institutional care; incontinence; lost eye glasses, dentures and hearing aids; how often to visit; special problems of spatially separated family; reality orientation.

Part B. Role play of 3 members of a family discussing responsibility for visiting and dealing with the institutional staff. Discussion of lessons for entire group.

SESSION IV.

Part A. Problems of depression; paranoia; sexuality.

Part B. Case examples of alternative methods of management.

SESSION V.

Part A. Role of religion and other ethical belief systems; social value issues.

Part B. Participants' discussion of personal ways of dealing with conflicting values.

SESSION VI.

Part A. Problems of the families of mentally impaired aged in the context of bureaucratization and social systems. Litwak's balance theory.

Part B. 1) Simulation of Community Board hearing application for opening a day center for mentally impaired aged.  
2) Participants' evaluation of training program.

APPENDIX 4

TRAINING PROGRAM FOR RELATIVES OF THE MENTALLY IMPAIRED AGED.

QUESTIONNAIRE

Introduction. The purpose of this questionnaire is to provide us with information which will be used to evaluate this training program. Please answer all of the questions which pertain to you, so that we may develop a picture of how you are dealing with the problem of your mentally impaired relative, and what some of your feelings and beliefs are about related issues.

For this program, when we speak of the mentally impaired aged, we shall mean those older persons who suffer from confusion, extreme forgetfulness, changes in personality, suspiciousness, etc. In order to shorten the questions, when we refer in the questionnaire to the mentally impaired older relative with whom you are currently involved, we shall only refer to him or her as "your relative."

All information given in this questionnaire will be treated confidentially. When the findings of our study are analyzed and discussed, no names will ever be used.



8. Which best describes his/her mental status?

CIRCLE A NUMBER FOR EACH ITEM.

	<u>Often</u>	<u>Sometimes</u>	<u>Never</u>
A. Confused	1	2	3
B. Forgetful	1	2	3
C. Hostile	1	2	3
D. Cooperative	1	2	3
E. Argumentative	1	2	3
F. Suspicious	1	2	3
G. Irritable	1	2	3
H. Poor judgement	1	2	3
I. Hallucinates	1	2	3

9. Has there been any change in your visiting pattern in the last 6 weeks?

1. Yes

2. No

If yes, for what reason? \_\_\_\_\_

10. What is the approximate total number of visits your relative receives per month from you and all other family members:

1. 30 or more

4. 4-5

2. 20-25

5. 2-3

3. 10-15

6. 1 or less

11. A. Do you feel it is often enough to meet the needs of your relative?  
a...yes b...no c...unsure

B. Do you feel it is more often than needed by your relative?  
a...yes b...no c...unsure

C. Does your relative feel it is often enough?  
a...yes b...no c...is unaware

12. Which family members help by visiting?

	<u>Often</u>	<u>Sometimes</u>
_____	1	2
_____	1	2
_____	1	2
_____	1	2
_____	1	2
_____	1	2

13. Which family members maintain contact by telephone with your relative?

	<u>Often</u>	<u>Sometimes</u>
_____	1	2
_____	1	2
_____	1	2
_____	1	2
_____	1	2
_____	1	2

14. Which family members take your relative on outings?

	<u>Often</u>	<u>Sometimes</u>
_____	1	2
_____	1	2
_____	1	2
_____	1	2
_____	1	2
_____	1	2

15. Does it upset you if all who should be involved are not?

a...yes      b...no

16. Which problems related to your relative are the most difficult for you at this time?

FOR THOSE OF YOU WHOSE RELATIVE RESIDES IN AN INSTITUTION:  
PLEASE ANSWER THE FOLLOWING NUMBER 17 THROUGH 32:

17. How often do you and/or your other family members speak with the following members of the staff on your relative's behalf?

	<u>Often</u>	<u>Sometimes</u>	<u>Never</u>
A. Doctor	1	2	3
B. Nurse	1	2	3
C. Aide or Attendant	1	2	3
D. Social Worker	1	2	3
E. Dietary Personnel	1	2	3
F. Activities Worker	1	2	3
G. Administrator	1	2	3
H. Other _____	1	2	3

18. Do you feel that speaking with the staff results in improved care for your relative? Circle only those applicable.

	<u>Yes</u>	<u>No</u>	<u>Unsure</u>
A. Doctor	1	2	3
B. Nurse	1	2	3
C. Aide or Attendant	1	2	3
D. Social Worker	1	2	3
E. Dietary Personnel	1	2	3
F. Activities Worker	1	2	3
G. Administrator	1	2	3
H. Other _____	1	2	3

19. Do you feel the nursing home is the most appropriate place for your relative?

a...yes b...no c...unsure

20. Would you prefer to have him/her in your home, if space and help were available?

a...yes b...no c...unsure

21. Do you feel guilty that your relative is in a nursing home?

a...yes b...no c...unsure

22. Do you bring favorite foods to your relative?  
a...often b...sometimes c...never
23. Do you telephone your relative?  
a...often b...sometimes c...never
24. Do you telephone the nursing home about your relative?  
a...often b...sometimes c...never
25. Is your relative paying privately for his/her care, or on Medicaid?  
a...private paying b...Medicaid
26. Do you contribute regularly toward the cost of care?  
a...yes b...no
27. Does anyone else in the family contribute toward the cost of care?  
a...yes b...no
28. If yes, who? \_\_\_\_\_
29. Do you think whether one contributes towards the cost of care in an institution should affect the kind of demands made for proper care?  
a...yes b...no
30. Do you think you are influenced by this factor?  
a...yes b...no
31. Which needs of your relative are unmet or inadequately met?
32. For what reason?

FOR THOSE OF YOU WHOSE RELATIVE IS NOT IN A NURSING HOME, PLEASE ANSWER THE FOLLOWING NUMBER 33 THROUGH 35

33. Do you and/or your family provide any of the following services to your relative:

	<u>Yes</u>	<u>No</u>	<u>Specify Which Member of Family Provides Services</u>
A. Live in same household	1	2	_____
B. Take care of shopping	1	2	_____
C. Take care of house-cleaning	1	2	_____
D. Take care of cooking	1	2	_____
E. Take care of personal clothing	1	2	_____
F. supervise finances	1	2	_____
G. Supervise personal hygiene	1	2	_____
H. Manage finances	1	2	_____
I. Pay for housekeeping services	1	2	_____
J. Arrange for house-keeping services (paid by relative)	1	2	_____
K. Take home for frequent visits	1	2	_____
L. Take home for occasional visits	1	2	_____
M. Take to senior citizen center	1	2	_____
N. Take to medical appointments	1	2	_____
O. Supervise medications	1	2	_____

34. Please circle the letter in front of all of the following statements which applies to you or with which you tend to agree:

- A. I feel my relative should go into a nursing home, but he/she does not want to.
- B. My relative would go into a nursing home, but it would cause financial hardship for a spouse.
- C. My relative would go into a nursing home, but he/she wanted to leave his/her money to the family.
- D. I respect my relative's right to live as he/she wants, even though he/she is no longer mentally competent.
- E. My concern for my relative's well being and safety makes me take over responsibility for his/her care, even over his/her protest of independence.

- F. My relative complains everytime I visit that it isn't often enough, and makes me feel so guilty that I visit as seldom as possible.
- G. My relative complains everytime I visit that it isn't often enough, and makes me feel so guilty that I visit much more than is necessary to look after his/her needs.
- H. Taking care of my relative's needs is a real burden, but he/she is too proud to allow me to apply for public assistance to get other help.
- I. I agree that filing for public assistance should be very complicated to discourage people from applying. People should save enough for the future so that they don't have to depend on welfare in their old age.
- J. Social agencies (such as Catholic Charities, Community Service Society or Jewish Association for the Aged) are for the poor, or for those who have no relatives to help them.
- K. I wouldn't even know where to start to get outside help for my relative or for myself in dealing with his/her problems.
- L. Very few old people were able to save enough to take care of all their needs if they are not in good health, and they have a right to be helped financially, which should be made as easy for them as possible.
- M. It is better for old people to be in a home with their own age group than with their family where everyone is busy with their own interests.
- N. It is better for old people to live with their family than in an old age home, even though they would be with their own age group.
- O. It is better for old people to live independently, but near their family so they can be helped.
- P. Even though my relative is no longer mentally competent, he/she would be very offended and angry with me if I attempted to make decisions affecting his/her life.
- Q. My family would not approach our relative as a group in order to influence him/her because it would seem as if we were ganging up on him/her,
- R. It is better to take a firm, authoritative position with your mentally impaired relative, and take whatever steps are necessary for his/her protection.

**FOR EVERYONE TO ANSWER:**

35. Please circle the letter in front of all of the following statements with which you agree:
- A. The problems of my relative are interfering with other important aspects of my life.
  - B. The time I am devoting to my relative is depriving my spouse of time which should be spent with him/her.
  - C. The time I am devoting to my relative is depriving my children of time which should be spent with them.
  - D. Worry about my relative is interfering with my health.
  - E. Worry about my relative is interfering with my job.
  - F. I am unable to enjoy enough leisure time activities because of the time I devote to my relative.
  - G. I am unable to devote as much time as I would like to community activities (civic, volunteer, political, etc.) because of the time I devote to my relative.
  - H. I am unable to buy all I would want for myself and my family because of the expenses I incur on behalf of my relative.
  - I. I do more than I should because the other members of the family don't do as much as they should.
  - J. I do as much as I do because there is no one else who can or should take responsibility.
  - K. I do not resent what I do, because my relative deserves my concern.
  - L. I do as much as I can without interfering with the needs of other members of our family.
  - M. I do as much as I can without becoming resentful.
  - N. If there is a conflict between duty to old parents or duty to children, preference should be given to parents because they don't have much left to their lives and their children should do everything possible to make the last few years comfortable.
  - O. If there is a conflict between duty to old parents or duty to children, preference should be given to children because any time and effort given them early in life to help them be happy and productive could pay off for a longer period of time.

- P. My religious belief sustains me through this difficult period.
- Q. The family has the basic responsibility for the protection and care of all its members.
- R. When the family is not able to meet the protective needs of all its members, then society should take over the responsibility.
- S. When an institution assumes responsibility for the protective needs of an infirm member of society, the family should not interfere by making suggestions or criticizing the quality of care being given.
- T. When an institution assumes responsibility for the protective needs of an infirm member of society, it should encourage the family to share this responsibility in as many ways as possible.
- U. I do not expect my children to take care of me if I am unable to care for myself.
- V. I would prefer to have my children take care of me if I am unable to care for myself.
- W. I would prefer to be in a nursing home than have my children take care of me if I am unable to care for myself, or am unable to arrange for adequate private help.

THESE NEXT QUESTIONS DEAL WITH WHAT WE KNOW ABOUT AGING AND MENTAL IMPAIRMENT.

36. It is important to keep an old person active and stimulated to delay mental deterioration.
- a...always true
  - b...always false
  - c...depends upon degree of mental impairment
  - d...depends upon past pattern of activities
37. The greatest social problem for the aged is the breakdown of the family which has led to their neglect.
- a...true
  - b...false
  - c...unsure
38. Senility is a psychological condition which results from isolation and lack of involvement with the family.
- a...true
  - b...false
  - c...unsure

IN ALL QUESTIONS WHOSE ANSWERS ARE EXPRESSED IN FIGURES, CHOOSE THE FIGURE CLOSEST TO WHAT YOU BELIEVE IS CORRECT.

39. Mental impairment is one of the most distressing problems in society. Among the aged in the community it affects
- a...80%
  - b...50%
  - c...25%
  - d...15%
  - e...5%
40. Among the aged in nursing homes it affects
- a...80%
  - b...50%
  - c...25%
  - d...15%
  - e...5%
41. How many aged are there in the United States today?
- a...2,500,000
  - b...12,000,000
  - c...18,000,000
  - d...21,000,000
  - e...50,000,000
42. What percentage are in nursing homes?
- a...2%
  - b...5%
  - c...10%
  - d...25%

43. Mental impairment in old age<sup>4</sup> can be related to intelligence level in younger years.  
a...true b...false c...unsure
44. Mental impairment in old age can be influenced by social factors.  
a...true b...false c...unsure
45. Mental impairment in old age can be influenced by emotional factors.  
a...true b...false c...unsure
46. Mental impairment in old age can be influenced by physical factors.  
a...true b...false c...unsure
47. Mental impairment in old age can be related to nutrition.  
a...true b...false c...unsure
48. Mental impairment in old age can be related to medications.  
a...true b...false c...unsure
49. Mental impairment in old age can be related to hardening of the arteries.  
a...true b...false c...unsure
50. Mental impairment in old age can be related to heart ailments.  
a...true b...false c...unsure
51. Mental impairment in old age can be related to diabetes.  
a...true b...false c...unsure
52. Senility is a normal stage of aging which comes to everyone if they live long enough.  
a...true b...false c...unsure
53. Personality traits in the aged are the same as when they were young, only more so.  
a...true b...false c...sometimes true
54. Incontinence (losing control of bowel and bladder) is evidence of regression to the stage of second childhood.  
a...true b...false c...sometimes true
55. Incontinence is a call for attention.  
a...true b...false c...sometimes true
56. Depression is a normal reaction to old age, and the family must learn to live with this as a permanent condition.  
a...true b...false c...sometimes true
57. When an old person leaves a gas jet open, it is time for him/her to be put in a nursing home.  
a...true b...false c...sometimes true

58. When an old person who has shown evidence of confusion, and who has refused to go to a nursing home has to be hospitalized, it is best to give up the apartment quickly so that he/she has no choice but to go into a nursing home from the hospital.

- a...True                      b...False                      c...Sometimes true

59. In 1900 the average life expectancy in the United States was:

- a...35  
b...45  
c...65  
d...80

60. In 1970 the average life expectancy in the United States was:

- a...60  
b...70  
c...75  
d...85

50. Was the training program helpful to you personally?

1. Yes
2. No

A. If yes, please list briefly in which areas of your life you feel it was helpful.

B. If no, please list briefly in which way you were disappointed, or in which way you feel it could be improved.

My thanks go out to all of you for taking part in this pioneer program.

Florence Safford

APPENDIX 5

VALUE SURVEY

NAME \_\_\_\_\_

INSTRUCTIONS

On the next page are 18 values listed in alphabetical order. Your task is to arrange them in order of their importance to YOU, as guiding principles in YOUR life. Study the list carefully and pick out the one value which is the most important for you. Write it, in pencil, in Box 1 on the left. Then pick out the value which is second most important for you. Write it in Box 2. Then do the same for each of the remaining values. The value which is least important goes in Box 18.

Work slowly and think carefully. If you change your mind, feel free to change your answers, by erasing and re-writing. The end result should truly show how you really feel.

1	
2	
3	
4	
5	
6	
7	
8	
9	
10	
11	
12	
13	
14	
15	
16	
17	
18	

- A COMFORTABLE LIFE**  
(a prosperous life)
- AN EXCITING LIFE**  
(a stimulating, active life)
- A SENSE OF ACCOMPLISHMENT**  
(lasting contribution)
- A WORLD AT PEACE**  
(free of war and conflict)
- A WORLD OF BEAUTY**  
(beauty of nature and the arts)
- EQUALITY** (brotherhood,  
equal opportunity for all)
- FAMILY SECURITY**  
(taking care of loved ones)
- FREEDOM**  
(independence, free choice)
- HAPPINESS**  
(contentedness)
- INNER HARMONY**  
(freedom from inner conflict)
- MATURE LOVE**  
(sexual and spiritual intimacy)
- NATIONAL SECURITY**  
(protection from attack)
- PLEASURE**  
(an enjoyable, leisurely life)
- SALVATION**  
(saved, eternal life)
- SELF-RESPECT**  
(self-esteem)
- SOCIAL RECOGNITION**  
(respect, admiration)
- TRUE FRIENDSHIP**  
(close companionship)
- WISDOM**  
(a mature understanding of life)

WHEN YOU HAVE FINISHED, GO TO THE NEXT PAGE.

Below is another list of 18 values. Arrange them in order of importance, the same as before.

1	
2	
3	
4	
5	
6	
7	
8	
9	
10	
11	
12	
13	
14	
15	
16	
17	
18	

**AMBITIOUS**  
(hard-working, aspiring)

**BROADMINDED**  
(open-minded)

**CAPABLE**  
(competent, effective)

**CHEERFUL**  
(lighthearted, joyful)

**CLEAN**  
(neat, tidy)

**COURAGEOUS**  
(standing up for your beliefs)

**FORGIVING**  
(willing to pardon others)

**HELPFUL** (working  
for the welfare of others)

**HONEST**  
(sincere, truthful)

**IMAGINATIVE**  
(daring, creative)

**INDEPENDENT**  
(self-reliant, self-sufficient)

**INTELLECTUAL**  
(intelligent, reflective)

**LOGICAL**  
(consistent, rational)

**LOVING**  
(affectionate, tender)

**OBEDIENT**  
(dutiful, respectful)

**POLITE**  
(courteous, well-mannered)

**RESPONSIBLE**  
(dependable, reliable)

**SELF-CONTROLLED**  
(restrained, self-disciplined)

APPENDIX 6

SUMMARY OF SIGNIFICANT PRINCIPLES AND PROBLEMS  
COVERED IN PROGRAM CONTENT

SESSION I.

1. INTRODUCTION:

- a. Behavior is learned through roles.
- b. Modern society is complex, change occurs rapidly. Families cannot train their younger generations sufficiently for skills they will need when adults.
- c. There is no model for the role of relative to the mentally impaired aged. Program will develop model.
- d. Myth that modern family does not take care of its aged. However, some functions are too difficult for small units of modified extended family, such as care of mentally impaired aged.
- e. Nursing homes and institutions were developed to provide technical, specialized care for infirm, particularly aged, while families must continue emotional and protective function.

2. a. Physiological and psychological aspects of mental impairment. Characteristic interrelationship of cause and effect on the behavior of the impaired aged.

- b. Effect on relationship with family members.  
Problems:
  - i. How to assume filial role of responsibility without need to be omnipotent.
  - ii. Need to balance freedom and independence with need for protection and dependency. Not role reversal, but assumption of new role. Principle of allowing as much choice as possible while aware of boundaries of responsibility.
  - iii. Recognition of risks - in community and institutions.
  - iv. Recognition of impaired kin's need to deny, retain control.
  - v. Recognition of own reactions: frustrations, shame, anger, sibling rivalry, fear of senility as hereditary.
  - vi. Dealing with separation and anticipatory grief.

- c. Frustrations over institutional care experienced as major problem for relatives of institutionalized aged. Staff seems to be judgmental toward relatives.
  - i. Rights of relatives to organize as family council, if wanted. Residents now have Bill of Rights. Relatives Council as means of insuring rights, and of formalizing role in institutional system.
3. Opportunity for informal discussion over coffee and cake.

## SESSION II.

1. Philosophical and psychological framework: motto of Alcoholics Anonymous, "Grant me the serenity to accept that which cannot be changed, the courage to change what should be changed and the wisdom to know the difference."
2. Practical management problems for community.
  - i. Dealing with symptoms.
  - ii. Adequacy of care.
  - iii. Cost of care.
  - iv. Dealing with denial.
  - v. Individual plan based on needs and wishes of impaired kin balanced against needs and wishes of family members and resources available.
3. Practical problems in Nursing Home:
  - i. Quality and quantity of visits.
  - ii. Relations with staff.
  - iii. Establishing priorities in dealing with complaints, sorting out the important from the unimportant.
4. Role play of family making decision about whether or not to institutionalize parent. How to sort out urgent problems and weigh risks. Principle of crises as opportunity for family growth as well as threat.
5. Informal group interaction over coffee and cake.

## SESSION III

1. Information and referral sources for community.
  - a. Important to know as many options as possible. Mechanics and ethics of involuntary placements.

- b. Informal network of neighbors, elevator operators, postmen, shopkeepers, all potential resources.
2. Nursing Home problems:
  - i. Lost eyeglasses, dentures, hearing aids and consequences.
  - ii. Recognition of guilt.
  - iii. Feelings when kin no longer relates.
3. Understanding the new world of the mentally impaired aged.
4. Role play of family discussing responsibility for visits, and dealing with institutional staff.
5. How to involve more family members in sharing responsibility.
6. Confirmed right of relatives to organize own Council with administrative approval.
7. Group interaction over coffee and cake.

#### SESSION IV.

1. Management of depression, incontinence, resistance to bathing, paranoia. Family role in providing feedback to medical staff on behavior and reactions to medications used for management. Right to information about medical treatment.
2. Understanding sexuality in old age, and sexual behavior related to mental impairment.
3. Reality orientation. Applicability for use during family visits.
4. Use of reminiscence and life review with family albums.
5. Amount of activity always to be individualized. Individualization requires communication between staff and family.
6. Family must be knowledgeable about "chain of command" in institutions, lines of communication.
7. Group interaction over coffee and cake.

#### SESSION V.

1. Role of religion and other ethical belief systems.
2. Value issues influenced by culture. Personal ways of dealing with conflicting values. Discussion of value survey and example of how they may influence decisions about role toward mentally impaired aged. Myth of independence in society.

3. Morality, ethics, values. Issues of trust, privacy, reciprocity, freedom of choice. Balanced by right to protection, right to appropriate care. Attitude toward death as preference to loss of freedom.
4. Understanding guilt. Sometimes has useful function when it leads to appropriate degree of responsibility.
5. Group interaction over coffee and cake.

SESSION VI.

1. Review of Litwak's balance theory - need for balance of function between primary group and bureaucratic institution.
2. Task for family in Nursing Home system is to balance involvement with interference.
3. Task for family in community is realistic assessment of total situation leading to appropriately protective care.
4. Nursing Home participants took responsibility for organizing Relatives Council. First meeting to follow end of training program.
5. Evaluation of program by participants: would have liked more sessions to continue working out individual problems.

APPENDIX 7, TABLE A

SUMMARY OF DATA

VISITING

N.H. Part- ticip- ant	Fre- quency of vis- its by			Direc- tion of Change	Conflict/Visits Yes No Often Enough?	Kin Pro- Kin file irri			Kin dis- satis- fied with # of visits			
	T1	T2	T3			+/-	table	visits				
1	3	2	2	incr.	x		B	C	B	+	x	x
2	4	4	4	no ch.		x	A	A	A	-	x	x
3	3	3	3	no ch.	x		C	C	C	-	x	x
4	4	4	4	no ch.		x	A	A	A	-	x	
5	4	4	4	no ch.		x	A	A	A	-	x	
6	4	4	4	no ch.	x		C	A	A	+	x	
7	4	4	3	incr.	x		C	B	B	+	x	
8	3	3	2	incr.		x	A	A	A	+		
9	2	2	2	no ch.		x	A	A	A	+		
10	4	4	3	incr.	x		B	B	B	+		x
11	2	2	2	no ch.	x		A	A	C	+		
12	3	3	2	incr.	x		B	A	A	+		
13	2	2	2	no ch.		x	A	A	A	-	x	x
14	3	3	3	no ch.	x		B	A	C	-	x	
15	4	5	5	decr.	x		B	B	B	-	x	x
16	4	4	-	no ch.	x		C	A	-	+	x	C
17	4	4	4	no ch.		x	A	A	A	-	x	C
18	3	3	3	no ch.		x	A	A	A	-	x	C
19	5	4	-	incr.	x		B	B	-	-	x	
21	3	3	3	no ch.		x	A	A	A	+		C
22	3	3	3	no ch.		x	A	A	A	+		C
23	4	4	6	decr.	x		B	B	B	+	x	x
24	4	4	-	no ch.		x	A	A	A	-		x
25	2	3	2	incr.	x		A	B	A	+	x	
26	1	2	-	decr.	x		A	B	-	-	x	x

\*Category/per month

- 1 = 30+
- 2 = 20-25
- 3 = 10-15
- 4 = 4-5
- 5 = 2-3
- 6 = 1 or less

- A = Yes
- B = No
- C = Unsure

C = Unaware

APPENDIX 7, TABLE B

SUMMARY OF DATA

TEST SCORES, STAFF CONTACTS, IDENTIFICATION OF NEEDS

Parti- cipant	Test Score (# Correct)			Con- tacts/ Staff		Contacts satis- fac- tory		Kin's needs unmet
	T1	T2	T3	T1	T3	T1	T3	
1	17	16	19	5	5	3	3	x
2	12	15	19	4	3	4	3	
3	9	7	19	3	3	3	0	x
4	15	15	16	5	3	2	0	x
5	16	15	16	4	3	3	0	x
5	11	12	14	7	6	3	3	x
7	13	9	9	2	2	0	0	
8	16	19	18	2	2	0	0	
9	18	17	19	5	5	2	0	
10	12	9	10	1	2	1	1	x
11	17	18	19	5	5	2	3	
12	17	13	17	5	-	2	-	x
13	0	9	15	1	2	1	2	
14	16	15	15	6	7	0	3	x
15	7	9	10	4	4	2	2	x
16	16	15	15	7	5	7	4	x
17	15	7	8	4	4	2	2	x
18	11	8	12	3	3	2	0	x
19	21	20	20	3	3	2	0	x
21	14	18	22	3	2	0	0	
22	11	15	21	3	2	0	0	
23	17	17	21	5	5	0	4	
24	6	11	11	1	5	0	4	
25	11	14	19	7	4	0	2	x
26	11	18	18	5	5	0	0	
<hr/>								
C1	18	20	21					
C2	19	18	-					
C3	13	18	20					
C4	16	17	21					
C5	13	8	9					
C6	11	12	14					
C7	12	17	18					

APPENDIX 7, TABLE C

SUMMARY OF DATA

SELECTED ROLE ORIENTATIONS AND ATTITUDES FROM QUESTIONNAIRE

- A = Problems interfere with other important aspects of my life.
- B = Problems interfere with spouse.
- C = Problems interfere with children.
- D = Problems interfere with health.
- E = Problems interfere with job.
- F = Problems interfere with leisure.
- G = Problems interfere with civic duties.
- H = Problems interfere with buying all I want.
- I = I do more than I should because other relatives don't.
- J = No one else can/should take responsibility.
- K = I don't resent what I do, my relative deserves it.
- L = I do as much as I can without interfering with others in family.
- M = I do as much as I can without resentment.
- N = In conflict, duty first to parents.
- O = In conflict, duty first to children.
- Q = Family has basic responsibility for care.
- R = When family can't, society has responsibility.
- T = Institution should encourage family participation.
- V = In my old age, prefer help from children.
- W = In my old age, if I can't manage, prefer to go into Nursing Home.

APPENDIX 7, TABLE C  
(Continued)

	A	B	C	D	E	F	G	H	I	J
	T1T2T3	T1T2T3	T1T2T3	T1T2T3	T1T2T3	T1T2T3	T1T2T3	T1T2T3	T1T2T3	T1T2T3
1									x x x	- x -
2									- x -	x x x
3										x x -
4										- x -
5										
6										- - x
7	- x -			x x -		- x -	- - x		x - -	x x x
8										x x x
9										
10					x - -	- x x				- x -
11										
12									- - x	
13										x x x
14	- x x				x x x	x x -			- x x	- - x
15	x x -			x - -		x x -			x x x	x - x
16	- x -			x x -						- x -
17										x x x
18										- x x
19	x x -	x - -		x - -		x - -			x x -	
21										
22										
23	x x x	x x -	- x -			x - x	- x x		x x x	x - -
24										
25										- x x
26	- x -			- x -					x x -	
C1										
C2	x x -				x - -					
C3							- x -			
C4	x x -			- - x	x x x	x x x				x x x
C5							x x x			x - -
C6							x x x			x x x
C7	x - -					x - -	x - -	- - x		x x -



APPENDIX 7, TABLE D

SUMMARY OF DATA

RATING OF ELEVEN CATEGORIES OF TABLE 33\*

Nursing Home Parti- cipants	<u>RATING OF ELEVEN CATEGORIES OF TABLE 33*</u>										
	1	2	3	4	5	6	7	8	9	10	11
1	+	+	+		+	-				+	+
2	+	+	+		+					+	+
3	+	-					+	+		+	+
4		+	+		+		+			+	+
5					+					+	+
6	-			+	+	+				-	+
7	-	-	+	-	-	-				-	-
8	+	+			+					+	+
9	+	+	-	-	-					-	-
10	-	+	-		+	-		+		+	+
11	+	+	-	+		-				+	+
12	+	-			+	+				+	+
13	-			+						+	+
14	-	+		+	+	-	-	-		+	+
15	-	+	+			-		-		+	+
16							-			+	+
17	-				+					+	+
18	-				+					+	+
19	+	+	-			-				+	+
21	+		+							-	-
22	+		+							+	+
23	+	+	-	+		-	+			+	+
24	-		+	+						+	+
25	+	+	+	+		+	+			+	+
26	+	-				-	-	-		+	+
Community Participants											
C1	+		+						+	+	+
C2	+	+	+						+	+	+
C3	+	+	+							+	+
C4	+	+	+		+				+	+	NH
C5	-	-	-					-	+	-	-
C6	-		+						+	+	NH
C7	+	+	-						+	+	NH

\*Better = +, Needs Improvement = -

No Change = no entry; NH = Transfer to Nursing Home from community

APPENDIX 8

SUMMARY OF DATA

NINE SELECTED RANKED TERMINAL VALUES PER TABLE 27\*

Parti- cipants	1		2		3		4		5		6		7		8		9	
	T1	T2	T1	T2	T1	T2	T1	T2	T1	T2	T1	T2	T1	T2	T1	T2	T1	T2
1	9	11	18	17	3	3	8	8	4	4	1	1	14	12	13	18	2	2
2	4	5	16	11	9	4	13	7	1	1	3	3	10	15	18	18	6	8
3	9	11	13	12	5	3	10	8	1	6	3	5	11	9	17	16	6	1
4	13	16	12	11	1	4	3	1	11	13	16	14	9	10	18	18	2	2
5	16	16	4	9	12	8	5	1	13	-	11	-	15	-	18	18	2	7
6	13	12	14	13	15	14	11	8	3	1	7	4	17	16	18	18	6	9
8	13	16	11	13	8	1	7	7	12	5	1	2	18	17	2	3	5	4
9	16	12	12	11	3	3	7	9	8	5	1	1	15	13	18	18	2	2
11	8	7	15	12	1	14	11	6	3	1	2	3	13	10	18	-	7	2
12	16	12	7	14	3	3	9	8	14	17	1	2	15	16	18	18	2	4
14	9	7	16	-	17	9	8	-	2	1	1	2	3	10	6	5	7	4
15	8	9	-	17	1	2	14	10	2	7	9	8	16	16	11	5	3	6
17	9	9	14	14	13	12	1	1	12	11	2	2	17	17	18	18	7	7
21	16	13	14	11	4	3	11	10	5	9	10	8	17	17	18	18	6	14
22	17	13	13	15	2	1	8	4	9	8	6	10	16	14	18	18	3	6
23	17	18	4	9	6	8	2	3	12	15	10	4	15	16	1	1	7	5
25	11	13	10	10	8	5	3	8	12	7	5	3	13	14	16	17	7	11
C1	7	7	18	2	14	5	4	9	12	4	11	14	9	1	1	17	2	13
C3	11	17	9	12	3	2	15	6	1	4	12	10	14	16	18	18	5	9
C4	7	10	11	13	5	5	6	17	-	7	4	2	8	8	3	4	2	3
C6	13	11	7	12	15	18	3	3	4	5	1	9	12	16	18	17	5	13
C7	11	12	8	7	2	2	7	8	10	5	15	4	16	16	18	18	1	1
<u>18</u>	6	6	17	17	5	5	1	1	14	14	7	7	16	16	11	11	8	8
Total	23																	

\*1 = A comfortable life

6 = Inner harmony

2 = World of beauty

7 = Pleasure

3 = Family security

8 = Salvation

4 = Freedom

9 = Self-respect

5 = Happiness

APPENDIX 8 (CONTD)

SUMMARY OF DATA

NINE SELECTED RANKED INSTRUMENTAL VALUES PER TABLE 28\*

Parti- cipants	1		2		3		4		5		6		7		8		9	
	T1	T2	T1	T2	T1	T2	T1	T2	T1	T2	T1	T2	T1	T2	T1	T2	T1	T2
1	3	1	18	4	17	10	16	9	1	3	4	11	15	8	12	17	2	6
2	3	6	14	11	13	7	12	5	5	2	4	16	8	10	9	4	1	1
3	6	10	7	6	17	18	16	16	2	2	3	11	10	3	18	17	1	1
4	9	5	15	16	12	13	8	12	6	6	1	1	14	15	18	18	2	7
5	10	11	13	14	15	15	5	10	9	6	4	4	7	3	18	18	12	8
6	9	3	11	9	13	11	6	16	1	1	17	15	7	2	8	18	2	14
8	15	17	7	7	1	1	6	2	2	3	13	8	3	4	10	12	5	9
9	6	8	11	11	14	9	13	10	2	4	3	1	1	5	17	17	5	7
11	17	10	5	7	6	8	7	9	1	1	8	12	10	2	15	18	4	14
12	6	6	4	5	7	9	12	10	3	3	8	2	1	1	18	18	2	4
14	17	4	6	11	3	2	4	3	5	-	8	-	1	1	12	-	9	-
15	9	9	10	4	18	5	2	1	3	6	4	7	-	11	-	17	5	2
17	9	9	18	18	6	6	7	7	2	2	8	8	14	14	17	17	3	3
21	4	4	12	11	17	17	6	2	7	12	1	3	15	13	14	15	8	1
22	3	10	15	15	12	17	11	7	2	1	10	2	6	12	17	16	1	3
23	9	9	12	12	1	1	14	14	5	5	6	6	2	2	17	17	7	7
25	10	9	13	2	2	3	8	13	9	6	16	11	3	5	14	17	11	12
C1	1	9	8	18	18	3	14	16	3	15	6	6	15	7	12	12	10	5
C3	9	2	11	13	5	9	8	5	1	3	3	11	4	7	15	14	7	4
C4	7	7	11	4	8	6	15	12	10	10	1	3	5	5	16	13	4	1
C6	4	4	9	12	5	15	11	5	6	14	10	6	7	8	17	17	8	11
C7	16	12	9	8	6	5	10	7	2	3	11	6	1	2	18	17	3	4
18	12	12	6	6	5	5	4	4	1	1	13	13	9	9	11	11	2	2

\*1 = Capable

6 = Independent

2 = Cheerful

7 = Loving

3 = Forgiving

8 = Obedient

4 = Helpful

9 = Responsible

5 = Honest