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Demographic Characteristics, Rehabilitation Outcomes, and Family Concerns of Individuals Who Are Older and Blind

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DEMOGRAPHIC CHARACTERISTICS, REHABILITATION OUTCOMES, AND FAMILY CONCERNS OF INDIVIDUALS WHO ARE OLDER AND BLIND

by

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This study was conducted to create a description of the demographic characteristics, rehabilitation outcomes, and concerns of the family members of a group of people who are older and blind. The sample for this study included 112 people who were blind and over the age of 55. In addition, the study included a description of the concerns of 40 family members who had a spouse or parent who was older and blind.

Five instruments where used to gather data for this study. A survey instrument provided demographic data and reported levels of productivity for each client. A functional assessment form was used to characterize the ability of clients to perform certain tasks at the beginning and after the completion of rehabilitation services. Exit productivity data were also collected. Family members completed a survey to report their concerns regarding their family member at the beginning of services and after rehabilitation services were completed.

The major findings showed that over two-thirds of the individuals served in the program were women. The

average age was 78, ranging in age from 55 to 103. Most individuals reported an onset of vision impairment after age 60, and most reported age-related eye pathologies. Individuals in this study also reported significant age-related disabilities. The research also revealed that women generally continue to perform household tasks at much greater levels than men.

The study also revealed strategies for measuring rehabilitation outcomes. In addition, the study indicated that gender and living arrangement appeared to be important variables in establishing gains, sustained levels of performance, and losses that these 112 individuals reported.

Finally, this research indicated that family members reported significant levels of concern regarding their spouse or parent who is older and blind. After rehabilitation services were completed, each group of family members reported lower levels of concern.

This study also reported the characteristics that define rehabilitation concerns of aging and disability, and it further made recommendations for additional areas of research in aging, disability, and the family.

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John E. Crews

TABLE OF CONTENTS

Table of Contents--Continued

CHAPTER

Table of Contents--Continued

LIST OF TABLES

List of Tables--Continued

LIST OF FIGURES

CHAPTER I

INTRODUCTION

The "Graying of America" has now become a ubiquitous refrain defining public policy decisions affecting the United States as the nation struggles to deal with large numbers of its citizens who are aging. As the ranks of the elderly swell, the consequences of the population shift will be experienced at every level of our social structure. As individuals attempt to come to terms with their own aging process, families will struggle to care for them, and policy makers will strive to make rational decisions as they allocate scarce resources for increasing demands. Nowhere will the demands be greater than among older people who experience vision impairment and other age-related disabilities. For the first time, it is age, not trauma or disease, that predicts blindness in America. Wilson (1986) provided a sobering assessment when he recently observed,

> The greatest number of disabled people is obviously amongst the massive populations of Africa, Asia and Latin America. However, the highest prevalence of disability is almost certainly found here in North America among your elderly population. Take blindness for example. In the total population of the United States one person in 500 is blind. Over age 65 one American in 60 is blind--about equal to the blindness rate in Bangladesh. Over age 80 one

> American in 16 is blind--equal to some of the worst blindness areas of Africa. (p. 2)

While the prevalence of blindness among the elderly points to the importance of this policy domain, the increasing numbers of older people experiencing severe vision impairment suggest the public policy imperative. In the three decades between 1980 and 2010, for example, the absolute number of severely visually impaired older people will, in all probability, increase from 2,000,000 to 3,800,000.

The phenomenal advances in medical technology, communication, and the explosion of knowledge and information do nothing to respond to the needs of the most fundamental unit of society--the family. As America ages, policy makers and service providers must make sound, responsive decisions to serve older blind people and the families who care for and about them.

While the blindness system has a long and proud history, it is in the 1990s that fundamental assumptions can be tested. Policy makers have spoken for decades of the need to serve older blind people; it is only now that the discipline is sufficiently sophisticated to help shape public policy in a meaningful way.

Studies addressing the concerns of older visually impaired people have largely focused upon broad policy issues associated with a lack of service or program

models. Virtually no scholarly research has addressed rehabilitation outcome measures that are available to the field of blind rehabilitation. This paucity of research is not a fault of the blindness system, but rather it reflects the current status of evaluation research and outcome measures. With the publication in 1980 of The International Classification of Impairments, Disabilities, and Handicaps (ICIDH, World Health Organization, 1980), policy makers and practitioners have for the first time developed a rigorous theoretical model to frame policy questions and develop outcome measures. Moreover, this research comes at a time when sociologists, the aging community, and individuals are increasingly interested in the impact of disability upon the family. The pioneering studies in disability and the family by E. M. Brody (1981) and S. J. Brody (1978) occurred just as Wood completed publishable drafts of the ICIDH. It is the confluence of these two developments that makes this research possible.

The aim of this research is threefold. The first objective is to create an accurate description of a population of older people who are blind. Practitioners, researchers, and policy makers have only a minimal understanding of the characteristics of this group; therefore, prudent policy and research decisions cannot be made with accuracy or precision.

The second objective of this research is to measure rehabilitation outcomes among older people who are blind. This portion of the research raises a series of questions about how to establish protocols to quantify gains that older blind people may experience as a result of a rehabilitation intervention. At present, empirical data are sadly lacking and are badly needed to characterize the effectiveness of rehabilitation programs and to allocate scarce resources.

The third objective of this study is to examine the concerns of family members who are in a caregiving role for an older blind person. This research focuses upon issues that may create stress in normal family roles. This portion of the research also measures changes in caregivers' concerns after a rehabilitation program has been completed. While research has often focused upon caregivers of older disabled people, no research has addressed the specific concerns of caregivers of older individuals who are blind.

None of these objectives is easily achieved. A review of the literature reveals that as yet far more questions are asked about aging, blindness, and the family than are answered. Framing questions, however, is a critical first step. For example, Fuhrer's (1987) observations define a significant domain of this research. He writes,

> References to theory are lacking in most studies of rehabilitation outcomes. As much as anything else, this omission reflects unavailability of well-elaborated theories of rehabilitation and disablement. The paucity of theory makes it difficult to organize knowledge in the field of rehabilitation into a coherent framework. Another result is an inability to arrive deductively at well formulated hypotheses regarding new, potentially effective, interventions. Consequently, the development of new treatment methods becomes a matter of trial and error based on informed speculation. Relationships among problems encountered during service provision are not made explicit, so attempted solutions tend to be piecemeal. (p. 13)

Little satisfactory research has been accomplished in outcome evaluation in rehabilitation, and virtually nothing has been done in establishing outcome measures in blind rehabilitation.

In her review of the literature of family caregiving and the elderly, Horowitz (1985a) deals with broad issues of aging and disability, and she concludes that a variety of research needs remain. She asserts,

> There is a critical need for evaluations of interventions in support of families and older persons for whom they care. Respite care, financial incentives, tax proposals, skill training, and support groups have all been proposed as potential supports to families. Controlled field studies are needed to determine their effects in improving the quality of care on families. They also need to specify the types of supports that are most appropriate for different types of families and under varying caregiving conditions. (p. 234)

And, in addition, she says that, "The qualitative

relationships between primary caregiver and the older person, and how it affects and is affected by caregiving, requires further specification" (p. 235).

The concerns identified by Fuhrer (1987) and Horowitz (1985a) address the central issues raised in this research. In order to better serve elders experiencing blindness, reseachers and policy makers must better understand the characteristics of this population. In all probability, the needs of older people who are blind are more complex and fluid than policy makers have assumed. While older blind people are undoubtedly a heterogeneous group, it is imperative that they are characterized accurately. Understating the problem may mean that important services are not provided. Overstating the problem may overwhelm policy makers. Characterizing a group of older blind people in a manner that respects their dignity, yet is empirical, creates an important foundation upon which to build public policy.

In addition, policy makers have assumed that rehabilitation services lead to greater independence and, therefore, more satisfying lives. Thus, in order to positively evaluate the effectiveness of a rehabilitation program, practitioners must be able to demonstrate sustained levels of independence or some increased functional gain, albeit small. An intervention simply

must make a difference in the lives of the people it purports to serve.

There is no question that as blindness affects the life of an older person, it has some impact upon the family. Here, too, it is imperative that the problem not be understated or overstated. In order to better serve those individuals thrust into caregiving roles, researchers, practitioners, and policy makers must better understand what concerns the family. Caregiving spouses and adult children may have differing concerns that create stress and tax resilience in different ways, and the concerns of each may change as an older blind person completes a rehabilitation program. Knowing these concerns and the magnitude of change helps to direct public policy decisions and theoretical inquiry.

This research is an effort that creates a foundation of knowledge that leads to a better understanding of the circumstances of older people who are blind, and it suggests ways to measure changes that occur among this population. This study, therefore, addresses three issues: (1) it characterizes a group of older people who are blind; (2) it develops outcome measures to quantify rehabilitation gain; and (3) it characterizes the concerns of the caregivers of blind elders. As a consequence of this increased knowledge, rigorous questions can be asked that lead to informed policy decisions.

This research does not purport to design the ideal rehabilitation model. It does, however, ask rigorous questions the answers to which should contribute to the body of knowledge regarding blindness, aging, rehabilitation, and the family. The aggregate of this research and studies to follow should help to shape policy decisions in the decades to come.

CHAPTER II

REVIEW OF THE LITERATURE

Although there are about three million older Americans experiencing severe vision impairment (K. A. Nelson, 1987), a recent American Foundation for the Blind bibliography (Rosen, 1987) lists only 85 items dealing with the topic of aging and blindness. This lack of critical research is even more surprising when one realizes that well over 75% of all those experiencing severe vision impairment are older (National Center for Health Statistics, 1986). Virtually no critical attention has been given to exploring family relationships or measuring rehabilitation outcome in interventions designed for older people who are blind. There is, however, a rich and growing body of gerontological literature that explores the impact of disability upon the family, and much of it has ready application to blind elders. There is, as well, an emerging body of rigorous research that deals with measuring rehabilitation outcomes and is applicable to blind rehabilitation. In order to understand the complex issues of rehabilitation and the family addressed in this research, it is useful to explore the literature from a variety of disciplines.

A review of the literature, therefore, must address four broad issues that influence this research. The first concern focuses upon demographics and the policy domain of aging, disability, and severe vision impairment, as well as the economic and social implications of these increasingly complex matters. The second issue deals with the role of rehabilitation as a service delivery model that is available to older people experiencing vision impairment. The third topic addresses the role of the family and the impact of aging and disability upon this fundamental unit of our social structure. The final issue concerns the development of outcome measures to quantify functional gain. Understanding these issues allows us to create a conceptual framework that leads to a better understanding of policy decisions and the application of those decisions for people who are both older and disabled.

Demographic Pressures

The demographic realities facing this country are at once sobering and encouraging. America obviously is graying, and the implications of the growth of the older population will in time impact upon every thread of the social fabric of this country. The family and the economy, as well as the health and social support systems, will be affected. A Senate Select Committee on

Aging report characterizes the increase in older citizens as "one of the most significant demographic trends of the twentieth and twenty-first centuries" (U. S. Senate, 1984, p. 24). At the turn of the century, one person in ten was over the age of 55, and in 1982 over one-fifth of the population was over age 55. If current trends continue, by the year 2010 one-fourth of the total U. S. population will be over the age of 55, and by the year 2050, one person in three will be over the age of 55 (Brotman, 1982). These figures, just as age itself, are relative. Continued advances in medical technology may very well increase life expectancy even beyond current projections.

Age also has relative implications. Age 55 is no more meaningful than the current accepted age of retirement at age 65, established by Otto Von Bismarck long ago (National Council on the Aging, 1977). The population segments experiencing the greatest rate of growth are the over 75 and over 85 population groups. In 1900, for example, only 772,000 people in the United States were between the ages of 75 and 84, and only 123,000 were 85 years of age or older; yet by 1980, 7,727,000 persons were between the ages of 75 and 84, and 2,240,000 were 85 years or older. By the year 2050, the proportion of those 85 and older will jump from 1% to 5% of the U. S. population (National Council on the Aging, 1981). These

trends have far-reaching policy implications since it is generally the "older old," the frail elderly, who have the greatest needs for social services, income maintenance, and housing, as well as health and rehabilitative services.

There are grave dangers in either overstating or understating the condition of the elderly. Many older people lead productive, vigorous lives well into advanced years, and most older people live quite independently. Yet the dynamics of aging invite a variety of factors that lead to decreased independence and increased disease. Only 5% of all older U. S. citizens reside in institutions at any one time (National Center for Health Statistics, 1987). Although 85% of noninstitutionalized Americans over the age of 65 have at least one chronic health condition (Blake, 1984), over half (57%) of all older people are free of functional limitations. Of the remaining 43%, the National Center for Health Statistics (1982) estimates that 17% are unable to carry out major life activity; 21% are "limited in the amount of or kind of activity"; and 5% are "limited, but not in major activity."

Aging and Disability

Aging is not a disease process, but it marks a time when the individual is increasingly exposed to the

likelihood of disease. Moreover, diseases associated with aging occur at a time when support systems and resiliency may be limited. Williams (1984), the Director of the National Institute on Aging, noted that two out of three people will die as a disabled person, and Katz et al. (1983) remarked, "Instead of death, the end point of active life expectancy is the loss of independence in daily living" (p. 1218).

The numbers presented by demographers thus do not tell the whole story. For the first time, developmentally disabled people are living past middle age. In addition, adults who have experienced trauma at an early age are aging in larger numbers (Trieschmann, 1987). Finally, there are dramatic increases in those who have become disabled because of trauma (especially falls) or diseases which become more prevalent or intense among the elderly (Fenderson, 1986). Often medical or surgical interventions prove effective but create residual impairment. Being old cannot be equated with being disabled, but there is a direct relationship between the incidence of impairment and advancing age (Blake, 1981; DeJong & Lifchez, 1983; Myers, 1985).

Accurate data regarding the prevalence of impairments are difficult to obtain. The best studies are compiled through the Health Interview Surveys (HIS) of the National Center for Health Statistics (NCHS). Never-

theless, since many older people have multiple impairments, there may be a tendency to undercount impairments or to focus upon the major disabling condition. Indeed, sensory impairments (hearing and vision) may be neglected because of the difficulty of obtaining diagnosis by observation. Blake (1981, 1984) provided data from National Center for Health Statistics studies that offer much insight into the condition of older disabled people. The leading chronic health conditions for the older population are presented in Table 1.

The quality of these data becomes immediately suspect. Vision impairment is defined as the inability to read newspaper print with the best possible correction; therefore, the condition extends from severe vision impairment (a visual acuity of about 20/100) to total blindness. Moreover, the impairment of cerebral vascular accident, that is, stroke, is hidden in hypertension, heart disease, and arteriosclerosis. Alzheimer's disease does not appear because it is so often misdiagnosed. In addition, Medicare and Medicaid treat Alzheimer's as a mental health condition and will only pay $250 annually for care. Physicians, therefore, may tend to diagnose Alzheimer's as some other condition in order to allow for third party pay, thereby relieving patients of extraordinary health care expenses.

Table 1

Chronic Conditions Reported by Noninstitutionalized Persons, Aged 65 and Over

Condition	Percent
Arthritis	44.3
Hypertension	38.5
Hearing impairment	28.2
Heart disease	27.4
Arteriosclerosis	12.0
Visual impairment	11.9
Diabetes	8.0

Source: Blake, R. (1984). What disables the American Elderly? Generations, 8(4), p. 6. Used with permission of Generations.

Another NCHS study cited by Blake (1981) explores the causes of death among persons over age 65. (See Table 2.) However, the data are suspect because an individual may have multiple impairments at the time of death.

Also, the data are confusing because one cannot relate death to impairment. For example, because of a mobility disability an older person may travel slower and exert considerable energy to cover limited territory; the mobility disability may lead to extended exposure to inclement weather that results in pneumonia.

Table 2

Death Rates for the 10 Leading Causes of Death for Ages 65 and Over, 1976

Rank and Cause of Death	Deaths per 100,000 population
1. Diseases of the heart	2,393.5
2. Malignant neoplasms	979.0
3. Cerebrovascular diseases	694.6
4. Influenza and pneumonia	211.1
5. Arteriosclerosis	122.2
6. Diabetes mellitus	108.1
7. Accidents	104.5
Motor Vehicle	25.2
All Other	79.3
8. Bronchitis, emphysema, & asthma	76.8
9. Cirrhosis of liver	36.5
10. Nephritis & nephrosis	25.0
11. All other causes	677.5

Source: Blake, R. (1981). Disabled older persons: A demographic analysis. Journal of Rehabilitation, 47(4), p. 23.
Used with permission of the Journal of Rehabilitation.

By the same token, a fall (accident) may occur because a visual impairment restricts the ability of an older person to see obstacles.

Because these issues are so very complex and confusing and because of conflict among the service models assisting people who are disabled, it is no wonder that a comprehensive national policy has not yet emerged. In addition, there is a tendency to fragment the complexity of these grave problems among specialized disciplines and advocates of particular disabilities. The physician in rehabilitation medicine, for example, may become so involved with the medical model that the importance of the family is forgotten. By the same token, those people serving a specific disability, say blindness, may ignore the impact of other disabilities on the rehabilitation process. In a sense, simplifying the problem may be the only way to keep these complex issues under control; yet simplification ignores the fundamental reality of aging and multiple disabilities.

Prevalence of Severe Vision Impairment

Researchers have been frustrated in their efforts to determine the number of individuals experiencing severe vision impairment or blindness. So-called "legal blindness" relies upon a clinical measure of visual acuity and visual fields and is defined as an acuity of 20/200 or worse in the better eye with the best possible correction or a field restriction of twenty degrees or less (Kahn & Moorehead, 1973). Good data regarding legal blindness

have been difficult to obtain primarily because of the extremely small population involved and the methodological problems in gathering data.

The Model Reporting Area for Statistics on Blindness (Kirchner, 1985) is a roster of legally blind individuals in sixteen states. These registers, unfortunately, have often proven unsatisfactory. Kirchner asserts,

> Because they depend on reported cases, state blindness registers undercount the legally blind population to an unknown degree, and furthermore are probably biased--i.e., those who are registered may not be representative of all persons who could be defined as legally blind. (p. 4)

Most research on severe vision impairment has relied heavily upon data collected by the National Center for Health Statistics (NCHS). The NCHS has developed a series of functional questions addressing near, intermediate, and distance vision tasks. Severe vision impairment is defined as the inability to read newspaper print with corrective lenses. Research over the last decade has often cited statistics available from a 1977 NCHS study (NCHS, 1982). For example, in a 1979 article Kirchner examined NCHS data and projected that 990,000 persons over the age of 65 could not read newspaper print. Kirchner used NCHS prevalence rates and applied them to census data to obtain her estimates; in addition, she applied the prevalence rates to census projections for the year 2000 and calculated a total of 1,760,000

older people experiencing severe vision impairment, "an increase of 78 percent!" (p. 76).

Subsequently, in 1984 the National Center for Health Statistics intensified its efforts to gather data about older people. This additional study, the Supplement on Aging (SOA), was much more rigorously designed and more inclusive than earlier NCHS research, and the findings underline the policy implications of an aging society (National Center for Health Statistics, 1986). K. A. Nelson (1987), referring to the 1979 Kirchner projection, observed,

> The future, it appears, has already arrived. According to recently released data from the National Center for Health Statistics (NCHS), the number of noninstitutionalized elderly people who were severely visually impaired in 1984--2,038,000--considerably surpassed the number previously projected for the year 2000. A comparison of 1984 and 1977 data shows that the number of severely visually impaired elderly persons is twice as great as previously estimated. (p. 331)

Table 3 illustrates the application of 1977 NCHS estimates to 1980 census data. Clearly, vision impairment is age related. For those under the age of 24, the prevalence of severe vision impairment is 0.5 per 1,000. By contrast, for those over the age of 85 the prevalence is 180 per 1,000. In other words, for those under age 24, one person in 2,000 experiences blindness or severe vision impairment; for those over age 85, the incidence is approximately 1 in 5. Table 3 below helps to

illustrate the gravity of the problem. This table, for example, applies the 1977 NCHS study to 1980 census data, and it reveals that a total of 1,670,000 individuals experienced severe vision impairment in the United States. Of those, 1,250,000 are over the age of 65.

Table 3

Prevalence of Severe Vision Impairment
United States, 1980

Age range	U. S population	Prevalence per 1,000	Number with severe vision impairment
0-14	51,290,339	0.528	27,081
15-24	42,486,828	0.528	22,433
25-34	37,081,839	1.230	45,610
35-44	25,634,710	1.680	43,066
45-54	22,799,787	4.800	109,438
55-64	21,702,875	7.800	169,282
65-74	15,580,605	22.300	347,447
75-84	7,728,755	64.900	501,596
85+	2,240,067	180.500	404,332
Totals	226,545,805	6.6	1,670,285

Source: National Center for Health Statistics (1981) applied to U. S. Bureau of the Census (1982) data.

Table 4 dramatically illustrates the impact of the 1984 National Center for Health Statistics (1986) Supplement on Aging study. Table 4 stands in stark contrast to Table 3. By applying the new prevalence rates to 1980 census data, the total population of those experiencing severe vision impairment surges from 1,670,000 to 2,474,000. The prevalence of severe vision impairment for those between the ages of 65 and 74 increased from 22.3 per 1,000 to 47 per 1,000; in the age group 75-84, the prevalence increased from 64.9 to 99 per 1,000, and in the over age 85 age group, the prevalence increased from 180 per 1,000 to 250 per 1,000. For non-institutionalized individuals over the age of 85, one person in four is unable to read newspaper print (K. A. Nelson, 1987). The increase in those over 65 experiencing severe vision impairment based upon the two NCHS studies increased from 1,250,000 to 2,057,000.

Projecting the population of older severely visually impaired people into the future reveals numbers that are far more alarming than planners had expected. Table 5 demonstrates the increase in the number of severely visually impaired older people from 1960 to 2020. From 1980 to 2010, the number of severely impaired elders will increase from 2,000,000 to 3,800,000. The population roughly doubles during that thirty year period. In addition, increases in the over age 85 population begin to

have an important effect. In the year 2000, the number of those 85 and over experiencing severe vision impairment begins to exceed the age group 75 to 84.

Table 4

Prevalence of Severe Vision Impairment
United States, 1980--Revised

Age range	U. S. population	Prevalence per 1,000	Severe vision impairment
0-14	51,290,339	0.528	27,081
15-24	42,486,828	0.528	22,433
25-34	37,081,839	1.230	45,610
35-44	25,634,710	1.680	43,066
45-54	22,799,787	4.800	109,438
55-64	21,702,875	7.800	169,282
65-74	15,580,605	47.000	732,288
75-84	7,728,755	99.000	765,147
85+	2,240,067	250.000	560,016
Totals	226,545,805		2,474,361

Source: National Center for Health Statistics 1984 Supplement on Aging (1987) applied to 1980 U.S. Bureau of the Census (1982) data.

Figure 1 illustrates increases among older people who are severely visually impaired in a graphic way.

Table 5

Prevalence of Severe Vision Impairment
Age 65+ in United States, 1960-2020

	1960	1970	1980	1990	2000	2010	2020
65-74	516,859	584,445	732,307	873,307	830,819	954,946	1,402,245
75-84	458,716	605,781	765,151	1,024,551	1,219,482	1,220,274	1,434,114
85+	232,250	377,750	560,000	828,250	1,231,500	1,637,700	1,770,250
	1,207,825	1,567,976	2,057,458	2,726,108	3,281,801	3,812,920	4,606,609

Source: National Center for Health Statistics 1984 Supplement on Aging (1987) prevalence rates applied to 1980 census reports (U. S. Bureau of the Census, 1982).

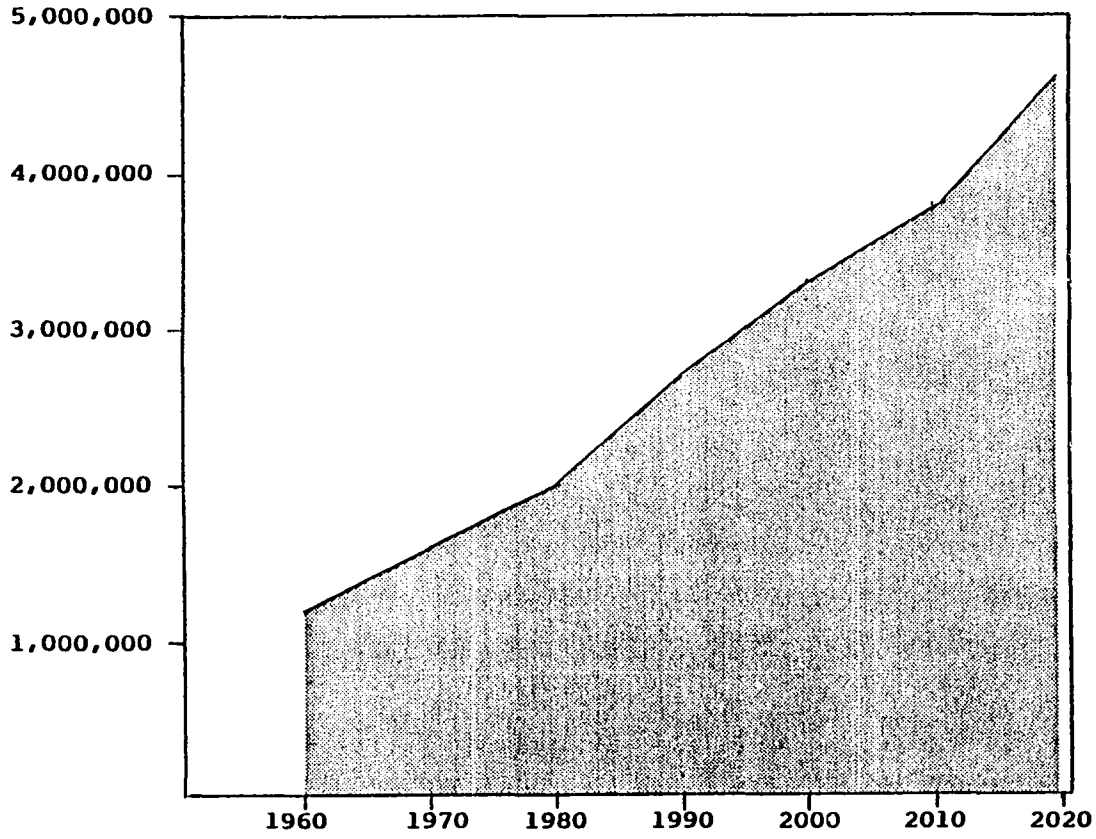

Figure 1. Severe Vision Impairment, Persons 65+, United States, 1960-2020.

Source: National Center for Health Statistics 1984 Supplement on Aging (1987) prevalence rates applied to 1980 census reports (U. S. Bureau of the Census, 1982).

Available data also suggest that most older blind people experience multiple impairments. The National Center for Health Statistics (cited in Kirchner & Peterson, 1980b) estimates that 79% of the visually impaired over the age of 65 have multiple disabilities, primarily hearing impairment, non-paralytic orthopedic impairments, or complete/partial paralysis. The average number of impairments among those with multiple impairments is 2.49.

It is unclear to what degree severe vision impairment is a factor that leads to institutionalization, a serious concern among the elderly. Available information suggests that elders who are visually impaired comprise a disproportionately high percentage of nursing home populations. A 1976 study indicates that 48.3% of all nursing home residents in the United States experience limitations of vision: 32.5% have "some limitation"; 12.8% experience "severe limitation," and 3.1% are "unable to see" (U. S. Bureau of the Census, 1978). Only walking limitations (at 65.9%) exceed vision as a documented disability. These estimates are reinforced by a survey of 56 nursing homes by the Industrial Home for the Blind in New York. Of 5,376 residents examined in 1969, 13.3% were discovered to be legally blind (Salmon, 1969). In many situations, however, vision problems are not addressed because more visible impairments gain the

attention of physicians or nursing home staffs. Peterson and Kirchner (1980a) noted, "One study of 27 nursing homes reports that a mere 5% of visual problems were identified by routine medical examinations; the remaining 95% were only discovered if the patient complained" (p.402).

Medical and Rehabilitation Models

Given these realities, the so-called "Medical Model" that relies upon precise diagnosis and acute care no longer responds to the rehabilitative needs of older people. Preservation of life and the quantifiable success in meeting that goal say nothing about the quality of life and the degree of independence that the elderly enjoy. Granger (1986) wrote,

> Traditionally, medical and allied health educators have focused on the curative aspects of the disease process--the diagnosis and treatment of an organic impairment--rather than the long-term management of its consequences. Although such an approach may be satisfactory for treating acute conditions, it is inadequate when caring for patients with chronic health impairments. Diagnoses are an inadequate index of health because the range of severity within a diagnosis is often greater than among diagnoses. (p. 28)

The rehabilitation model, however, has not been much more responsive to the needs of older people (Benedict & Ganikos, 1981). In this country, rehabilitation is clearly tied to educational outcomes for children and

vocational outcomes for adults. Prior to the 1940s, not much was done in the United States in the way of rehabilitation; those who survived with developmental disabilities and physical disabilities were most often confined to institutions or were cared for at home. In the 1940s, however, rehabilitation efforts focused upon childhood diseases, especially polio myelitis, and the needs of disabled veterans who were casualties of World War II. Because these veterans had worked and because work was a valuable ethic, rehabilitation models came to stress vocational outcomes as the only legitimate activity falling under the rubric of rehabilitation. This emphasis was also reflected in the 1950s as vocational rehabilitation models moved away from war veterans to the civilian population, and rehabilitation focused on industrial trauma and injuries from automobile accidents. The goal of these services reflected social concerns and the cost of dependency but virtually ignored the cost of failing to serve the elderly (Bowe, 1980).

In the 1960s and 1970s, individuals with developmental disabilities were recognized as not inevitably handicapped, and programs emerged to provide independent living rehabilitation as well as vocational rehabilitation. The returning veterans of the Viet Nam War helped to redefine rehabilitation models. Many Viet Nam veterans--young, educated, and aggressive--demanded that

housing, education, and transportation be accessible. As a result, barrier free legislation and to some extent independent living legislation have materialized.

The emerging philosophy of independent living rehabilitation is clearly applicable to the needs of older disabled people. Yet, because of age bias and a rigid model of vocational rehabilitation outcomes, the rehabilitation profession has had little to do with older clients. Vocational rehabilitation programs have done little to serve older workers, and for those requiring independent living rehabilitation, legislative mandates have prevented agencies from providing those services. This trend is only now beginning to shift (Bozarth, 1981). Williams (1984) pointed to the value of rehabilitation, particularly geriatric rehabilitation, when he wrote,

> Rehabilitation is an approach, a philosophy, and a point of view as much as it is a set of techniques. The aim of rehabilitation, "to restore an individual to his/her former functional and environmental status, or, alternatively, to maintain or maximize function," should be at the heart of all of aging persons in order to help them continue to live as full a life as possible. (p. xiii)

Economic and Social Costs

While substantial resources are expended upon the elderly, it is not clear whether policy decisions are encouraging a wise use of scarce resources. The costs of

caring for the elderly, for example, are becoming astronomical. A recent report by the Population Reference Bureau (1984), Death and Taxes: The Public Policy of Living Longer, notes that one-fourth of the total federal budget is currently spent on individuals 65 and older. Furthermore, the study projects that by the year 2025, perhaps 50% of the federal budget will be expended on older people (Population Reference Bureau, 1984). While the cost of nursing home care ranges from $15,000 to $24,000 annually for an older person, all of these figures do not account for the impact of aging and disability upon larger social issues, including health care financing, the family, and social support systems.

Other social issues and conflicting public policies only exacerbate the plight of older disabled people. Older women comprise the fastest growing poverty group in this country, and they are twice as likely to experience poverty as their male counterparts. In 1978, one woman in six over age 65 lived in poverty. Warlich (1983) concluded, "Indeed, poverty statistics suggest that for a woman not to ponder her future economic circumstances with caution, and in some cases despair, is to defy the hard facts of economic reality" (p. 35). Elderly persons who are minorities and those who live in rural areas face additional obstacles (Browne, 1983).

The aging network and the public policy that created the Older Americans Act (P. L. 89-73, 1965) have largely overlooked the rehabilitation needs of older disabled people. The most popular and visible program funded by this federal aging legislation is the Title III nutrition program. While this program retains its popularity and worth because of its health and social implications, those older disabled people who have severe mobility problems (about 20% of the older population) may often be excluded (NCHS, 1982). The companion program--home delivered meals--while often worthwhile, may by contrast reinforce dependency. There is, even in this network, an implicit lack of recognition of the rehabilitation potential of the elderly (Myers, 1985).

The rehabilitation model, particularly geriatric rehabilitation, is concerned with quality of life, and this goal is often equated with the achievement of optimum self care. Williams (1984) noted correctly and wisely,

> Another major consideration in the rehabilitative approach to elderly persons is the importance of what may seem to be small gains in function. Such "small gains" can make all the difference between being able to live in one's own home and requiring care in a long term care institution. (p. xiii)

Williams further cites the example of maintaining the individual's ability to transfer from bed to chair to wheelchair or commode. This level of independence would

permit one to carry out most of life's activities. The scale tips both ways, however, and while small gains allow for independence, small losses, over time, create dependence. Granger (1986) underscored this issue when he observed, "It's not bricks but feathers that make all the difference" (p. 99).

Cost-Benefit Analysis Issues

Although the legislative history reveals considerable progress, the elderly continue to be served by a hodge podge of programs and entitlements. No public policy has evolved, and in fact, policies are inconsistent and often create strong disincentives for the elderly disabled individual. For example, while vast resources are expended upon long term care, little is spent on rehabilitative services that might avoid institutionalization. Although the language of national policy appears to suggest that the elderly and handicapped are treated equally in federal legislation, that is simply not true. The elderly disabled do not receive their fair share of recognition or service in terms of rehabilitative interventions (Myers, 1985). And Davis and Onyemelukwe (1977) concluded: "The impaired elderly are used by advocacy groups to convince law makers to approve funds, but in the final slicing of the cake the special

needs of the handicapped elderly are not properly addressed" (p. 449).

Older people comprise over 75 % of the visually impaired population; yet the elderly receive only about 10% of rehabilitation services. Virtually all the rehabilitation services provided to younger visually impaired people have been supported by the state-federal vocational rehabilitation program. Until 1985 no federal appropriations were made to provide specifically for rehabilitation services for the older blind. Cost-benefit arguments that favor greater support for younger people have historically been used to argue for continued funding for vocational rehabilitation programs (E. Berkowitz, 1985). M. Berkowitz and E. Berkowitz (1983) observed,

> Soon after the passage of the Vocational Rehabilitation Act in 1920, its advocates used the rhetoric and logic that lie behind benefit-cost analysis to justify the program's existence. They wanted to show that the taxpayers' money was being put to good use, or better yet, that the program would return more than it took from federal and state funds. The federal coordinating council for the vocational rehabilitation program stated the matter bluntly. "The justification of vocational rehabilitation is based on its economic returns to society. It is primarily economic." (p. 2)

Advocates of vocational rehabilitation pushed the concept of benefit-cost analysis to the limits. In the 1920s, the director of the Wisconsin VR program figured costs ($11,659.36) and benefits ($1,722,419.76) to the penny;

yet Conley (1965) remained troubled because of the imprecise quality of the economic research. He wrote,

> There has been an amazingly wide variability in published benefit-cost ratios for the Vocational Rehabilitation Program. Most estimates have ranged between 6 and 35--all favorable. The annoying variability is largely the consequence of crude and speculative data, especially with regard to mortality, job retention rates, future earnings, and what would have happened without rehabilitation; the use of different discount rates; and the use of different cost concepts. All computed benefit-cost ratios are based upon incomplete measures of benefits (most measure only the increase in earnings). All benefit-cost studies had methodological deficiencies in calculation of costs and benefits which seriously distorted the results. (p. 99)

A study published by Rehabilitation International, The Economics of Disability: International Perspectives, takes a global point of view as its authors, Hammerman and Maikowski (1981), wrestle with complex issues of public social policy and economics:

> Social scientists and economists have succeeded in developing certain indices of social phenomena. In general these measures are limited by methodologies which reduce the phenomenon analyzed in at least two dimensions: the "social" phenomenon is isolated in time, and is studied without reference to the processes by which it came to appear; the "social" phenomenon is limited in space, and seen as a self-contained entity separated from the "economic" sphere; it is not linked to the organization of production. As a result, indices produce compartmentalized descriptions which do not always take into account the linkages between different aspects of social reality. Multiple dependencies exist between the system of production, the social system, and the cultural system. It is known that social measurement systems must take into account these multiple dependencies if they are to predict cor-

> rectly the effects and implications of particular social policies. In other words, the social must include the economic. As yet, models of social and economic accounts systems which recognize this integral relationship do not exist. The analysis of problems in which economic and social factors are very closely linked thus becomes extremely difficult, and, quite obviously, the rehabilitation of disabled people is one problem involving such close linkages. (p. 102)

Intense debate has evolved in public policy discussions as economists, rehabilitation researchers, and advocates have attempted to come to terms with defining both monetary and nonmonetary benefits measuring rehabilitation and social gain. Clearly, economists are uncertain about their ability to create adequate models because of the troublesome issues of measuring monetary and nonmonetary costs and benefits, as well as a grave uncertainty about calculating an appropriate discount rate to evaluate the stream of benefits and costs (E. Berkowitz, 1985).

Debate is even more heated with regard to the emerging issue of independent living that has evolved since the passage of the Title VII amendments to the Rehabilitation Act of 1978 (P. L. 93-112, 1973). The independent living movement champions the rights of disabled people to be self-directive in creating choices and alternatives for economic and social independence. Doyle and Rice (1976) have defined this movement by writing,

> Independent Living Rehabilitation has as its ultimate objective, the ability of severely

> handicapped people to determine their own destinies, to participate in all aspects of society, and to contribute, as well as share responsibility, in community life. . . . [It] may be defined as control over one's life based on the choice of available options that minimize reliance on others in making decisions and in performing everyday activities. (p. 69)

Cost benefit arguments have, by and large, not been used to justify programs for people who are older and blind (Gross, 1979). Available data, however, suggest the potential to develop cost benefit models. The prevalence of vision impairment among nursing home residents is clearly higher than that of the general older population, and as one would expect, residents of nursing homes are older and experience greater disabling conditions than the general older population (Kirchner & Peterson, 1980b; NCHS, 1987). A 1976 Michigan Office of Services to the Aging (OSA) study notes that 26% of the elderly residing in institutions received only personal care services, and an additional 12.7% received neither personal care nor professional nursing care. In other words, 38.7% of the elderly in institutions are receiving more expensive and more extensive services than required (Alternatives to Institutionalization, 1976).

These figures become more alarming when one recalls that 48.3% of nursing home residents experience some degree of visual limitation (U. S. Bureau of the Census, 1978); one would suspect that these two groups would

merge to some extent. The OSA study concludes, however,

> This is a strong indication that the national long term care effort is misdirected. . . . The reasons for this misdirection are many. The health care system has always been "acute problem" oriented, and little emphasis or attention has been placed on the management of chronic diseases. Groups supporting the need for higher appropriations for institutions are more organized politically to fight for their interests than have alternative service advocates, when federal health care dollars are being appropriated (Alternatives, 1976, p.10).

Often rehabilitation models support the concept of a continuum of support services that encourages disabled people to live as independently as possible and thereby avoid institutionalization. A study at the Benjamin Rose Institute in Cleveland measured the effect of home health aides upon quality of life; the study found that people receiving services in their homes had more favorable perceptions of life satisfaction, and moreover, they spent only one-seventh as much time in institutions over a one-year period as did a control group (Nielson, Blemhner, Bloom, Downs, & Beggs, 1972).

The Michigan Department of Social Services (DSS) has made a strong commitment to the concept of Adult Home Help, a service funded though Title XIX, Medicaid funds (Social Security Act, 1935, as amended). A 1982 DSS report reveals that 19.3% of the Adult Home Help caseload was comprised of older visually impaired persons; the total Medicaid outlay for this population, 3,060 people,

exceeded $7,300,000. Adult Home Help pays for chore providers to perform tasks to sustain an older disabled person at home; by contrast a rehabilitation service would encourage an individual to learn strategies to performs those tasks by themselves. Although Adult Home Help funds in all probability are often well spent because older visually impaired individuals are able to remain at home, no one knows whether appropriate rehabilitation services could reduce these costs.

Of greater concern, however, is the cost of institutional care and the issues raised by the Michigan Office of Services to the Aging study (Alternatives to Institutionalization, 1976). The cost for nursing home care in this country ranges between $15,000 and $24,000 annually. If 15.9% of nursing home residents are severely visually impaired, then this figure in Michigan would account for 8,873 people at an annual cost of at least $159,700,000. Nationally, of the 1,550,100 people residing in nursing homes, severe vision impairment would account for 246,465 people at an annual cost of at least $4.9 billion (Crews, 1987b). While these figures appear startling, projecting these costs into the future suggests even more staggering costs.

Public policy has not seriously addressed issues of aging and severe vision impairment because the prevalence of vision impairment is a rather low incidence condition,

and advocates of older visually impaired people are largely unorganized and therefore ineffective. By contrast, recent strides in treatment of Alzheimer's disease illustrate how public policy decisions have changed rapidly to respond to public demands. Not so many years ago, no one had even heard of Alzheimer's disease, although people were aware of "senile" old people who were institutionalized. Attention to Alzheimer's today has created a high degree of public awareness; yet Alzheimer's affects about 3 million people, not many more than those who experience severe vision impairment. While Medicaid, Medicare, and private insurance carriers continue to treat Alzheimer's as a mental rather then a physical disorder, and therefore base their payments on mental health reimbursement schedules, comparatively large resources are being directed toward research--about $36 million in 1986. The treatment, too, is beginning to reflect a rehabilitation approach (Reifler & Teri, 1986). Most attention has focused upon family members, especially in providing emotional and physical support as the abilities of the Alzheimer's patient decline (Mace & Rabins, 1981). In recent years, however, a rehabilitation approach to serving Alzheimer's patients has experienced some success.

The current policy of ignoring the rehabilitation needs of the older visually impaired person clearly has

great economic implications. Moreover, while visually impaired older people are institutionalized at 4 times the rate of nonvisually-impaired older people, no study has ever examined the degree to which vision impairment is a risk factor which directly leads to institutionalization. While no one would reasonably argue that all older blind people could avoid institutional care, even a 1% or 2% delay for only 1 or 2 years could have a significant impact upon the $4.9 billion annual outlay that this country is already experiencing as it struggles to pay its nursing home bill.

Granger (1986) noted the logical linkages between economic costs and social benefits; he wrote,

> Although rehabilitation is expensive, it is often the most cost-effective method of reducing the burden of care that results from disability. Rehabilitation is a necessary part of social policy if we are to maintain as many elderly as possible at home with family members or within appropriate community settings in preference to custodial institutional placement. (p. 33)

Impact on the Family

In a 1985 article, Horowitz (1985a) observed,

> Over the past several years we have witnessed an explosion of professional and scholarly interest in the family relationships of older people and the implications of these relationships for both the care of the frail elderly and the well being of their caregiving families (p. 194).

As the body of literature has expanded, myths and stereotypes have dissipated, and clinical and theoretical attention have shifted to more complex and elusive issues.

Scholarly concern has focused especially on the frail elderly, those often characterized as being over the age of 75. However, just as the clinical definition of blindness does not predict disablement, age does not predict frailty. Horowitz defined frailty as a time when "the conditions under which reciprocal family exchanges begin to shift and the move is made into a caregiving relationship" (p. 195).

While relationships may shift, most older people remain a part of family networks. Over 50% of the elderly are married. Nearly three-quarters share a household with another family member; 80% have at least one living child, and over 75% have siblings. Only 3% of the noninstitutionalized elderly are kinless (Cicirelli, 1983; Shanas, 1979a, 1979b). Shanas (1979a) observed that 84% of older people with living children have an adult child living within an hour's travel time, and while intergenerational families often do not choose to live with one another, they usually do prefer to live near each other (E. M. Brody & Lang, 1982; Sussman, 1977). Half of all older people see their children daily, and nearly three-fourths see a child at least once

a week. For those who have no children, siblings provide support. Cicirelli (1983) reported that while adult children experience a wide range of attitudes towards parents, most family members generally view the relationship as warm and satisfying. Reciprocal mutual assistance occurs throughout intergenerational relationships, until health or financial status shifts. When health fails, it is the family, not professionals, that typically emerge as caregivers (Shanas, 1979b).

E. M. Brody (1985a) and Shanas (1979a) have observed that the family provides 80% of the caregiving to the elderly disabled, and 80% of individuals requiring caregiving rely upon family members (Gurland, Dean, Gurland, & Cook, 1978). The policy impact of this support becomes apparent as one recognizes that for every person in a nursing home, two equally disabled people reside in the community to some degree dependent upon the family caregiving support system (E. M. Brody, 1985a; Shanas, 1979b). Indeed, it is clear that widowhood, living alone, and childlessness are the most significant predictors of institutionalization (Barney, 1977; Branch & Jette, 1983; Shanas & Sussman, 1981). S. J. Brody (1978) observed, "The presence of the family and its availability as a source of support are salient factors in delaying, if not preventing, institutionalization of the chronically ill older person" (p. 82). Those people,

for example, with family support networks enter nursing homes with much higher levels of impairment than those for whom no family support is available (Barney, 1977; Dunlap, 1980). Indeed, Horowitz (1985a) observed that institutionalization is precipitated not by the older individual's declining health, but by a failure in the support system. She wrote,

> For older people with family, exhaustion of family resources, excessive burden on family members, and change in family circumstances were found to be more often the primary precipitant of nursing home placement than was a change in the older person's health status. (p. 199)

Caregiving appears to follow a clear selection hierarchy. The primary caregiver is the spouse, and if no spouse is available, caregiving falls to the child, primarily the daughter or daughter-in-law. If no children are available, caregiving roles are assumed by other kin--siblings, grandchildren, nieces, or nephews. Rarely do friends or neighbors assume caregiving responsibilities (Silverstone & Horowitz, 1987). In addition, as one might expect, the closeness of the relationship defines the extent of care provided. Spouses provide the most care and in all probability tolerate greater levels of disability (Cantor, 1983; Horowitz, 1985b). Children provide intense care, as well. By contrast, friends and neighbors typically provide only minimal levels of care (Cantor, 1983).

E. M. Brody (1985a) noted that as four generation families become more typical, adult children may find themselves caring for both an aging parent and an aging grandparent. She further noted that children and parents age together, and families are "unrehearsed" for these duties (E. M. Brody, 1986). Current social trends of working women, smaller families, and dispersed families only exacerbate a difficult situation. Those who traditionally assumed caregiving roles are simply too occupied or unavailable to assume caregiving responsibilities. E. M. Brody (1985a) asserted that "competing values and demands" create "emotional and economic costs" as families attempt to preserve independence. The responsibility of caring for a disabled parent upsets family stability and creates conflict and tension as decisions are made about caregiving duties or financial obligations. Just when many adults expect to enjoy the rewards of middle age, multiple competing demands are placed upon family members. Tensions arise among adult children regarding appropriate responses to parental needs, and demands on adult children increase just as their capacity decreases (E. M. Brody, 1985a; S. J. Brody, 1978; Horowitz, 1985a; Shanas, 1979b). E. M. Brody (1985b) concluded,

> Demands for parent care, then, occur at a time of life when the adult children on whom the old depend themselves may be experiencing age-related interpersonal losses, the onset of chronic ailments, lower energy levels, and even retirement. Their responsibilities often ex-

> tend both upward to the old and downward to the young. (p. 189)

Emotional stress and physical exhaustion often result from the constant concern given to the older disabled person's health and safety, as well as the necessity to redefine roles and relationships. Emotional strains are characterized by lack of personal time, restrictions in preferred activities, such as vacations, and forced rearrangements of work schedules. Moreover, the male spouse may find himself in an unfamiliar nurturing role, or the female spouse may be forced to become the "buffer" between home and society. Children, likewise, experience the stresses of caregiving roles.

E. M. Brody (1981, 1985a) has written of the "women-in-the-middle" to characterize the role of adult women attempting to care for a disabled parent while trying to continue with work activities and the role of spouse and parent. Indeed, it may be that the caregiving roles of the female spouse and daughters often force women out of the workforce (Cantor, 1983). Yet, Cantor (1983) found that most women continue to work and care for their nuclear families as well as their disabled parents or spouse. Rather than relinquishing these responsibilities, E. M. Brody (1985b) observed they sacrifice "their own free time, opportunities to relax, socialization,

recreation, and the like" (p. 191). E. M. Brody concluded,

> Middle-aged women, then, may not only be experiencing their own age-related problems, but their responsibilities may peak rather than diminish at this stage in their lives. Their traditional roles as wives, homemakers, parents, and grandparents have been augmented to an extent greater than ever before by the role of caregiver to an elderly person. Many such women now have the additional role as paid worker in the labor force (some because of career commitment, but most because the money is needed). Sixty percent of women between the ages of 45 and 54 work, and an even more surprising, 42% of women between 55 and 64 are in the workforce. (p. 192)

Horowitz's (1985a) survey of the caregiving literature reveals that the family provides support in four areas: emotional support (social interaction and "cheering up"), direct service provision (shopping, transportation, meal preparation, and personal care), mediation with organizations (serving as a buffer to bureaucracies), and financial assistance. Given these multiple roles of the family, Horowitz (1985a) and E. M. Brody (1985b) asserted the necessity for families and service providers to work together to serve both the older disabled person and relieve caregiver stress. Horowitz observed that contrary to popular belief, community support systems do not substantially reduce the level of family caregiving. Rather, formal support systems often reduce stress or provide respite. Horowitz drew five

conclusions about family support that serve to guide policy decisions:

> First, we know that having the family available not only reduces the probability of institutionalization but also reduces the probability of utilizing formal services in the community. Second, when formal services are used, the family continues to provide the major portion of care. Third, higher levels of formal service utilization tend to be associated with higher levels of family care, suggesting that it is the very impaired elderly who are receiving extensive assistance from both sectors. Fourth, when family caregivers do approach formal service providers, they tend to be very selective and modest in their service requests, often requesting far less than professionals would have recommended. Fifth, the types of services families report as most needed and desirable typically represent some form of respite from the ongoing responsibility of care. (p. 224)

The Dilemma of Measuring Success

Service models make assumptions about the person served: vocational rehabilitation demands work as an outcome; the medical model defines success in terms of healing; and the aging network defines itself by caregiving. Additional questionable assumptions are often made by equating disease or physical impairment with functional ability. One does not have to look far to find an example; a person experiencing a heart attack may often draw unfounded conclusions about the period of recovery, stamina, and appropriate range of activities. Conclusions may be drawn from personal experience or anec-

dotal information. The chances of all one's assumptions being correct are, indeed, remote. Moreover, the medical model, which depends heavily upon accurate diagnosis, often becomes inadequate, especially if the diagnosis is one in which medical or surgical intervention appears unproductive or inappropriate. A good example is Alzheimer's Disease. A diagnosis of Alzheimer's for many suggests that nothing more can be done. A medical model of illness ends with disease and does not adequately account for the consequences of disease. It is becoming increasingly clear that knowing the etiology is not enough. The language further complicates the situation; the words "handicapped," "disabled," "impaired," and sometimes "crippled" are used synonymously. Attention of the most forward thinkers in the rehabilitation community has consequently turned toward creating a unifying conceptual framework for understanding the role of assessment of functional ability.

Additional frustration evolves around the problem of developing functional assessment tools in the rehabilitation community because there is little agreement over rehabilitation goals and outcomes. Different disabilities as well as specific disciplines tend to focus on narrow functional concerns, often to the exclusion of others. In addition, data are collected so haphazardly that practitioners and policy makers alike are unable to

aggregate data (Frey, 1984; Wood & Badley, 1980). Problems of functional assessment are compounded by the conflict that often arises between the medical treatment (curative) model and the rehabilitation model (Granger, 1986). Moreover, confusion occurs because there often appears to be little relationship between conducting functional assessment and delivering rehabilitation services. Granger (1986) noted the theoretical and practical utility of accurate assessment:

> Functional assessment, as a means of determining service needs, can provide a suitable conceptual framework by providing a common understanding of functional capacity and overall well-being. The conceptualization of functional status and services into standardized components provides a basis for identifying, with some precision, the ways that clients present problems. (p. 32)

Fuhrer (1987) defined rehabilitation outcome "as changes produced by rehabilitation services in the lives of service recipients and their environment" (p. 4), and he goes on to argue that rehabilitation outcome studies become "equivocal" (p. 4) because,

> First, we know relatively little about <u>how</u> our interventions produce changes in service recipients. Therefore, we are unable to argue cogently why a given change should have been observed. Second, a multiplicity of factors can produce changes that are observed. (p. 4)

Fuhrer's (1987) review of rehabilitation outcome studies led him to conclude that there are four "purposes" of rehabilitation outcome studies and two "types."

This two dimensional discussion is useful. Fuhrer observed that the first purpose of evaluation focuses upon management studies that evaluate the need for programs and then monitoring for results in terms of conforming to established program goals. He noted, "In all of these instances, evaluation activities are intended to be at the service of management decision making of one kind or another" (p. 4). The second purpose of evaluation includes quality assurance-oriented studies. These "procedures are designed to identify and correct deficiencies in the appropriateness and adequacy of client services" (p. 5). The third purpose is to contribute to the body of theory and knowledge of rehabilitation. Fuhrer observed, for example,

> Many discipline-oriented outcome studies conform to a research model comprised of five classes of variables pertaining to: (1) service recipients, (2) service recipients' environment, (3) rehabilitation interventions, (4) time, and (5) observed results. Service recipient variables may pertain to the types and severity of impairments, disabilities, or handicaps as well as age, economic status, educational attainment, or intelligence. Environmental factors may include degree of family support, ethnic background, availability of transportation, or status of the local economy. Rehabilitation interventions deal with the nature and intensity of the service provided. Time, a frequently overlooked consideration, may involve a variety of different intervals. A good deal of current rehabilitation research is devoted to understanding how results are influenced by varying an intervention and holding constant the other classes of variables. Other research holds constant the service being provided and attempts to learn how

> outcomes can be predicted by characteristics in the environment. (p. 5)

The fourth purpose of outcome studies includes examination of rehabilitation policy. Fuhrer notes that policy research generally emerges from funding organizations, and the research must be timely in order to assist in policy decision making.

Blum (1974) and later Wood and Badley (1980) reaffirmed Fuhrer's (1987) hierarchy. Blum, for example, expanded the hierarchical considerations by considering the philosophical and ethical domains of evaluation. It does not matter how effective a program is; if society does not support it, lower levels of evaluation, in fact, are no longer of importance.

In addition to his four purposes, Fuhrer (1987) identified two types of "outcome analysis"--effectiveness and efficiency:

> A program is effective to the extent that its performance is congruent with expectations. Efficiency is concerned with the relationship between an intervention's inputs and outputs. It involves consideration, therefore, of the intervention's effectiveness with respect to the resources consumed by it. (p. 6)

In addition, Fuhrer (1987) asserted there is a general lack of theory behind functional assessment and outcome measurement. He observed that,

> References to theory are lacking in most studies of rehabilitation outcomes. As much as anything else, this omission reflects unavailability of well elaborated theories of rehabilitation and disablement. The paucity of theory

> makes it difficult to organize knowledge in the fields of rehabilitation into a coherent framework. Another result is inability to arrive deductively at well-formed hypotheses regarding new, potentially effective interventions. Consequently, the development of new treatment methods becomes a matter of trial and error based upon informed speculation. Relationships among problems encountered during service provision are not made explicit, so attempted solutions tend to be piecemeal. (p. 13)

Frey (1984) addressed the conceptual model of functional assessment in an historical context, and he asserted, "The inherent complexity of rehabilitation is itself mirrored in the complexity of assessment issues" (p. 11). He observed that the goal of rehabilitation is "a process of integrating persons with physical or mental impairments into the community life" that "assist[s] these individuals in obtaining those roles, rights, and responsibilities that define life in the surrounding community." The goal of assessment "refers to a dynamic process of determining the quantitative and qualitative needs of the client" that defines service plans and establishes "baseline information required for evaluating client progress and service effectiveness" (p. 12).

Frey (1984) acknowledged environmental and social changes that led to shifts in assessment practices, and he identified three historical periods defining policy concerns: 1920-1940, 1940-1960, and 1960-1983. The period 1920-1940 was marked by an interest in assessment to measure loss of function in order to respond to

emerging worker's compensation laws; this period resulted in an effort to clarify the distinction between anatomical loss and functional ability.

The second period, 1940-1960, marked a shift toward "teaching the impaired person to use and adapt residual capacities to reach maximum vocational potential, and to get the most out of life as possible" (p. 18). Frey (1984) continued,

> Development of the role of assessment during this period was affected by three general factors: (1) the emergence of a holistic philosophy in rehabilitation, (2) an increase in the number of impaired people in the general population and (3) legislative changes that extended the scope and content of rehabilitation services. No longer were measurements of range of motion and muscle strength sufficient for determining rehabilitation services. (p. 18)

These shifts in philosophy, population, and policy created an environment that challenged service delivery models. Frey asserted,

> Traditional methods of medical diagnosis and classification of disease, and specification of anatomical deficiencies, proved to be of little value in setting up treatment strategies. Hospital charts and medical records did little to explain what a patient could and could not do in his or her surrounding environment. (p. 19)

The third period, 1960-1983 (ending with the publication of his study), constituted an era that demanded accountability. The federal government expanded services to individuals with developmental disabilities and invested heavily in rehabilitation programs. Therefore, the Con-

gress and federal agencies demanded accountability. The concept of assessment expanded to include the individual functioning in the environment. Frey (1984) concluded,

> Information obtained from traditional assessment approaches provided little relevant information relating to outcomes of environmental functioning and adaptation. No longer was the purpose of assessment primarily to yield diagnostic labels. . . . Instead, the purpose of assessment was extended to identify specific client problems that could be ameliorated through training and/or environmental modification. This change in focus led to the development of a type of assessment that has been labeled "behavioral assessment." (p. 24)

Contemporary events continue to influence the role of functional assessment. The independent living movement demands recognition of the disabled individual's control over service provision, and, therefore, requires that functional assessment be both relevant and client centered (Nosek, 1987). Moreover, changes in health care financing may demand new measures of accountability. DeJong (1987) cited changes in medical reimbursement that have evolved with the advent of diagnostic related groups (DRGs), health maintenance organizations (HMOs), and preferred provider organizations (PPOs), and concluded,

> The chill in medical rehabilitation's spine is that, as the health care market shifts to new methods of payment, the effectiveness of medical rehabilitation services will be subjected to greater scrutiny. Herein lies the concern for outcome measurement. (p. 264)

While DeJong's comments are directed toward medical rehabilitation, similar policy shifts may impact upon the

larger domain of vocational and independent living rehabilitation.

Fuhrer's (1987) discussion of outcome analysis reinforces Frey's (1984) observations about current concerns of accountability. Fuhrer observed,

> Rehabilitation outcome studies may have different purposes reflecting the interests of program managers, sponsors of the studies, outcome analysts themselves, or the perceived needs of audiences for which the information is intended. Most of these purposes fall into one of four groupings: (1) contributing to improved management of the program commissioning the study; (2) fulfilling quality assurance requirements of the program; (3) producing a foundation of generalizable knowledge for the rehabilitation discipline, or (4) meeting the needs of policy makers. Although these four purposes are not mutually exclusive, studies reflecting one or the other tend to be different in focus, scope, and resourcing. (p. 4)

Pioneering work to sort out these confusing, often amorphous, issues has been conducted by Wood. In 1980, the World Health Organization (WHO) under the guidance of Wood proposed a classification system, The International Classification of Impairments, Disabilities, and Handicaps (ICIDH), that allowed practitioners to distinguish between diagnosis (and etiology) and functional ability. While Wood's study conducted for the World Health Organization does not represent the first efforts to perform this task (Duckworth, 1984; Nagi, 1965), the work does provide the most comprehensive and systematic classification developed to date.

The WHO conceptual model develped by Wood creates a distinction between disability and disease and the consequence of disease (WHO, 1980; Wood & Badley, 1980). Wood defined four planes of experience in the WHO conceptual model. In the first plane, "A chain of causal circumstances, the 'etiology,' gives rise to changes in the structure or functioning of the body, the 'pathology'"(p.25). If pathological changes make themselves evident, they "are described as 'manifestations', which, in medical parlance, are usually distinguished as 'symptoms and signs'" (p. 25). The following illustration reflects the medical model:

Etiology ---> Pathology ---> Manifestation

At the second plane, an individual becomes aware that he or she is unhealthy, and behavior is affected as "the pathological state is exteriorized" (p. 27). Consequently, "[i]llness heralds recognition of impairments," which Wood (WHO, 1980) defines as "any loss or abnormality of psychological, physiological, or anatomical structure or function" (p. 27).

The third plane of experience occurs since "[the] performance or behavior of the individual may be altered as a result of this awareness, either consequentially or cognitively. Common activities may become restricted, and in this way the experience is objectified" (WHO, p. 26). Disability, therefore, is defined as "any

restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being" (p. 28).

The fourth plane of experience, handicap, occurs as "altered behavior or performance" places "the individual at a disadvantage relative to others, thus socializing the experience. This plane reflects the response of society to the individual's experience" (WHO, p. 26). In Wood's (WHO, 1980) definition, handicap "is a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfillment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual" (p. 29). Thus, the last three planes of experience create a conceptual scheme that defines three levels of concern: the organ, the person, and the society (Granger, 1984). Wood uses the terms "disablement" as a collective descriptor of the planes of experience defined by impairment, disability, and handicap. See Figure 2.

Disease or Disorder (intrinsic situation)	--> Impairment (exteriorized)	--> Disability (objectified)	--> Handicap (socialized)

Figure 2. Planes of Experience in Disablement.

Source: International Classification of Impairments, Disabilities, and Handicaps. Geneva: World Health Organization, 1980. Used with permission of WHO.

Wood observed that this illustration "suggests a simple linear progression along the full sequence": yet, "the situation is much more complex" (p. 30). Disability and handicap may or may not result from impairment. Wood (WHO, 1980) observed,

> Thus one can be impaired without being disabled, and disabled without being handicapped. The corollary of this is that there can be striking disparities in the degree to which the various elements of the sequence depart from their respective norms, and, as a result, one cannot assume consonance in the degrees of disability and handicap. (p. 30)

Some examples will serve to clarify these issues. A person may have diabetic retinopathy (disease) resulting in blindness (impairment) that limits his or her ability to read (disability) that in turn prevents the individual from finding employment (handicap). By way of contrast, Wood (WHO, 1980) presented the example of someone who has red-green color blindness (impairment). The impairment would probably not restrict ability (disability), and would not constitute a handicap unless it prevented him or her from following an occupation.

The illustration below in Figure 3 from Granger and Gresham (1984) helps to clarify these relationships. The Granger and Gresham model becomes especially useful in isolating the disciplines that attend to each area of disablement.

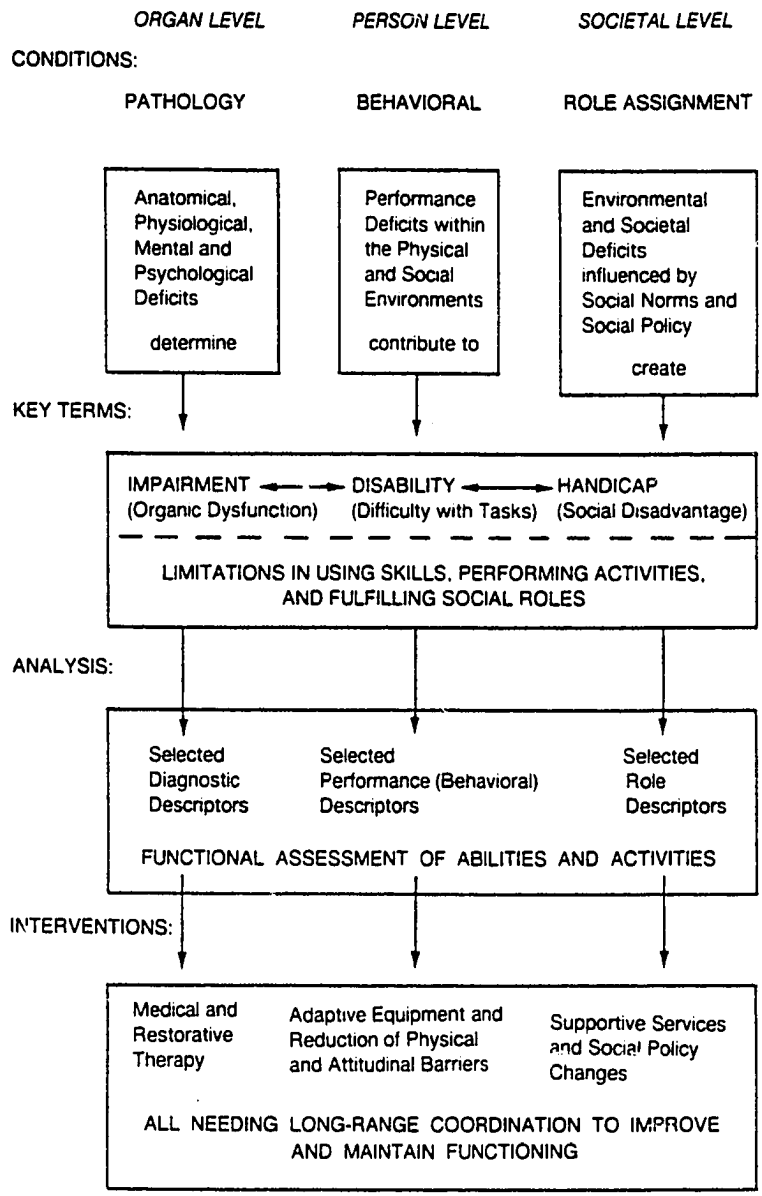

Figure 3. Functional Assessment in Rehabilitation (Granger, 1984).

Source: Granger, C. V. (1984). A conceptual model for functional assessment. In C. V. Granger & G. E. Gresham (Eds.), Functional assessment in rehabilitation medicine. Baltimore: Williams & Wilkins, p. 20.
Used with permission of Williams & Wilkins Publishers.

Although this classification system may appear rather complex, the distinctions among impairment, disability, and handicap become immediately useful in understanding public policy and practical considerations in serving older disabled people. Impairments are traditionally addressed by the medical model and the medical community. Disability is addressed as part of the rehabilitation model, by rehabilitation medicine, vocational rehabilitation, and independent living rehabilitation. Handicap, then, measures, in a broad sense, the success the two have in integrating an individual into the community, and, therefore, is concerned with education, employment, and social policy. Wood's (WHO, 1980) model forces us to move away from drawing conclusions that equate impairment and disability, and this is a clear strength of his conceptual model. Fuhrer (1987) writes,

> The ICIDH affords a promising, albeit partial, foundation for a satisfactory theory of disablement and the rehabilitation process. The constructs of impairment, disability, and handicap are cogently formulated, amenable to operationalization, and potentially comprehensive from the standpoint of rehabilitation program goals. A theory constructed on that conceptual foundation would explain, for example, why there are such prominent individual differences in the severity of disability, despite similar kinds and degrees of impairment. A parallel effort will be required to model essential characteristics of the rehabilitation process as they impact impairment, disability, and handicap. (p. 14)

Just as the ICIDH framework creates distinctions that tend to resolve difficulty in understanding the

relationship between disease and the consequence of disease, the model also serves to define practice and policy issues. Wood and Badley (1980) suggest in an essay following the publication of the ICIDH that a systematic method of collecting data may not be particularly useful to the practitioner serving the patient or client. The feedback system may be sufficiently immediate that progress can be measured. Many practitioners, for example, can readily observe client improvement. The physician determines success as the patient becomes well. The primary value of organizing functional assessment schemes, however, occurs as data begin to be aggregated. Wood and Badley describe a model of the "caring system" illustrated below in Figure 4.

Because "caring professionals" generally serve patients or clients in some kind of organizational framework, the "caring organization" is forced to measure resource utilization by the various bureaucratic means available to it. Often, measures are defined in terms of people served, units of service delivery, or dollars expended. However, Wood and Badley asserted that effectiveness must also be measured by the positive effect of the caregiving organization upon the individual:

> The simplest requirement of a care system is that some beneficial change in the individual's situation or status should result from contact with the system. If no such change can be detected, then the value of a given care process is seriously open to question. The

challenge can be met, therefore, by devising a means of describing the status of the individual in such a way that, by assessing status when contact is first made and then again after the system has responded, change can be recorded. This change would provide a measure of outcome. (p. 82)

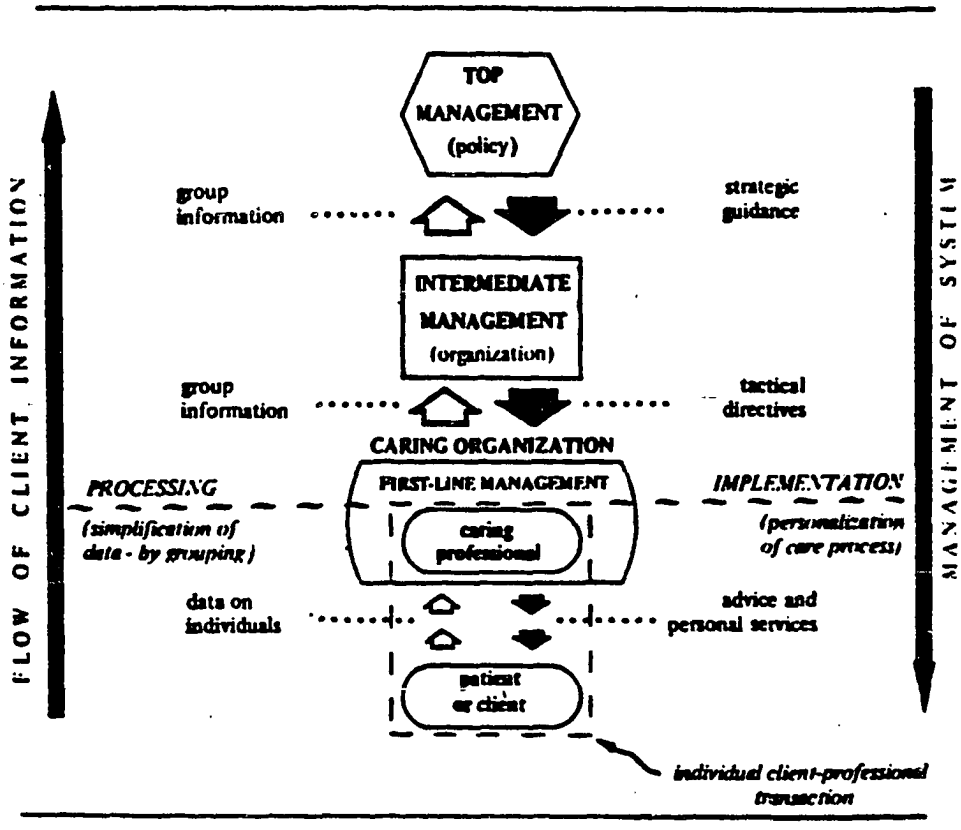

Figure 4. General Model of a Caring System (Wood & Badley, 1980).

Source: Wood, P. H. N. & Badley, E. M. (1980). People with disabilities: Toward acquiring information which reflects more sensitively their problems and needs. National Institute of Handicapped Research, Washington, DC: U. S. Department of Education, p. 71.
Used with permission of the publisher.

Aggregated data can be passed up through the caregiving organization to direct management decisions regarding the effectiveness of serving clients, the efficiency of expending resources, and the focus of policy decisions.

Wood and Badley (1980) do not underestimate the power of the ICIDH scheme as it applies to evaluation. They cited the work of Blum (1974) to define six planes of evaluation. The first three, Wood and Badley asserted, are the ones which generally receive serious attention. The first "plane" reports that an activity is taking place; the second "considers availability of activity to a target population" (p. 82).

While most evaluation activities focus on these two issues, the third plane addresses efficiency to determine the optimum outputs in relation to inputs. Of the fourth plane, Wood and Badley (1980) contended:

> The more telling component of evaluation concerns the problems we have already considered, what happens to the individuals who make up the case load--i.e. have they benefited, or has their status at least been altered in some way by contact with the system? This relates to effectiveness, the extent to which outcome objectives are attained. As Cochran . . . has shown, this is the most important question and yet the one that has been looked at the least. (p. 84)

The fifth plane evaluates the worth of a rehabilitation activity, "the effectiveness of a process" (p. 84). They further argued that samples should be measured at two

different moments in time: "Differences in disablement status could then be related to rehabilitation inputs" (p. 84). Finally, of the sixth plane, they wrote:

> The sixth plane of evaluation considers whether the whole operation actually satisfies societal value judgments. In other words, do the activities of the system accomplish, or are they at least compatible with, societal goals? This plane is evaluated in a totally different way--by the ballot box and by deliberations of controlling agencies such as Congress, for State and Federal systems, and by continued support or otherwise voluntary initiatives. However, although this evaluation is essentially political, information can exert a powerful influence on the process. Much impact can be made by emotive estimates of need, although evidence that the system meets such needs effectively is far more potent (p. 84).

The ICIDH framework becomes an elegant conceptual model to distinguish between disease and the consequences of disease, and it creates a consistency of terminology that sorts out the domains of medical care, rehabilitation, and public policy. It also allows for communication to occur among disciplines. Used in conjunction with other evaluation strategies, the ICIDH allows managers and policy makers to address complex, perplexing issues ranging from measuring outcomes to shaping policy.

Outcome Measures and Rehabilitation of Elders

There is broad disagreement about the function of independent living rehabilitation. For those involved in vocational rehabilitation, a job becomes the measure of

success, and this is the value that has controlled public policy decisions. Services to children have stressed equal access to education in the least restrictive environment, a much broader issue than employment. In recent years disabled veterans and other disability groups have championed the concept of independent living. This issue began by focusing upon barrier free design but has increasingly emphasized the concept of maximizing the individual's control over life choices. However, conceptual models to measure success have not kept pace with the sweeping changes occurring in the role of individuals who are disabled in society.

As a result, an enormous amount of frustration has evolved around the problems of developing assessment tools in the rehabilitation community. There is, for example, little agreement over rehabilitation goals and outcomes, and therefore, different disability professions tend to focus upon relatively narrow concerns to the exclusion of broader issues. For example, blindness evaluation systems may focus upon braille and cane skills and exclude larger issues of social integration. Those concerned with mental retardation may focus upon toileting and self-care skills. Broad theories fail to tie these diverse issues together. In addition, data are collected so haphazardly that practitioners and policy makers are unable to aggregate data (Frey, 1984).

Problems of functional assessment are further compounded by conflicts that arise between the medical model and the rehabilitation model.

As Fuhrer (1987) surveyed these changes in an increasingly complex environment, he observed,

> These and other tensions are resulting in a reexamination of the basic premises of rehabilitation, including its purposes and justifications. Outcome analysis is at the forefront of such concerns because it encompasses the central question of what rehabilitation services ought to achieve for the person receiving them. In turn, that question raises the issue of what rehabilitation actually achieves for the service recipients and how those achievements can be identified and measured. (p. 1)

As noted above, a comprehensive theory of rehabilitation is lacking in terms of service models and outcome evaluation. Therefore, it is difficult to determine which of the broad array of rehabilitation services are most useful and achieve the desired outcomes. That is, it is difficult to measure the effectiveness of a rehabilitation intervention. Wood's (WHO, 1980) theoretical model is useful in resolving these confusing issues. The International Classification of Impairments, Disabilities, and Handicaps (ICIDH) allows practitioners to distinguish between diagnosis (and etiology) and functional ability. Recall that in Wood's model, impairment is the result of disease, injury, or disorder; the model characterizes the problem at the organ level. Disability

generally defines the result of the impairment upon the person, and therefore, disability characterizes an individual's ability to perform tasks. Finally, handicap characterizes the social disadvantage that may result from impairment or disability. Fuhrer (1987) characterized Wood's ICIDH model by asserting, "A theory constructed on that conceptual foundation would explain, for example, why there are such prominent individual differences in the severity of disability, despite similar kinds and degrees of impairment" (p. 13).

A graphic representation may help to illustrate and simplify the complex environment of measuring rehabilitation outcomes among elders who are blind. A traditional "open systems" model is often used in business to characterize the manufacturing process. In this model, raw materials undergo some process that create finished goods. Raw materials (steel, fabric, rubber, and plastic) are the "inputs" to the system. The manufacturing process is the "throughput" that "adds value" to the raw materials and thus more can be charged for them, as, say, steel, fabric, rubber, and plastic are transformed into an automobile. The open systems model is illustrated in Figure 5.

The "value added" quality is central to this concept. Efficiency measures generally relate the costs of inputs to outputs. In rehabilitation, input may be

measured by referrals, and consequently, output is often measured by the number of individuals served or the number of rehabilitations achieved. Efficiency, then, is measured in terms of the cost per individual or per unit served. Organizations strive to reduce the cost per unit of service to increase efficiency. However, the efficiency measures say nothing about the quality of a service or product. One can, for example, manufacture poor quality automobiles very efficiently.

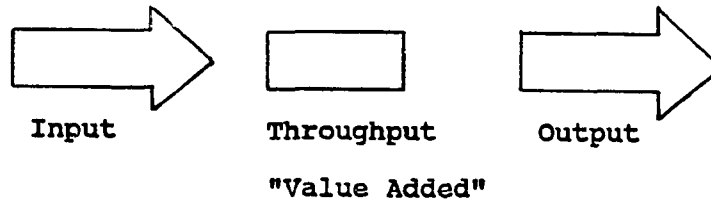

Figure 5. Open Systems Model.

However, by expanding the model, one can illustrate the importance of measuring outcome in addition to output. In order for a rehabilitation program to be "effective" it must result in a positive effect upon the lives of the people it purports to serve. One might ask, for example, can an individual perform more activities after rehabilitation than before? More specifically, can individuals perform activities they want to perform more

successfully after rehabilitation? Measures of units of service, that is, outputs, do not portray effectiveness. Effectiveness addresses the impact of the throughput, that is, the rehabilitation process, on defined outcomes. The concept is portrayed in Figure 6.

In rehabilitation, input is measured by referrals received and budget and manpower resources. Throughput is described in terms of organizational characteristics and types of services. Some examples may be low vision services or family counseling. There are, of course, multiple services and strategies. Output is exhibited in successful rehabilitations and resources consumed. Outcome becomes a key element here to measure rehabilitation gain. The intervention must have a measurable impact upon the lives of service recipients to perform certain tasks.

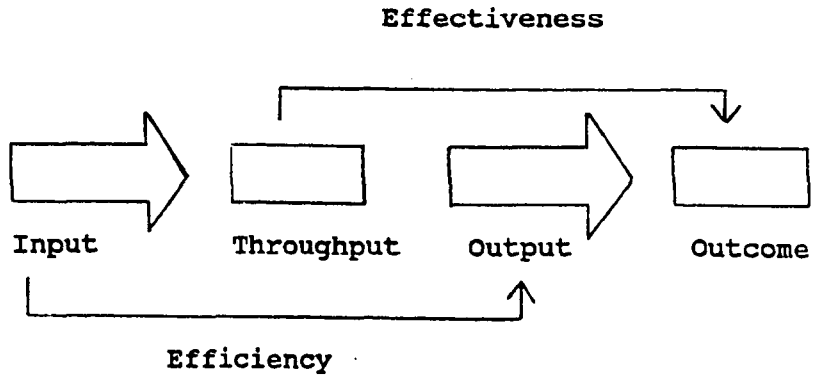

Figure 6. Enriched Open Systems Model.

Most organizations are forced to balance efficiency and effectiveness concerns. For example, the best teaching--the most effective teaching--probably occurs during one-to-one tutorials or very small groups. However, costs become exceedingly high. By contrast, an efficient strategy for teaching would be to have very large numbers of students in one large lecture hall. While this arrangement is efficient, effectiveness is probably compromised. Consequently, in teaching situations, some balance is sought; one attempts to determine the largest number of students that can be taught effectively. This same dilemma occurs as virtually all organizations attempt to conduct their business.

An outcome-based functional assessment gauges the effectiveness of rehabilitation interventions, and these quantitative measures in turn complement existing strategies to determine efficiency. While the importance of quantitative measures need not be argued, it is important that whatever measure is used be sufficiently sensitive to small gains in functional terms.

The dilemma of measuring organizational inputs and outputs is that the practice does not determine whether the individual is better off. People are not machines, and the circumstances of older people are often fluid; determining causality is difficult at best. Nevertheless, this simplified model may help to tease out

relevant issues that measure rehabilitation gain. The intervention must "add value" to the lives of the people it serves.

The discussion above points to the complexity of creating an appropriate model for the rehabilitation of elders. The ICIDH model, for example, emphasizes the dilemma of confusing diagnosis with functional ability, and that model asserts the importance of acknowledging the social dimensions of disablement. Moreover, Frey (1984) argues the goal of rehabilitation focuses upon assisting individuals to obtain the "rights, roles, and responsibilities" (p. 12) that establish one's identity in the larger community. Yet, for older people, disability does not occur as a single, isolated event. It occurs at a time when other demands and events often compete to deny independence. As a consequence, the chain of events that threatens independence may become confusing and perplex efforts to determine cause.

A Model of Rehabilitation and Aging

A number of writers have addressed discrete characteristics of a rehabilitation model for people who are older and experience disability. However, these elements have not led to a robust theoretical frame. Some of the elements of such a model include issues of "active and dependent" life, sustained as well as increased function-

al ability, small gains, and the social implications of disability.

A model of rehabilitation services for older persons must focus both upon the individual, the environment in which he or she may live, and the context of the aging process. Fulton and Katz (1986) help to define the context of aging in their study of "active" and "dependent" life expectancy. For example, they argue that an individual between the ages of 65 and 69 has a life expectancy of 16.5 years. They classify life expectancy into two categories, and they assert that a 65 years old would experience 10 years of "active life" and 6.5 years of "dependent life" (see Table 6). For purposes of this study, Fulton and Katz define "independent" as independent in six activities of daily living, including bathing, dressing, transferring, eating, personal grooming, and walking across a room. "Dependent" is defined as being dependent on another person for at least one of these activities.

This distinction between dependence and independence points to the important roles of rehabilitation among elders. In this context, the goal of rehabilitation is to preserve independence for as long as possible and to mitigate against dependency as much as possible. There is no question that at some point many older people will experience dependency, but if independence can be main-

tained for, say, a full 10 years for a 65 year old, then rehabilitation must be judged successful.

Table 6

Active and Dependent Life Expectancy

Age group	Life expect-ancy	Active life expectancy	Dependent life expectancy	Age begin dependency	Age end dependency
65-69	16.5	10.0	6.5	75.0	81.5
70-74	14.1	8.1	6.0	78.1	84.1
75-79	11.6	6.8	4.8	81.8	86.6
80-84	8.9	4.7	4.2	84.7	88.9
85+	7.3	2.9	4.4	87.9	92.3

Source: Fulton, J. P. & Katz, S. (1986). Characteristics of the disabled elderly and implications for rehabilitation. In S. J. Brody & G. E. Ruff (Eds.), Aging and rehabilitation: Advances in the state of the art. New York: Springer, p. 27.
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S. J. Brody (1986) and Williams (1984) defined the second dimension of an appropriate model of rehabilitation for older people. They acknowledged that sustaining a level of function may be equally important to increasing function. The goal of rehabilitation, S. J. Brody (1986) wrote, is "to achieve maximum physical and mental restoration and/or maintenance of functional

skills for independent living and the prevention of institutionalization" (p. xvii). Maintenance becomes a critical concept. As people age, the cascade of events associated with aging and disability may suggest that maintaining a given functional level is a desirable outcome that sustains quality of life.

A third dimension of rehabilitation has to do with expectations. Williams (1984) wrote of the importance of "small gains," and he cited the example of transferring from wheelchair to bed to commode. He noted that small gains may make the difference between an independent and institutional living arrangement, and he asserted the importance of small gains for increasing an individual's quality of life.

A fourth characteristic of a rehabilitation model for elders must consider the distinction between disability and handicap that the ICIDH proposes. A rehabilitation intervention may be able to successfully address disability issues, and thus increase a person's ability to perform various tasks. Of greater importance, however, may be strategies to reduce handicap. Even if an individual experienced reduced capacity to perform certain tasks, the ability to sustain or increase social integration, that is, issues related to quality of life, may be of greater value to the individual.

A fifth characteristic of a rehabilitation model for older people must be a recognition of the remarkably heterogeneous quality of elders. Their needs and support systems undoubtedly vary considerably. Their resiliency and response to disability may also represent a wide range of human experience. Even the breadth of the age range suggests a wide variety of needs. The condition of being older and disabled does not sufficiently describe or predict the rehabilitation needs of a particular individual.

Kemp (1990) asserts the importance of the psychosocial dimensions of this model. He wrote, for example, "By definition chronic diseases cannot be cured. Success of an intervention, therefore, cannot be measured in terms of physical recovery. Chronic diseases that result in disability must be viewed in terms of helping the individual adapt to a life that is permanently changed" (p. 42). Kemp classified changes in three areas: "These changes include (1) a decrease in daily living skills and social independence, (2) an impact on sources of life satisfaction, and (3) the potential impact a disability has upon self-esteem" (p. 42).

Conclusion

Blindness agencies have been largely unsuccessful in establishing a rehabilitation model for severely visually

impaired older persons as a national public policy. Older severely visually impaired people have been able to achieve a high degree of independence in those situations where rehabilitation efforts have addressed issues of functional independence--most notably communication skills (braille, large print, recording devices), mobility (cane travel, public transportation), activities of daily living (meal preparation, telling time, identifying coins and currency), and low vision (Crews, 1984, 1987a; Gross, 1979; Myers, 1981; Perlman, 1977). These generic rehabilitation issues parallel the rehabilitation model used with stroke patients. Yet, blind rehabilitation is not third party payable by Medicare, Medicaid, or private insurance carriers. Moreover, few units of rehabilitation hospitals address the issues of severe vision impairment. State blindness agencies have traditionally served younger blind people with vocational potential, and state blindness agencies have often been frustrated in their efforts to serve older people utilizing a vocational goal of "homemaker" (Crews, Frey, & Peterson, 1987; Koestler, 1976; Scott, 1969). Congressman Edward Roybal held Congressional hearings in 1985, but only $5 million was appropriated to serve older blind people (Select Committee on Aging, 1985). While the hearings provided a forum, and while the funding was a step in the right direction, these resources are simply

inadequate to meet the need. Private blindness agencies have often served the interests of older people, but their financial resources are traditionally very limited, and they generally serve only metropolitan areas (Koestler, 1976). Since most older blind people are poorer, more disabled, and generally comprised of larger numbers of women (U. S. Bureau of the Census, 1982), larger aging issues of poverty, rural and urban issues, and women's concerns have particular significance for this population. As a result, older blind people have few options.

Because so few rehabilitation options exist, it is no wonder that many older visually impaired and blind people are forced to reside in institutional settings rather than more independent environments. It is no wonder, as well, that older blind people make greater demands on the family than they would like, and that existing social agencies and support systems do not know how to respond to the needs of their older visually impaired constituents.

Clearly, the issues confronting policy makers are both grave and complex. While most older people are enjoying productive, vigorous retirement years, for those who are visually impaired and experience other age-related disabilities, retirement may become a time of desperation. With the general aging of society, the

incidence of aging and blindness will likely become commonplace. These events do not, of course, occur in isolation. Blindness and disability impact upon the family and test its resources and resiliency. Chronic disability tests the methods and disposition of the medical profession geared to generating accurate diagnoses and acute care. Aging and blindness also test the assumptions of service providers and policy makers who, serving this population, must account for resource utilization. Increasingly difficult questions will be asked about assessment and evaluation as hard policy decisions are made. This review of the literature reveals the complexity of the issues before us; it also frames the direction for informed, intelligent decisions that will create opportunities to be responsive as services are designed for this emerging population.

CHAPTER III

METHODS AND PROCEDURES

The Problem

As the literature review demonstrates, very little knowledge exists about the characteristics of older people who are blind. There is, as well, little knowledge about rehabilitation outcomes for older blind people, and there is scant research exploring family concerns among older blind people and their family members. Each of these issues is critical in establishing policies that create appropriate, responsive programs for older people who are blind, and each issue must be better understood before more rigorous research designs can be constructed to assess theoretical and applied issues. This research, therefore, is concerned with establishing a knowledge base about older people who are blind, rehabilitation outcomes, and family concerns that can lead to applied policy formulation and rigorous theoretical inquiry.

Three research questions provide the framework for this study:

1. What are the characteristics of a group of older blind people who seek and receive rehabilitation services?

1A. What are the age, gender, ethnic characteristics, marital status, health concerns, and living arrangements of this group?

1B. What levels of productivity do these individuals report?

2. What are appropriate strategies for measuring rehabilitation gain among older people experiencing severe vision impairment?

2A. What are strategies for presenting rehabilitation gain?

2B. In what areas do elders who are blind demonstrate rehabilitation gain after receiving rehabilitation services?

2C. What impact do gender, health, and living arrangements have upon rehabilitation outcomes?

2D. What impact does the completion of rehabilitation services have upon reported levels of productivity?

3. What are the concerns of spouses and adult children regarding an older family member experiencing blindness?

3A. What are the concerns of spouses and adult children at the beginning of rehabilitation services?

3B. How do the concerns of spouses and adult children change after rehabilitation services?

Not much is known about the social and demographic characteristics of older people experiencing severe vision impairment. The first step in this research, therefore, is to accurately describe the characteristics of a population of older people who have experienced a rehabilitation program. The methodological considerations of describing older people who are blind as well as measuring rehabilitation outcomes and the concerns of the family merge disciplines concerned with aging, blindness, disability, and rehabilitation.

The primary emphasis of this study concerns the development of a body of knowledge as it applies to the rehabilitation of older people who are blind. Moreover, it contains dimensions that allow for program evaluation and policy analysis. In addition, this framework underlines the ambiguous qualities of research addressing the issues of a rehabilitation model for elderly blind individuals. It is, for example, difficult to gauge the impact of rehabilitation, and similarly, it is difficult to measure outcomes with an older population whose health and support systems may be fragile. Any research must recognize the remarkably heterogenous characteristics of an older population group.

In the program under investigation, training in various independent living skills is provided to individuals who are older and blind. In theory, training leads to increased ability to perform tasks (reducing disability); increased skills should lead to more productive activities and social integration (thereby reducing handicap). For example, increased abilities in travel skills should lead to more productivity (through increased skill, confidence, and motivation) as evident in visiting friends or relatives. Likewise, involvement of an older person in a rehabilitation program should reduce family concerns. If, indeed, the family perceives the older blind person to be more independent, the family should be less concerned about such issues as, say, safety. If this happens, then family members' productivity may also increase as, for example, a daughter feels more assured and returns to work or takes vacations.

Subjects

The first two research questions are addressed by data from 112 clients served by the Independent Living Rehabilitation Program of the Michigan Commission for the Blind. Individuals are referred into the program in a wide variety of ways; a referral is most likely to come through the informal network established by consumers of

service. Individuals must be legally blind and over the age of 55 in order to be eligible for service. However, eligible clients may choose not to participate in the rehabilitation program offered to them. In addition, potentially eligible clients may not seek out services from the agency even if they are aware of them. It is important to recognize, therefore, that a self-selection process is involved in obtaining rehabilitation services.

The third research question in this study is addressed by a body of data from 40 family members. This group does not represent a subgroup from the 112 individuals receiving rehabilitation services. Family members may choose whether they will participate in the program, and therefore, represent a second self-selection process. This study, therefore, is only concerned with older people who are legally blind who have completed rehabilitation services, and it only involves family members who express an interest in participating in this rehabilitation program.

While the elderly population as a whole is remarkably heterogeneous, the client pool in recent years has proven to be equally heterogeneous. The average age is almost 77, but the range is from 55 to 103. Two-thirds of the clients are women, and nearly 63% are either unmarried or have no surviving spouse. Their education ranges from 0 to 18 years, with an average of 10 years.

Most experience secondary health conditions that are at least as severe as those of the general older population.

Instrumentation

Five instruments were used in this research to gather information on the characteristics of the sample, measure outcomes, and gauge the concerns of the family: (1) The Survey of Rehabilitation Services (Michigan Department of Labor, 1987b), (2) The Functional Assessment Report (Michigan Department of Labor, 1987a), (3) Family Survey (Michigan Commission for the Blind, n. d.), (4) Family Exit Survey (Michigan Commission for the Blind, n. d.), and (5) Exit Survey for Rehabilitation Services (Michigan Department of Labor, n. d.).

Discussion of Instrumentation

Survey of Rehabilitation Services

The Survey of Rehabilitation Services captures demographic data, including age, gender, ethnic origin, marital status, education, and eye condition (See Appendix A). Moreover, the survey captures information about active pathologies that may or may not be secondary to blindness. The general health section reports current perception of health, the number of days that health has restricted activities, and the number of days of recent

hospitalization. This instrument also notes how the older blind individual ambulates as well as the method of mobility that is employed. Orientation within the home, neighborhood, and community are also reported.

Finally, this survey instrument gathers information regarding 14 measures of productivity. The following items are included: (1) meal preparation, (2) house cleaning, (3) laundry, (4) dishes, (5) food shopping, (6) supervision of children/adults, (7) yardwork, gardening, (8) public entertainment, (9) community center, (10) shopping (other than food), (11) visiting friends and relatives, (12) watch TV/listen to radio, (13) read newspapers/magazines, and (14) have friends or relatives visit.

All of these responses are client self report, and the respondent can indicate frequency in performing each of the activities by selecting one of the following categories: not done, once per week or less, a few times per week, and daily. Given the circumstances of the particular individual, patterns begin to emerge that characterize the person's level of health and general level of productivity. One would expect, for example, that an individual who is younger, healthier, and more productive will have different rehabilitation needs from someone who is considerably older, less healthy, and less productive. By aggregating data from this instrument, it is possible

to describe in some detail the varied characteristics of this population.

The Functional Assessment Report

This evaluation tool is used to gauge functional ability both when an individual begins a rehabilitation program and when that individual concludes training. This device is based on the conceptual model of the International Classification of Impairments, Disabilities, and Handicaps (ICIDH, World Health Organization, 1980). The Functional Assessment Report characterizes disability as it is presented in the ICIDH model. It has emerged as a result of several refinements using the ICIDH protocol. An original instrument was 23 pages long and used the ICIDH severity and outlook scales. It was field tested over a 2 year period. After numerous revisions, this instrument was reduced to a 57 item assessment that uses a two-dimensional measurement scale.

The assessment includes nine items dealing with orientation and mobility, four items concerning personal management, seven tasks associated with eating, four vision tasks, three hearing items, and six communication items. Ten tasks address kitchen skills, eight items concern home management, and three questions address time and money. In addition, one question deals with lifting and bending, another addresses safety (see Appendix B).

The 57 items on the Functional Assessment Report are as follows:

Orientation and Mobility
1. Walk one block/flat surface
2. Uneven terrain/up 20 stairs
3. Standing/sitting, lying position
4. Into/out of bus, public transportation
5. Ride distanced
6. Street crossing
7. Carry small package one block
8. To/from grocery store
9. Locating items while shopping

Personal Management
10. Dressing
11. Finding/organizing bathing items
12. Hygiene tasks
13. Using tub/shower
14. Selecting/matching clothes

Eating
15. Pouring from a pitcher
16. Dishing out food
17. Using cup or glass
18. Cutting meat
19. Buttering bread
20. Salt and peppering
21. Eating tasks

Low Vision
22. Spot reading
23. Continuous reading
24. Distance vision(TV, faces)
25. Distinguishing colors

Hearing
26. Hearing normal speech
27. Hearing during interview
28. Speaking/expressing

Communications
29. Printing/writing
30. Signature
31. Braille
32. Typing
33. Tape recording devices
34. Telephone

Adaptive Kitchen Skills
35. Opening cans/containers
36. Slicing/chopping foods
37. Measuring dry/liquids
38. Mixing, beating, or kneading foods
39. Serving foods
40. Refrigerator/cupboard organization
41. Washing dishes
42. Kitchen cleanup
43. Stove/oven
44. Switches, plugs, faucets, or dials

Home Management
45. Vacuum cleaner
46. Laundry
47. Making beds
48. Cleaning, dusting, polishing
49. Doorlocks, keys, handles
50. Opening/closing doors
51. Sewing
52. Organize home

Time and Money
53. Using clocks/watches
54. Identifying coins
55. Identifying currency

Other
56. Performing lifting, reaching, bending tasks
57. Personal safety

The ability to perform tasks is scored on two dimensions. One set of categories measures how the task is performed, and the second represents how well it is done. The Personal Performance Capacity, for example, essentially measures "how well" a specific task is performed. Five categories classify the performance level: <u>(0) normal</u> (task is performed with satisfactory completion), <u>(1) diminished capacity</u> (task is performed, but satisfactory completion is somewhat affected by problems with speed, pain, or confidence), <u>(2) reduced capacity</u> (task comple-

tion is seriously affected by problems of speed, pain, or confidence), (3) incapacity (task cannot be completed satisfactorily), and (9) no score (unable to obtain reliable rating). The aim of this scale is to create quantifiable measures to record small gains in functional ability. Both normal capacity and incapacity are anchored; the two remaining categories represent incremental levels between these extremes.

By contrast, the Independence Scale represents how a task is performed, and seven categories are presented: (A) alone (task is performed alone), (B) aided (aid or appliance is required for normal completion of task), (C) assisted/dependent performance (human assistance is required), (D) augmented performance (human assistance and aid are required), (E) hired (someone else does task), (F) no desire (no desire to have task done), (G) unable (task is impossible to achieve; assisted or augmented performance has safety or completeness of task concerns).

These two dimensions address fundamental issues related to defining criteria for measuring outcome expectations. Fuhrer (1987) observed that "An outcome study may be impeccably designed and implemented, but fail miserably because the data collected about the program participants are tangential to the outcome expectations of interest" (p. 11). Disappointment can be averted by "developing criteria applicable to each program expecta-

tion" (p. 11). Fuhrer (1987) concluded, "The criteria are such that when they are fulfilled, the outcome expectation is considered to have been accomplished" (p. 11). The criteria raised in the Functional Assessment Report address diminished disability levels resulting from rehabilitation activities.

The scales represented in this assessment protocol are a modified version of the ICIDH severity scale. The ICIDH scale assumes that it is preferable to perform a task alone rather than with an aid. Therefore, the ICIDH assumes a hierarchal progression from alone, to aided, to dependent, to augmented, to unable.

However, this hierarchy raises some important questions regarding the utility of the ICIDH scale especially in light of the impact of technology upon disability. For many blind individuals, the provision of a complex or even a simple adapted aid can increase significantly the speed, confidence, or precision with which a task is performed. For example, a large print telephone dial is a simple aid that may make it possible for a blind person to dial a telephone with relative ease and with normal speed. However, by using the ICIDH scale an individual using such an aid would probably score as less able. The introduction of the two-dimensional scale begins to resolve a critical problem concerning criteria in the ICIDH model.

The evaluation protocol requires that a client be assessed in 57 areas at entry to the rehabilitation system and at exit. The 57 items largely represent skills associated with blind rehabilitation; therefore, some tasks appear specific while others are more generic. For example, a series of four questions address the issue of low vision: (1) spot reading (reading a few letters or a word or two), (2) continuous reading (reading text), (3) distance vision (watching television, recognizing faces, or seeing street signs), and (4) distinguishing colors.

At the beginning of rehabilitation services a person might score 3 C on spot reading. The client cannot perform the task satisfactorily and depends on someone else to read a bill, for example. At exit, a low vision optical aid may have been provided, and if the person is proficient, the score would change to 0 B. The individual reads, say, a label with ease and confidence. While the individual uses an aid, the ability to perform the task increases significantly. The individual improves on the personal performance capacity scale, that is, on the "how well" scale. In this case, the individual "improves" on the Independence scale, as well. Yet, "how" the task is performed, while of importance, is not central, no more than getting to work depends on walking or driving; the aim is to arrive at work on time.

Family Survey

The third instrument used in this study was the Family Survey. The survey addresses two central issues: (1) caregiver's general concerns and (2) the effect of the client's blindness upon the caregiver. After family members complete the survey, it is either mailed back to the office or returned to professional staff.

The following issues are addressed in the Family Survey:

1. Caregiver's concern about client's blindness
   a. safety
   b. transportation
   c. doing house work
   d. preparing meals
   e. depression/anxiety
   f. paying bills
   g. how to spend time

2. Effect of blindness upon the caregiver
   a. knowing when to help
   b. knowing how to help
   c. knowing how much to help
   d. frustration over situation
   e. discomfort in public
   f. having enough time to help client
   g. taking time away from other family
   h. getting other work done
   i. leaving for short periods (6-8 hours)
   j. leaving for long periods (8 hours +)
   k. taking short car trips with client
   l. taking overnight trips with client

Questions in Sections 1 and 2 are scored no concern, some concern, important concern, and critical concern.

The Family Survey also includes series a of questions to characterize the caregiver. Questions include the caregiver's relationship to the client, employment

status, and interest in being involved in the rehabilitation program.

Family Exit Survey

Once rehabilitation services are completed, caregivers are requested to complete a Family Exit Survey (see Appendix D). This survey asks essentially the same questions as the Family Survey, and the same scoring was utilized. The Family Exit Survey is either hand delivered to the caregiver or mailed to the caregiver for completion.

Exit Survey for Rehabilitation Services

The final instrument used in this research was the Exit Survey for Rehabilitation Services (see Appendix E). This instrument has a series of items that parallel the intake survey. The questions about living arrangement, perception of health, and orientation within the home, neighborhood, and community are asked again. The 14 productivity questions in the initial survey are also repeated with the same scoring.

The analysis of these data begins by focusing upon the characteristics of the individuals served in this program. Information about eye conditions and other active pathologies parallel the concern about impairment in the theoretical framework of the International Class-

ification of Impairments, Disabilities, and Handicaps. The entry and exit questions that address ability to perform tasks in the Function Assessment Report are congruent with the issue of disability as presented in the ICIDH. The various productivity measures in the entry and exit survey parallel the concept of Handicap in the ICIDH model. Therefore, in keeping with the ICIDH conceptual approach, this research addresses each issue of impairment, disability, and handicap.

Impairment allows for a characterization of the population. Skills training and other rehabilitation activities should ameliorate disability, and some gain should be evident. Finally, the goal of rehabilitation is not to increase an individual's ability to perform tasks but rather to allow that individual to perform in the various social roles that are important. Therefore, if rehabilitation is to be effective, it should reveal a reduction in handicap.

Disability, as noted above, affects not only the individual, but it also has some impact upon the family and the caregiving support system. A concern of this research is for the caregivers of older blind people. Caregivers of older people, in all probability, can be expected to assume some caregiving role even if blindness does not occur. Here, the issues that concern the family can be related to the role of rehabilitation and the

model proposed by the ICIDH. One would expect that caregiver concerns would be ameliorated as a result of a rehabilitation program, and as a consequence of rehabilitation, caregivers would perceive their family member as less disabled. Again, this gain represents an effectiveness measure.

The matrix in Figure 7 illustrates the relationship of these discrete areas of discussion and the concepts defined by the International Classification of Impairments, Disabilities, and Handicaps. Data elements are collected at each level of this conceptual model.

Level of Discussion	Data Elements	
	Entry	Exit
Impairment		
	Eye condition Active pathologies	
Disability		
	Functional Assessment	Functional Assessment
	Client Productivity	Client Productivity
Handicap		
	Client Productivity	Client Productivity
	Caregiver Concerns	Caregiver Concerns

Figure 7. Research Matrix.

Procedures

Discussion of Instruments and Procedures

The data for this research were gathered during the routine provision of rehabilitation services to 112 older blind people served by the Independent Living Rehabilitation Program of the Michigan Commission for the Blind during the period October, 1988, to December, 1989.

Generally, the rehabilitation cycle requires a period of 12 to 14 months; thus, most of the cases involved in this study were opened after August, 1987.

Survey for Rehabilitation Services

Data for the survey (Michigan Department of Labor, 1987b) were collected by program field staff when an individual was referred for services. Staff are required to have all data, including productivity measures, completed by the time a rehabilitation plan is initiated. If an individual is found ineligible, data on this form may not be complete. A case may be closed as a result of ineligibility because the client may be younger than age 55 or because the individual is not legally blind. The case may also be closed because the person referred to the program is not interested in service. These individuals are excluded from the data base.

Since most referrals are made through an informal network primarily established by service recipients and referrals from low vision providers, it would be hazardous to generalize this sample to the larger population of people who are older and blind. The individuals in this research represent a self-selected sample.

Functional Assessment Report

Entry data for the Functional Assessment Report (Michigan Department of Labor, 1987a) are completed after referral and before rehabilitation services are provided. The Functional Assessment Report is used to determine the rehabilitation needs, and thus the specific rehabilitation program, for each client served in the program. Exit information for the Functional Assessment Report is completed after rehabilitation services are provided, prior to closing the case. All these data are gathered by professional staff as a part of developing a plan and closing a case. The assessment process allows professional staff to gather information by interview or observation.

Family Survey

The Family Survey (Michigan Commission for the Blind, n. d.) is completed by one family member who wishes to participate in a program of services designed to gather

information about family concerns. This individual completes the form prior to the implementation of a rehabilitation program. The Family Exit Survey (Michigan Commission for the Blind, n. d.) is completed at case closure by the same family member. Caregivers complete the form and return it to the Commission. Most people served in this program live by themselves, and consequently, it has proven difficult to identify a large pool of family members. Moreover, it has proven difficult to obtain exit data from those who have completed the initial survey. Only about half of those completing the first form have returned the second. The exact reasons are unknown. The 40 cases in this sample address the third research question in this study and do not represent a subgroup of the 112 cases completing a rehabilitation program discussed in the first two research questions.

No formal program is available for family members. While some may sit in on lessons, there is no discrete programming designed to address the concerns that family members may present. However, family members who reside with the elder who is blind will, in all probability, have a greater understanding of the content and purpose of the rehabilitation program offered to the older person.

Exit Survey for Rehabilitation Services

The Exit Survey (Michigan Department of Labor, n. d.) data is gathered at case closure to capture productivity measures. This information is completed by professional staff from client reports.

Data are collected by professional staff of the Commission for the Blind. All staff have considerable experience, and all possess master's degrees in rehabilitation teaching. No special activities to gather these data were required beyond the routine case management expected in this program. Data are generally collected over a 12 to 14 month period from referral to case closure. Figure 8 represents the series of events occurring during the rehabilitation process.

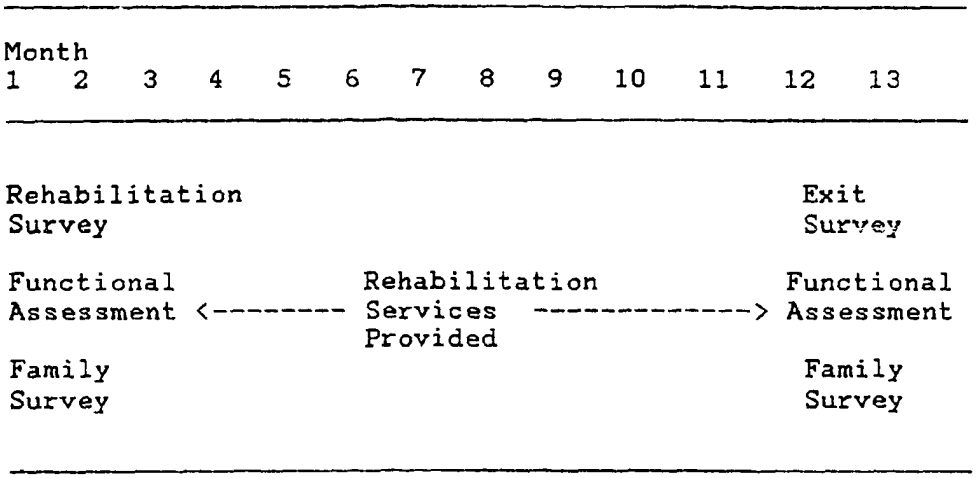

Figure 8. Schedule for Data Collection.

CHAPTER IV

FINDINGS

This chapter is divided into three sections, addressing the three primary concerns of the study. The first portion describes in some detail a population of 112 older blind people who have received various rehabilitation services. The second portion presents findings regarding the rehabilitation outcomes in a variety of areas for these individuals. Finally, the third section characterizes the concerns that a group of spouses and adult children expressed about the blindness that a family member experienced.

Demographic Characteristics

Gender, Age, and Living Arrangement

The first research question concerns the characteristics of 112 older blind people who have received rehabilitation services from the Independent Living Rehabilitation Program of the Michigan Commission for the Blind. This description does not represent the entire population of older people who are blind, just those seeking out and completing services of this rehabilita-

pleted rehabilitation services between October 1988 and December 1989. Specific questions have to do with age, gender, ethnic characteristics, marital status, living arrangement, health concerns, reported health conditions, and reports of productivity measures.

Two-thirds of this population is comprised of women, and the issue of gender becomes an increasingly important variable as men and women are described in this study. Therefore, most of the discussion here displays data by specific gender.

Figure 8 illustrates the age distribution of individuals comprising this study at the time of referral.

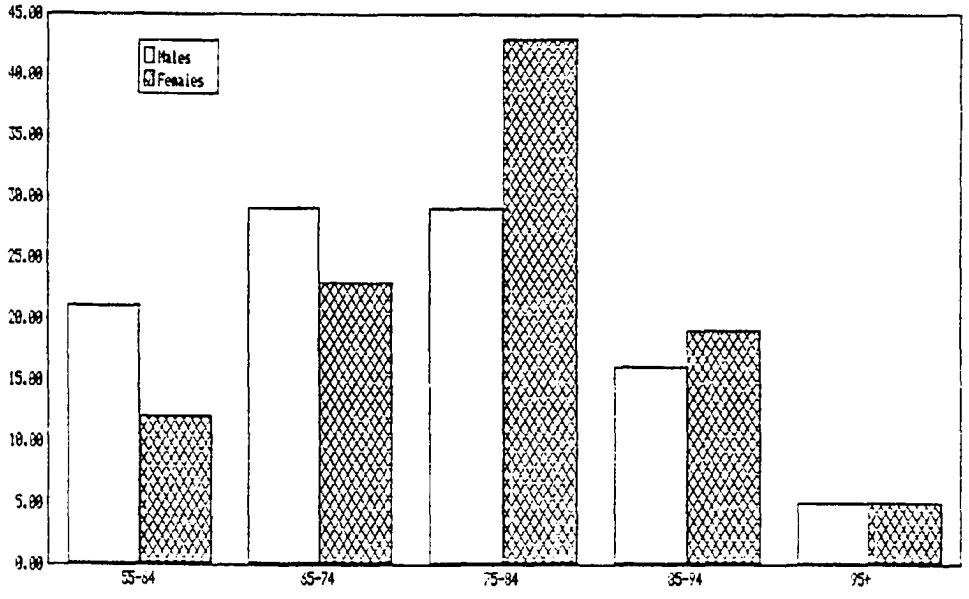

Figure 8. Age Distribution at Entry

The largest percentage of males and females referred for rehabilitation occurs between the years 75-84. The percentage of women is greater in the 75-84 and 85-94 age groups.

Table 7 reveals that the age ranges are similar for males and females; males range in age from 55 to 99, and females have an age range of 55 to 103. Women generally tend to be older; the mean age for men is 74.7, while the mean age for women is 77.4.

Table 7

Age Characteristics in Years of 112 Older Blind People Completing Rehabilitation Services

	Males	Females	Total
Range	55-99	56-103	55-103
Mean	74.69	77.39	76.49
S D	10.83	9.69	10.17

Table 8 reveals that 37.5% of this population were married, and 49.1% were widowed at the time of referral. However, both the conditions of marriage and widowhood are predicted by gender; 50.0% of the men are married, and only 31.1% of the women have a surviving spouse. By contrast, 31.6% of the men are widowed, and 58.1% of the women are widowed.

Table 8

Marital Status

Marital Status	Males		Females		Total	
	n	%	n	%	n	%
Married	19	50.0	23	31.1	42	37.5
Widowed	12	31.6	43	58.1	55	49.1
Separated/ divorced/ never married	7	18.4	8	10.8	15	13.4
Totals	38	100.0	74	100.0	112	100.0

Table 9 displays the ethnic characteristics of this sample of 112 individuals. Overall, 14.3% are black, and 85.7% are white; no other ethnic groups are represented in this sample. Of the men, however, 21.0% are black, and 79.0% are white, but black women comprise 10.8% of females in this sample.

Table 10 indicates that the education of these 112 individuals ranges from 0 to 18 years, and the average level of education for both men and women is 10 years. There are few differences between males and females, although more females completed high school than men. This educational level is similar to the larger population of individuals in this age group.

Table 9

Ethnic Characteristics

Ethnicity	Males		Females		Total	
	n	%	n	%	n	%
White	30	79.0	66	89.2	96	85.7
Black	8	21.0	8	10.8	16	14.3
Totals	38	100.0	74	100.0	112	100.0

Table 10

Education of 112 Individuals Completing Rehabilitation Services

Years	Males		Females		Total	
	n	%	n	%	n	%
0-8	11	28.9	18	24.3	29	25.9
9-11	8	21.0	19	25.7	27	24.1
12	7	18.4	20	27.0	27	24.1
13-15	7	18.4	12	16.2	19	17.0
16+	4	10.5	4	5.4	8	7.1
unrecorded	1	2.6	1	1.4	2	1.8
Totals	38	100.0	74	100.0	112	100.0
Range	0-16		2-18		0-18	
Mean	10		10		10	

From Table 11 it appears that 13.4% of these 112 individuals reside in an institutional setting. Nearly 87% of the individuals in this sample live alone or live with spouse or other family members. Two-fifths (41.9%) of the women live alone as the high incidence of widowhood might suggest; 44.6% of the women live with spouse, family members, or significant others. By contrast, only 23.7% of the men live alone, and 63.2% live with a spouse, family member, or significant other.

Table 11

Living Arrangement

Setting	Male		Female		Total	
	n	%	n	%	n	%
Alone	9	23.7	31	41.9	40	35.7
With spouse, significant other, family	24	63.2	33	44.6	57	50.9
Institution/ foster care	5	13.1	10	13.5	15	13.4
	38	100.0	74	100.0	112	100.0

Over half of this sample live in communities of more than 50,000 people, as a service area focusing upon metropolitan areas would suggest; 22.3% live in geograph-

ical areas with populations between 10,000 and 50,000. The balance (20.5%) reside in communities with a population below 10,000. Males and females demonstrate a similar distribution in each geographical area. These characteristics are displayed in Table 12.

Table 12

Geographical Setting

Community Size	Males		Females		Total	
	n	%	n	%	n	%
Under 10,000	7	18.4	16	21.6	23	20.5
10,000-50,000	10	26.3	15	20.3	25	22.3
50,000+	21	55.3	43	58.1	64	57.2
	38	100.0	74	100.0	112	100.0

Eye Impairments and General Health

Reported eye conditions displayed in Table 13 indicate that over a third of the respondents (33.9%) experience macular degeneration; 12.5% report glaucoma, and 15.2% indicate diabetic retinopathy. Only 2.7% report cataract. Another 18.8% report a combination of these four conditions. In other words, the four conditions of macular degeneration, cataract, diabetic retinopathy, and glaucoma account for 83.1% of the reported eye condi-

tions. The remaining pathologies are scattered among less common eye conditions. Retinitis pigmentosa accounts for 4.4% of the 112 cases, and stroke accounts for only 1.8% of those in this sample.

Table 13

Reported Eye Impairments

Condition	Male		Female		Total	
	n	%	n	%	n	%
Macular degeneration	9	23.7	29	39.2	38	33.9
Diabetic Retinopathy	7	18.4	10	13.5	17	15.2
Glaucoma	10	26.3	4	5.4	14	12.5
Cataract	2	5.3	1	1.4	3	2.7
Combination (glaucoma, diabetic retinopathy, cataract, macular degeneration)	6	15.8	15	20.2	21	18.8
Retinitis pigmentosa	4	10.5	1	1.4	5	4.5
Stroke	0	0.0	2	2.7	2	1.8
Other	0	0.0	11	14.8	11	9.8
Unrecorded	0	0.0	1	1.4	1	.9
	38	100.0	74	100.0	112	100.0

From Table 14 nearly 87% of the sample report the onset of vision impairment after age 60; 42% indicate that vision impairment occurred during their eighth

decade. For the women in this study, 67.6% indicate an onset of vision impairment after age 70, and 47.3% began losing their vision between the ages of 70 and 79. Over 20% indicate that problems with vision began after age 80. Men generally report an onset of vision impairment at a younger age. While 31% of the women indicate vision loss prior to age 70, 45% of the men report vision loss before their eighth decade. Moreover, while 47% of the women report loss of vision in their 70s, only 31% of the men indicate vision loss during that decade.

Table 14

Age at Onset of Vision Impairment

Age Range	Male		Female		Total	
	n	%	n	%	n	%
0-59	6	15.8	9	12.2	15	13.4
60-69	11	28.9	14	18.9	25	22.3
70-79	12	31.6	35	47.3	47	42.0
80+	6	15.8	13	17.6	19	16.9
Unknown	3	7.9	3	4.0	6	5.4
Totals	38	100.0	74	100.0	112	100.0

Over half (52.7%) of the respondents report their health to be "good" or "very good" when services were

initiated (see Table 15). Another 30% report health to be "fair," while 13.4% indicate their general health as "poor." Men and women report generally similar health status.

Table 15

Perception of General Health

Health	Male		Female		Total	
	n	%	n	%	n	%
Poor	5	13.2	10	13.5	15	13.4
Fair	10	26.3	24	32.4	34	30.4
Good/very good	21	55.2	38	51.4	59	52.7
Unknown	2	5.3	2	2.7	4	3.6
	38	100.0	74	100.0	112	100.0

Table 16 indicates that over 65% of the respondents report that during the last three months health has not prevented them from conducting activities that are a part of their normal day. Males and females report similar health status, 68.4% and 63.5%, respectively reporting no days lost to poor health. An additional 9.8% indicate that health has had an effect on daily activities for seven days or less. However, 12.5% report that health has affected the ability to perform daily activities from

8 to 89 days, and 10.7% report that health has affected the ability to perform normal activities every day over a 90 day period. Generally the limitation of activities does not differ between males and females, except for those who report the most limitation; 13.5% of women and 5.3% of men report that health has limited activity every day over the last 90 days. Of the women, half of those reporting the greatest limitation reside in institutional settings.

Table 16

Reported Days Normal Activities Affected by Health

Number of days	Male		Female		Total	
	n	%	n	%	n	%
0	26	68.4	47	63.5	73	65.2
1-7	4	10.5	7	9.5	11	9.8
8-89	5	13.2	9	12.1	14	12.5
90	2	5.3	10	13.5	12	10.7
Unknown	1	2.6	1	1.3	2	1.8
	38	100.0	74	100.0	112	100.0

Table 17 reveals that over 78% indicate that they have not been restricted to bed in the 90 days prior to the time the survey was taken. Another 7.1% report that

they have been restricted to bed less than 9 days during the previous 90 day period. In addition, 1.8% indicate that they have been confined to bed between 10 and 19 days. Only four individuals (3.6%) report bed restriction between 20 and 89 days. However, 7.1% report bed restriction for 90 days during the 90 days prior to inquiry. All of those reporting restriction to bed are women, and half of those reside in institutions.

Table 17

Reported Days Restricted to Bed

Number of days	Male		Female		Total	
	n	%	n	%	n	%
0	29	76.4	59	79.6	88	78.6
1-9	4	10.6	4	5.4	8	7.1
10-19	1	2.7	1	1.4	2	1.8
20-89	3	7.9	1	1.4	4	3.6
90	0	0.0	8	10.8	8	7.1
Unknown	1	2.7	1	1.4	2	1.8
	38	100.0	74	100.0	112	100.0

Another question regarding health has to do with the number of days that individuals have been hospitalized. Each respondent was asked to indicate the number of days

he or she had remained in the hospital as an inpatient. Table 18 shows that 62.5% report that they have not been hospitalized during the preceding year. Nearly 18% report having spent 1 to 9 days in the hospital. In addition, 8.9% report hospitalization of 20 days or more. Men appear to be hospitalized at slightly higher rates than women.

Table 18

Reported Hospital Days During Preceding Year

Number of days	Male		Female		Total	
	n	%	n	%	n	%
0	21	55.2	49	66.2	70	62.5
1-9	8	21.0	12	16.2	20	17.9
10-19	4	10.5	7	9.5	11	9.8
20+	4	10.5	6	8.1	10	8.9
Unknown	1	2.6	0	0.0	1	.9
	38	100.0	74	100.0	112	100.0

Respondents were requested to identify secondary health characteristics. Table 19 shows the report of additional disabilities. Individuals can report as many disabilities as apply to their situation; therefore, the totals exceed 100%. A significant number of age-related

disabilities are reported, and while some conditions appear related to gender, some are not. For example, 60.7% of all respondents report having arthritis; 46.4% of the men and women indicate hypertension, and 37.5% of the total report heart disease. In addition, 32.1% of all respondents indicate hearing impairment, and 5.4% indicate deafness. Over 28% report diabetes, and 9.8% indicate having experienced a stroke. Hearing impairment and deafness show a marked increase among men; in fact, 57.9% of the men report hearing impairment or deafness. Most of these men have lived, it should be recalled, in industrial regions of Michigan. In addition, respiratory diseases appear higher among men. All other disabilities appear to be distributed evenly between men and women. In all cases, these impairments are reported at higher rates than the general aging population. The National Center for Health Statistics reports (see Table 1, page 15) show chronic health conditions to be reported lower rates among the general population of elders. NCHS (Blake, 1984) data show 44.3% as having arthritis as compared to 60.7% of this sample. Diabetes is higher in this sample (28.6%) than in the general population (8.0%). Diabetes, it should be recalled, is a leading cause of blindness. Finally, vision impairment occurs in 11.9% of the aging population, and here 100% experience vision impairment.

Table 19

Reported Secondary Impairments and Diseases

Condition	Males		Females		Total	
	n	%	n	%	n	%
Arthritis	20	52.6	48	64.9	68	60.7
Hypertension	18	47.4	34	45.9	52	46.4
Heart disease	11	28.9	31	41.9	42	37.5
Hearing impairment	17	44.7	19	25.7	36	32.1
Diabetes	10	26.3	22	29.7	32	28.6
Respiratory disease	9	23.7	11	14.9	20	17.9
Kidney disease	4	10.5	10	13.5	14	12.5
Stroke	2	5.2	9	12.2	11	9.8
Cancer	3	7.9	8	10.8	11	9.8
Deafness	5	13.2	1	1.4	6	5.4
Amputation	1	2.6	2	2.7	3	2.7
Epilepsy	1	2.6	1	1.4	2	1.8
Multiple sclerosis	0	0.0	1	1.4	1	.9
Mental Illness	1	2.6	0	0.0	1	.9

Reported secondary impairments and diseases do not predict activity limitation, and given the ubiquitous quality and varied impact of some age-related conditions, such as arthritis and hypertension, it may be difficult

to anticipate the role of a disease in the life of an individual. Arthritis may, for example, range from being an annoyance to being debilitating. Hypertension, if treated, has little impact; untreated, it can be life threatening. Of the 14 reported impairments and diseases, four can be argued as probably being activity limiting conditions: heart disease, cancer, diabetes, and stroke. See Table 20.

Table 20

Activity-Limiting Impairments by Age

Age	1 or more		2 or more	
	n	%	n	%
55-64	11	65	6	35
65-74	10	40	7	28
75-84	23	53	10	23
85+	11	48	2	9
55-85+	55	51	25	23

However, it could also be argued that others should be included on this list. Nevertheless, 51% report having one or more of these four activity limiting impairments or diseases, and 23% report two or more. The youngest age group, those 55-64, report the highest incidence of these four secondary impairments and dis-

eases. Heart disease, cancer, and diabetes are diseases that often limit life expectancy and, therefore, may not be as prevalent among older groups. The prevalence of multiple activity limiting impairments decreases with age. Figure 10, for example, illustrates that older groups report fewer impairments than younger groups.

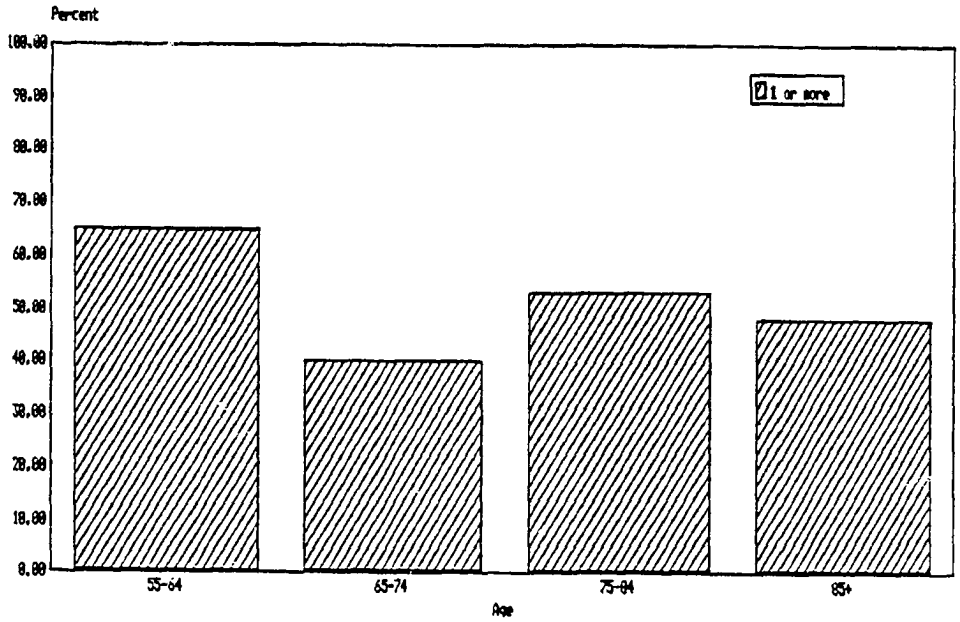

Figure 10. Activity Limiting Impairments.

Measures of Productivity

A series of 14 questions characterizes measures of reported productivity. Table 21 reports levels of productivity in disability area, that is, the ability to perform certain tasks, such as meal preparation, house cleaning, and doing dishes. Table 22 reports levels of

productivity in handicap areas, that is, social integration issues, such as visiting and having visitors.

Of the 14 items, half of the tasks and activities are "not done" by 50% or more of the respondents. For example, 50% of all respondents do not shop for food. Additionally, 51% of the men and women do not do laundry; 53% do not shop for items other than food. Moreover, 54% do not read. Finally, 83% of all respondents do not perform yardwork, and 86% do not supervise others (children or adults).

The completion of household domestic tasks appears to be predicted by gender. Many more women than men continue to wash dishes, do the laundry, and prepare meals on a regular basis than do men; yet, the one task that appears more traditionally a male's activity, yardwork, is not performed by 71% of the men in this sample.

Over 64% of the women prepare meals on a daily basis, while only 29% of the men do so. Likewise, 70% of the women do dishes daily, but only 26% of the men perform that task. As might be expected, men are generally less involved in all domestic tasks. Although men and women shop for food in about the same ratios, 50% of the respondents do not shop for food. Of those individuals surveyed, very few supervise other people (such as children); for example, 86% (including 89% of the women) do not supervise others at all.

Table 21

Reported Levels of Productivity in Disability

	Not done	Once per week	Few times week	Daily	No re-port
Meal Preparation					
Men	53%	5%	11%	29%	3%
Women	26%	7%	4%	64%	0%
Total	35%	6%	6%	52%	1%
House Cleaning					
Men	47%	24%	16%	11%	3%
Women	30%	30%	26%	10%	2%
Total	39%	28%	22%	10%	2%
Laundry					
Men	66%	16%	16%	0%	3%
Women	43%	23%	28%	4%	1%
Total	51%	21%	19%	3%	2%
Food Shopping					
Men	50%	39%	8%	0%	3%
Women	50%	43%	7%	0%	0%
Total	50%	42%	7%	0%	1%
Supervision of Others					
Men	79%	11%	5%	3%	3%
Women	89%	7%	1%	1%	1%
Total	86%	8%	3%	2%	2%
Yardwork					
Men	71%	11%	11%	3%	5%
Women	89%	5%	3%	2%	2%
Total	83%	7%	5%	2%	3%

Table 21--Continued

Task	Not done	Once per week	Few times week	Daily	No report
Dishes					
Men	42%	13%	16%	26%	3%
Women	23%	3%	4%	70%	0%
Total	30%	6%	8%	55%	1%

As a group, these individuals appear to be rather isolated socially, and therefore, the handicap issues do not reveal high social integration. For example, only 46% of the respondents attend a community center or similar activity once or more each week, and 47% shop for items other than food once or more each week. While 11.6% of the respondents do not have visitors, 62.5% have visitors once a week or more. Similarly, 15.2% do not report visiting others, and 53.9% visit others once a week or more. The only activity that presents itself as particularly popular is watching television or listening to radio; 76.8% of the respondents report performing this activity daily. Among the handicap issues reported at entry, there is little difference based on gender.

Table 22

Reported Levels of Productivity in Handicap

	Not done	Once per week	Few times week	Daily	No report
Public Entertainment					
Men	45%	48%	7%	0%	0%
Women	41%	32%	23%	3%	1%
Total	42%	38%	17%	2%	1%
Community Center					
Men	60%	32%	5%	3%	0%
Women	50%	35%	14%	0%	1%
Total	54%	34%	11%	1%	1%
Shopping (not food)					
Men	47%	53%	0%	0%	0%
Women	55%	32%	10%	0%	3%
Total	53%	40%	6%	0%	2%
Watch TV, Listen to Radio					
Men	5%	11%	13%	71%	0%
Women	5%	8%	4%	80%	3%
Total	5%	9%	7%	77%	2%
Reading					
Men	55%	5%	11%	29%	0%
Women	55%	14%	7%	23%	1%
Total	55%	11%	8%	25%	1%
Have Visitors In					
Men	13%	74%	11%	3%	0%
Women	11%	57%	23%	8%	1%
Total	12%	63%	19%	6%	1%

Table 22--Continued

	Not done	Once per week	Few times week	Daily	No report
Visit Others					
Men	21%	61%	16%	3%	0%
Women	26%	50%	19%	4%	1%
Total	24%	54%	18%	4%	1%

Of this sample of 112 individuals, 13.4% (5 men and 10 women) reside in institutional settings. These individuals present a particular set of productivity measures defined by their circumstances. As one might expect, this group is by and large uninvolved with disability tasks associated with maintaining independence. For example, Table 23 shows that no one does laundry or food shopping, and only 7% report meal preparation or doing dishes once or more during the week. Slightly more report activities that are associated with handicap (socialization). For example, 14% report shopping or reading once per week or more, and 29% report attending community center activities. Forty-three percent report visiting others once a week or more, and surprisingly 79% report having visitors at least once a week.

Table 23

Reported Levels of Activity for Men and Women Residing in Institutional Settings

n=15

Task	% not done at entry	% completing task once per week of more
Meal preparation	93%	7%
Housecleaning	87%	13%
Laundry	100%	0%
Food shopping	100%	0%
Supervision of others	100%	0%
Yardwork	100%	0%
Dishes	93%	7%
Public entertainment	79%	21%
Community center	71%	29%
Shopping (not food)	86%	14%
Reading	86%	14%
Visitors	21%	79%
Visit others	57%	43%

The first part of this study represents an analysis of the demographic characteristics of this population of 112 people. The descriptive study reveals that two-thirds of these individuals are women. The average age of all clients is 77, and nearly a quarter are over the

age of 85. Of the women in this study, 69% do not have a surviving spouse, and 41% of the women live alone.

Age-related ocular pathologies account for 87% of the causes of blindness with macular degeneration representing 34% of the total. Eighty-seven percent report an onset of vision impairment after age 60. While 53% report health to be good or very good, secondary impairments and diseases occur at rates higher than the general older population.

The productivity levels that these 112 individuals present clearly demonstrate limitations in both disability (task performance) and handicap (social integration) issues. Of those who are not institutionalized, a significant proportion--half--do not do seven of the 14 productivity items assessed at referral to services. The performance of domestic tasks appears to be related to gender; that is, women continue to perform household tasks more frequently than do their male counterparts. While these older men and women who are blind do not participate in household tasks or social activities, 88% have visitors at least once a week, and 76% visit others at least once during the week. By contrast, those who are institutionalized report little and often no productivity in disability issues and relatively little activity in handicap issues. However, 43% do report visit-

ing others at least once each week, and a surprising 79% report having visitors at least once a week.

Rehabilitation Outcomes

The second research question has to do with measuring rehabilitation outcomes. It asks what are strategies for measuring rehabilitation gain among older people experiencing severe vision impairment? The ICIDH suggests two domains in which outcome gains can be measured. The first domain includes strategies for addressing disability. For example, can a rehabilitation intervention increase or maintain a person's ability to perform certain tasks? The second domain for measuring rehabilitation outcomes addresses the issue of handicap. A rehabilitation program, one would assume, should allow people to exercise more control over their lives and increase or maintain social integration, and this portion of the research is concerned about how those changes can be presented. Four issues are addressed: (1) What are strategies for presenting rehabilitation gain? (2) In what areas do people who are older and blind demonstrate rehabilitation gain? (3) What impact do gender and living arrangement have upon rehabilitation outcome? And (4) what impact does the completion of rehabilitation services have upon reported levels of productivity?

The Functional Assessment Report (Michigan Department of Labor, 1987) is administered to every individual at the beginning of rehabilitation services. This instrument is intended to assess disability (task performance) issues, and all skills are assessed at entry. Based upon the assessment, the rehabilitation professional identifies the particular skills and services that will be addressed during the rehabilitation program. At the conclusion of services, exit data on the Functional Assessment Report are obtained. Only those items are evaluated where training has been provided. If, for example, an individual has received no services with respect to learning cooking skills (measuring, pouring, etc.), those skills will not be assessed at exit. If, by contrast, an individual receives low vision services, then that skill area is also assessed at exit.

The frequency with which items are addressed in the rehabilitation program by clients comprising this study suggests that many items are either of little significance or beyond the scope of the rehabilitation services offered to older individuals who are blind. While it is assumed that the client and professional staff agree upon the services to be provided, this decision may be tempered by the values and priorities of the client, professional, or family members in ways that cannot be determined in this study. See Table 24.

Table 24

Most Frequently Addressed Issues

Rank	Skill	Percent
1	Printing/writing	65
2	Signature	61
3	Pouring	58
4	Clocks/watches	57
5	Identify coins	47
6	Spot vision	44
6	Reading	44
8	Identify currency	41
9	Telephone	38
9	Switches/plugs	38
11	Stove/oven	37
12	Walk one block	26

Of the 57 items potentially addressed on the Functional Assessment Report (see Appendix F), some tasks such as operating a vacuum cleaner, making beds, and cleaning receive little attention. Only 2% of the cases receive training in these areas. By contrast, learning how to write a signature or telling time are addressed over 50% of the time. It must also be assumed that for

many individuals a particular skill is not of interest because the individual functions at an adequate level of independence. The skill of printing/writing is addressed in 65% of rehabilitation programs for this population of 112 people. Identifying coins and currency and using low vision aids to perform spot reading and reading of text is addressed by over 40% of these individuals.

The rank ordering of the 12 most frequently addressed tasks--those attended to at least 25% of the time--appears in Table 24.

Some skills receive very little attention. Table 25, for example, reveals that only 3% of the clients receive training in the use of the vacuum cleaner, and only 4% receive training in the areas of speaking/expressing, making beds, cleaning, opening doors, and organizing the home. Moreover, only 5% address the seven areas of carrying packages, dressing, organizing bath items, personal hygiene, tub/shower, eating, and lifting.

The Functional Assessment Report is designed to address both habilitation and rehabilitation skills. Older people in all probability learned these skills at an early age. For individuals with developmental disabilities, the tasks of bathing, dressing, and eating may be more central to a habilitation program. In the case of this study, the entire sample was over the age of 55, and consequently, those skills would not be expected to

be addressed very often. The completion of some tasks, such as speaking/expressing, opening doors, and perhaps dressing, may be compromised by a stroke, for example, and therefore, those tasks may be addressed in the context of a rehabilitation program. Those relationships are not explored in this analysis.

Table 25

Least Frequently Addressed Issues

Rank	Skill	Percent
57	Vacuum cleaner	3
54	Speaking/expressing	4
54	Making beds	4
54	Cleaning	4
54	Opening doors	4
54	Organizing home	4
48	Carrying packages	5
48	Dressing	5
48	Organizing bath items	5
48	Hygiene	5
48	Tub/shower	5
48	Eating	5
48	Lifting	5

Changes on Capacity Scale

In the case of some skill areas, respondents demonstrate significant gain in ability to perform tasks. They show almost 70% increases in the ability to perform the tasks of spot reading, using the telephone, and printing/writing on the capacity (how well) scale (see Table 26).

Table 26

Greatest Gains on Capacity Scale

Rank	Skill	% normal at entry	% normal at exit	% gain
1	Pouring (n = 65)	28	99	71
2	Spot vision (n = 49)	12	80	68
3	Printing/writing (n = 73)	25	93	68
4	Distance vision (n = 36)	3	70	67
5	Tape recorder (n = 35)	17	83	66
6	Clocks/watches (n = 64)	30	95	65
7	Butter bread (n = 19)	37	100	63
8	Doors/Keys (n = 10)	30	90	60
9	Signature (n = 68)	38	97	59
10	Stove/Oven (n = 41)	27	85	58
11	Sewing (n = 31)	29	81	52
12	Cup/Glass (n = 23)	48	100	52

Other tasks, such as eating and dressing, are performed successfully by almost all individuals at entry; only two could not, and in those two cases capacity was increased to 100% after service. Therefore, in both cases, the scale shows relatively little improvement, but maximum capacity was reached. See Figure 11.

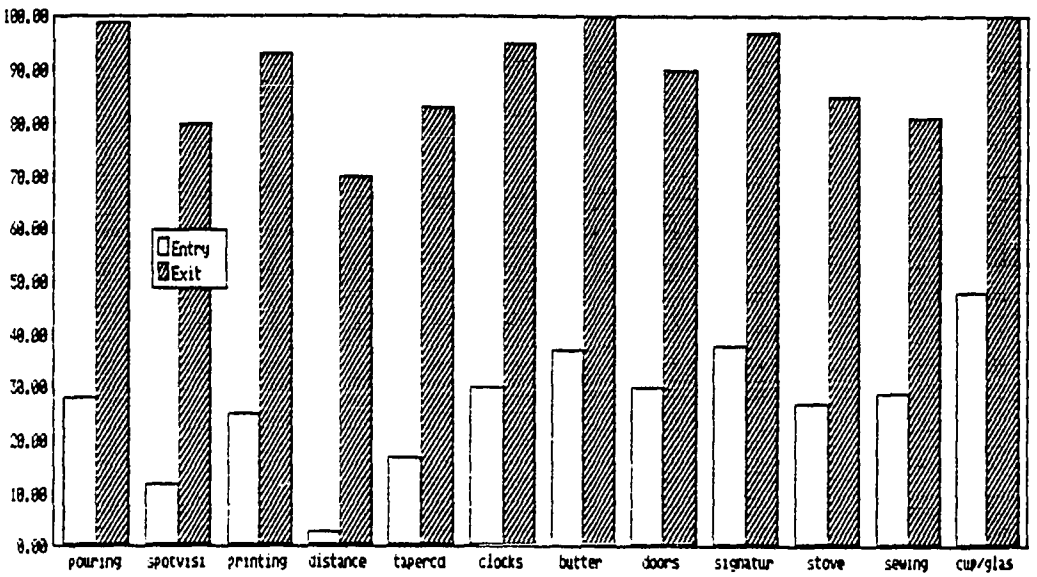

Figure 11. Gains on Capacity Scale: Entry and Exit.

One might also expect that there would be little change in some areas if a person is already performing at adequate levels to suit the individual's lifestyle. For example, if an individual is doing dishes daily, no improvement could be achieved. One would assume that if an individual is performing a task at an adequate level,

no training is provided. Moreover, for some individuals, especially older men, the task of doing dishes may not be performed if the spouse normally performs that task. In addition, it must be recalled, sustaining a level of activity may be of equal value to increasing it.

The greatest client gains in capacity (some or no difficulty) occur in the skills of pouring, spot vision, and printing/writing. Gains reflect the impact of skills training and adapted aids, and again, most gains appear to occur in those areas associated with blind rehabilitation teaching skills.

The changes for all items on the Capacity Scale are displayed in Appendix F.

Changes on Independence Scale

The most frequently addressed issues do not necessarily predict those skills in Table 25 where the most gain occurs on the independence scale, that is, the ability to perform a task alone or aided. See Table 27. While braille is addressed in only 10% of the cases, the skill demonstrates the most gain, 64%. Using tape recorders is addressed in 31% of the cases; yet, it shows a gain of 60%. Those tasks that may use an adapted optical aid to enhance vision (distance vision, spot reading, and writing/printing) account for significant levels of increased capacity.

Table 27

Most Significant Gain on Independence Scale

rank	skill	% normal at entry	% normal at exit	% gain
1	Braille (n = 11)	0	64	64
2	Tape recorder (n = 35)	26	86	60
3	Hygiene (n = 6)	0	60	60
4	Distance vision (n = 36)	31	89	58
5	Sewing (n = 31)	29	87	58
6	Locate Items While Shopping (n = 15)	14	71	57
7	Spot Vision (n = 49)	43	94	51
8	Street Crossing (n = 21)	23	73	50
9	Printing/Writing (n = 73)	44	88	44
10	Signature (n = 68)	53	97	44
11	Select Clothing (n = 27)	30	70	40
12	Washing Dishes (n = 10)	40	80	40
13	Doors/Keys (n = 10)	50	90	40
14	Clocks/Watches (n = 64)	58	98	40
15	Safety (n = 10)	40	80	40

Figure 12 displays the entry and exit levels for those tasks exhibiting the most gain, and it reveals graphically the relationship of these shifts in independence. For example, braille moves from 0% to 64%, but doing dishes shows a 44% gain, moving from 44% at entry to 88% at the completion of services. Both of these skills would be taught by the rehabilitation teacher. Similarly, spot vision moves from 43% on the Independence Scale at entry to 94% after rehabilitation services, a gain of 51%. Changes on all 57 items of the Independence Scale are displayed in Appendix G.

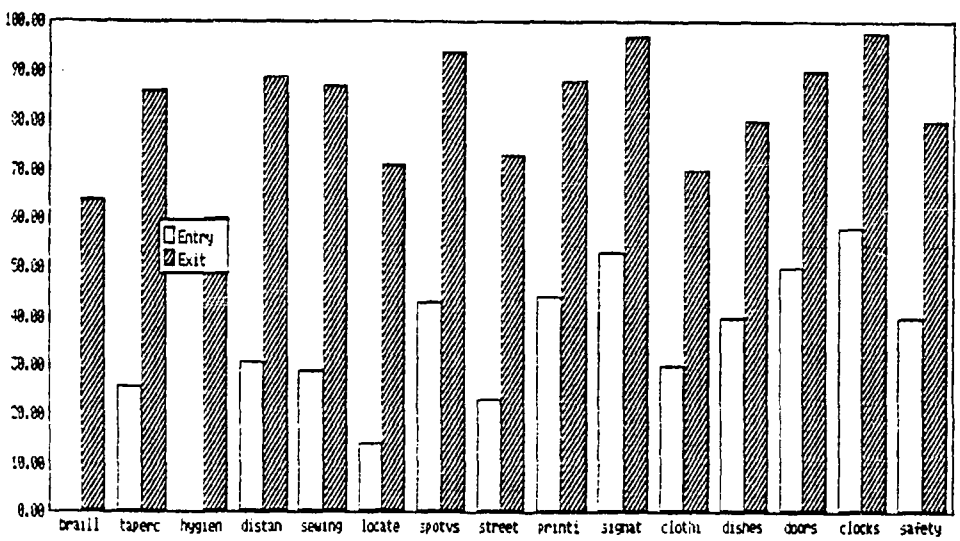

Figure 12. Gains on Independence Scale: Entry and Exit.

However, a review of those skills that receive the most training reveals that significant gains are demonstrated on the Independence Scale. See Table 28.

Table 28

Independence Gain of Most Frequently Addressed Skills

Skill	% addressed	Entry	Exit	% gain
Printing	65	44	88	44
Signature	61	53	97	44
Pouring	58	71	95	24
Clocks	57	58	98	40
Coins	47	49	87	38
Spot reading	44	43	94	51
Reading	44	50	77	27
Currency	41	46	83	37
Telephone	38	61	81	20
Switches	38	83	95	12
Stove	37	54	93	39
Walk One Block	26	46	76	30

For example, 6 skills (printing/writing, signature, clocks/watches, identifying coins, spot vision, and stove/oven) of the 12 most frequently addressed issues show a gain of at least 38%. These gains are displayed in Table 28. Therefore, those items that receive the

most attention, as one would expect, demonstrate considerable gain. These particular skills are by and large skills taught by rehabilitation teachers, and therefore attention at this intensity would not be out of order.

Disability and Handicap Outcomes

At the beginning of service, as noted above, clients are asked to report levels of activity in 14 areas of productivity. The 14 areas encompass disability--task performance--issues including meal preparation, house cleaning, laundry, dishes, and food shopping as well as activities that reflect social integration--handicap concerns--including public entertainment, attending events at community centers, and shopping. After rehabilitation services have been completed, clients are asked to respond to the same 14 issues.

The ICIDH model implies that homemaking skills belong to the disability arena, while those activities related to social integration are related to the handicap domain. These distinctions become increasingly important as measures of where rehabilitation creates successful outcomes.

Gender, living arrangement, and perception of health appear to become important variables as one assesses where gains occur. For purposes of this analysis, the

112 individuals in this research are divided into five groups: (1) women living alone (28%), (2) men living alone (8%), (3) women living with others (30%), (4) men living with others (21%), and (5) men and women who are institutionalized (13%).

Some productivity measures appear to be of little utility to this study. Virtually no one is involved in yard care, and hardly anyone is involved in childcare. By contrast, nearly everyone watches TV or listens to the radio. And it is difficult to say if watching more TV represents a greater level of productivity. Therefore, these items are not being examined in this analysis.

Women Living Alone

Women living alone demonstrate significant gains in both disability (task performance) and handicap (social integration) domains. Data presented in Table 29, for example, reveal that of women living alone, 28% report increases in doing laundry; 24% report increases in housecleaning, and 17% indicate greater activities in food shopping. Similarly, 28% report gains in participating in public entertainment and visiting others; 14% indicate that shopping for other than food has increased. In addition, 17% indicate that having visitors and being involved with community center programs have increased. While these last two items do not represent

the greatest gains among the five groups, these gains remain substantial. All men and women, regardless of living situation, report great strides in reading. Women living alone report the least gain in reading at 38%.

Table 29

Changes in Productivity: Women Living Alone

	% Gain	% Sustained	% Lost
Meals	14	83	3
Dishes	10	83	7
House cleaning	24	59	17
Laundry	28	62	10
Food shopping	17	76	7
Entertainment	28	65	7
Community center	17	69	14
Shopping	14	65	21
Visit others	28	55	17
Have visitors	17	62	21
Reading	38	45	17

Since women living alone report the greatest levels of gain, it is not surprising that they also report the least amount of loss in disability issues. Seventeen percent report less activity in housecleaning, and 10% report doing laundry less often. Only 7% report doing

dishes or shopping for food less often, and finally, only 3% report loss in meal preparation. By contrast, women living alone appear more handicapped; that is, they report greater losses in social integration activities. For example, 21% report shopping and having visitors less often; 17% report lower levels of attendance at community centers. Reading (essentially a disability issue) shows a 17% loss.

However, if one recognizes that sustaining a level of activity is equally important in rehabilitation to achieving gains when serving people who are old and getting older, the group of women living alone illustrates remarkable stability, especially in disability issues. Eighty-three percent of women living alone indicate gains or sustained levels of house cleaning; 90% report either gains or sustained levels of doing laundry, and 93% indicate a similar capacity in doing dishes or food shopping, and a remarkable 97% report gains or sustained ability to prepare meals. The ability to sustain levels of function combined with solid gains, results in an overall positive outcome for disability and handicap among women who live alone.

Figure 13 on p. 141 represents these relationships in a graphic way. The percentage of lost productivity, sustained productivity, and gained productivity are displayed for each item in the disability and each item

in the handicap domain. A pattern of relationships appears to emerge in regard to the regions of loss, stability, and gain. One could argue that the losses represented here would occur whether or not rehabilitation services were provided, and one would expect that some of the gain is a result of rehabilitation services. Finally, a rehabilitation program may have some impact, though unknown, in preserving a level of productivity. For the women living alone in this sample, the regions of loss and gain appear rather small especially in comparison to the other groups in this study.

Perception of health does not appear to play an important role in predicting loss of productivity for women living alone (see Table 30). In 7% of those specific items where losses occur, women living alone report poor health; 20% of losses occur where women living alone report fair health.

Table 30

Impact of Health on Productivity Loss

	Women alone	Men alone	Women w/ others	Men w/ others
Poor	7.1	44.4	19.2	16.7
Fair	20.0	22.2	40.4	56.7
Good	72.9	33.4	40.4	26.6

For other groups, however, a clearer relationship appears to exist between perception of health and losses in productivity.

Men Living Alone

In contrast to women living alone, men living alone represent a more unstable situation (see Table 31). While the gains are often quite great, the losses are great as well. The region of stability appears much smaller for men than for women (see Figure 14 on p. 141).

Men report substantial gains in disability issues; gains occur in doing dishes (43%), meal preparation (29%), housecleaning (29%), laundry (29%), and food shopping (14%). But similar percentages of loss occur, as well, in each area: doing dishes (29%), meal preparation (14%), housecleaning (29%), laundry (29%), and food shopping (43%). Yet, overall, nearly three-quarters of the men are able to demonstrate gain or sustained levels of productivity in disability issues. Women living alone exceed men's capacity, however, by nearly 20% across these five areas.

By contrast, men living alone do better overall in handicap (social integration) issues than women living alone. While the gains for men are generally comparable to women's, the group of men living alone report the greatest gain in three of five handicap issues: public

entertainment (29%), having visitors (29%), and shopping other than food (14%). However, if one combines the categories of gain and sustained levels of activity, the greatest success occurs in handicap productivity issues: entertainment (100%), having visitors (100%), visiting (86%), shopping (86%), and going to the community center (71%).

Table 31

Changes in Productivity: Men Living Alone

	% Gained	% Sustained	% Lost
Disability			
Meals	29	57	14
Dishes	43	28	29
House Cleaning	29	42	29
Laundry	29	42	29
Food Shopping	14	43	43
Handicap			
Entertainment	29	71	0
Community Center	14	57	29
Shopping	14	72	14
Visit Others	0	86	14
Have Visitors	29	71	0
Reading	43	43	14

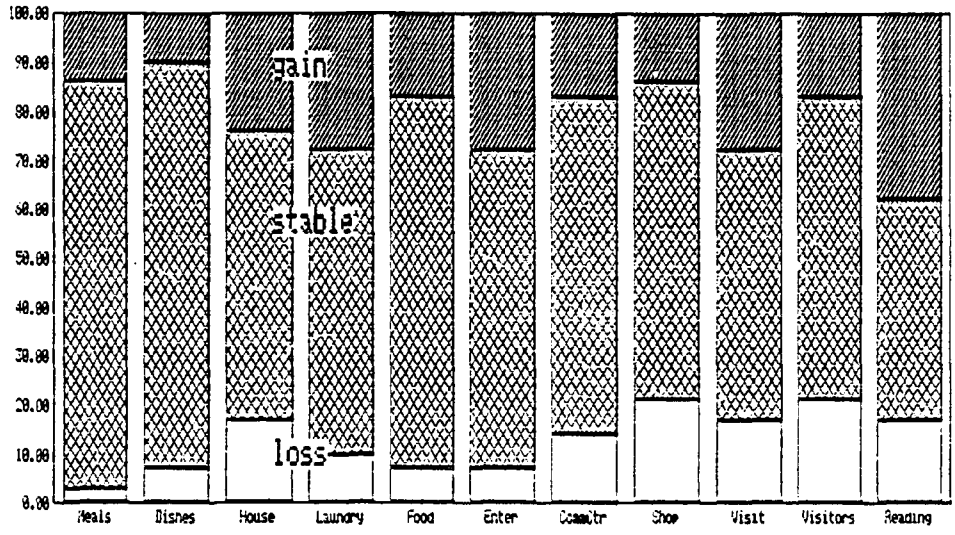

Figure 13. Productivity Changes for Women Living Alone: Disability and Handicap Concerns.

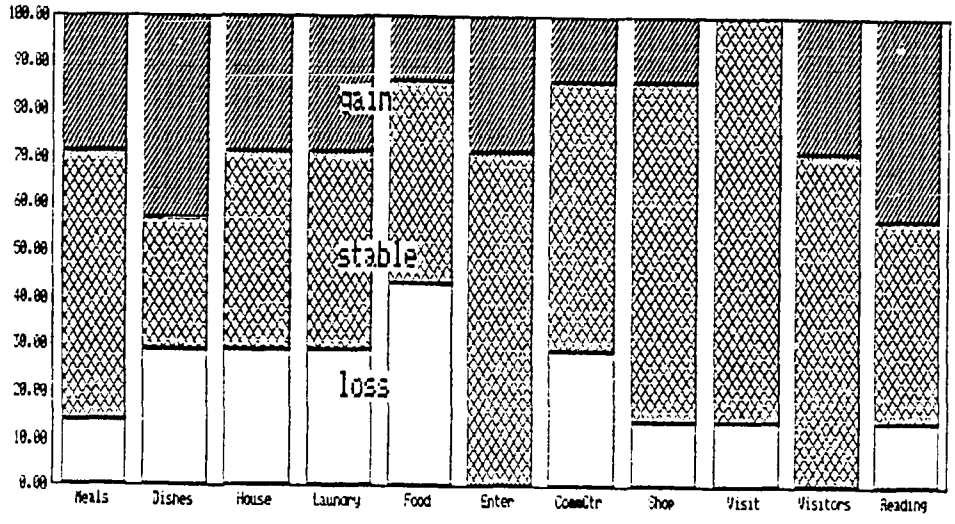

Figure 14. Productivity Changes for Men Living Alone: Disability and Handicap Concerns.

Perception of health appears to play an important role in predicting losses in productivity (see Table 30). For men living alone the report of poor health accounts for 44% of loss, and fair health accounts for 22%; in other words, in 66% of those cases where men lose productivity, they also report poor or fair health.

Women Living With Others

Women living with others present a different pattern of gain and loss (see Table 32). Generally, women living with others experience fewer gains, especially in disability areas. In the handicap arena, gains tend to be more similar in all four groups of noninstitutionalized individuals. Figure 15 on p. 147 displays these shifts in a graphic representation.

Disability gains for women living with others appear rather modest; meal preparation (13%), doing dishes (16%), housecleaning (13%), laundry (3%), and food shopping (13%) present less gain than in most of the five groups. Yet in handicap issues, women report strong gains. Involvement with community centers (28%), having visitors (22%) and reading (50%) present strong gains. Visiting (19%), public entertainment (13%), and shopping (6%) show less gain.

By contrast, losses in disability areas among women living with others tend to be greater than other groups;

meal preparation (16%), doing dishes (19%), housecleaning (35%), laundry (26%), and food shopping (10%) represent significant losses. Loss in handicap areas appears uneven; entertainment declines 9%, and involvement with community centers declines only 6%; yet shopping declines 19%, and having visitors declines by 16%; visiting drops by 25%, the greatest of any group.

Table 32

Changes in Productivity: Women Living with Others

	% gained	% sustained	% lost
Disability			
Meals	13	71	16
Dishes	16	65	19
House cleaning	13	52	35
Laundry	3	71	10
Food shopping	13	77	10
Handicap			
Entertainment	13	78	9
Community center	28	66	6
Shopping	6	75	19
Visit others	19	56	25
Have visitors	22	62	16
Reading	50	47	3

Health plays an important role in predicting these losses (see Table 30). In 19% of those productivity

measures where loss occurs, women report poor health; likewise 40% of loss in productivity occurs among those reporting fair health. Thus, poor and fair health account for nearly 60% of the losses this group reports.

Yet, even with the reported losses in handicap and disability measures that women living with others experience, by and large, they are able to sustain relatively high levels of productivity. Table 32 reveals that 84% of these women report gains or a sustained level of meal preparation and doing dishes. Only 65% show gains or sustained levels of housecleaning, a task that can be successfully neglected without threatening independence. Seventy-four percent sustain or increase activities in doing laundry, and a rather high 90% report gains or sustained levels of food shopping. In the three areas that cannot easily be neglected (meal preparation, doing dishes, and food shopping), the least decline occurs.

Women living with others reveal a greater capacity to sustain or create gains in handicap areas than their disability gains would suggest. While only 75% experience gains or remain at the same level for visiting others, both shopping and having visitors show an increase of over 80%. In the case of public entertainment and attending community centers, over 90% reveal a

capacity to sustain or increase productivity. A remarkable 97% show gain or sustained levels of reading.

Men Living With Others

Men living with others present a similar pattern (see Table 33); they show relatively little gain in disability issues, though some gains appear unusual, and losses in disability tend to be higher than for other groups (see Figure 16 on p. 147). In the daily activities of meal preparation and doing dishes, 19% of the men living with others show gain. But 24% show a loss in meal preparation, and 14% report doing dishes less often. The remaining half, of course, report no change. The other disability tasks of laundry (0%), housecleaning (5%), and food shopping (10%) show the least gain of the four non-institutionalized groups. Yet, this same group reports the greatest gain in reading (68%).

Handicap issues show solid gains; 41% attend community center events more often, and this rate of participation represents the highest among the four non-institutionalized groups. This group also reports an 18% gain in public entertainment and visiting; similarly, 23% report having visitors more often. Shopping, probably not a preferred social activity for older men, shows only a 6% gain.

Table 33

Changes in Productivity: Men Living with Others

	% gained	% sustained	% lost
Disability			
Meals	19	57	24
Dishes	19	67	14
House cleaning	5	62	33
Laundry	0	81	19
Food shopping	10	66	24
Handicap			
Entertainment	18	75	5
Community Center	41	41	18
Shopping	5	81	14
Visit Others	18	72	10
Visitors	23	72	5
Reading	68	22	10

While 43% of the men living with others report greater attendance at community centers, 18% report less activity. Only 5% report less involvement with public entertainment and having visitors. This level of loss is among the least of the four groups. Shopping declines in 14% of the cases, but again, shopping may not be perceived as a desirable activity among older men generally. Losses in reading are only 10%, the second smallest loss.

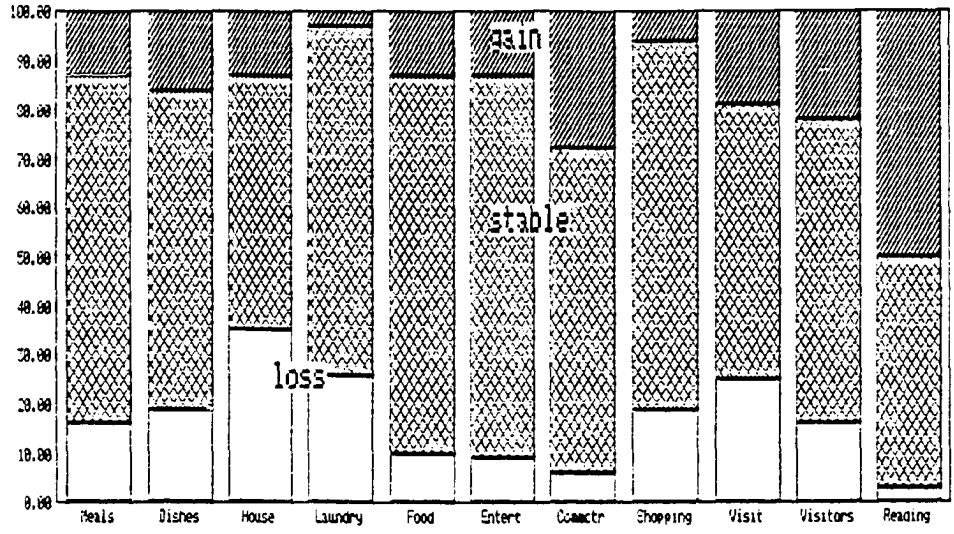

Figure 15. Productivity Changes for Women Living with Others, Disability and Handicap Concerns.

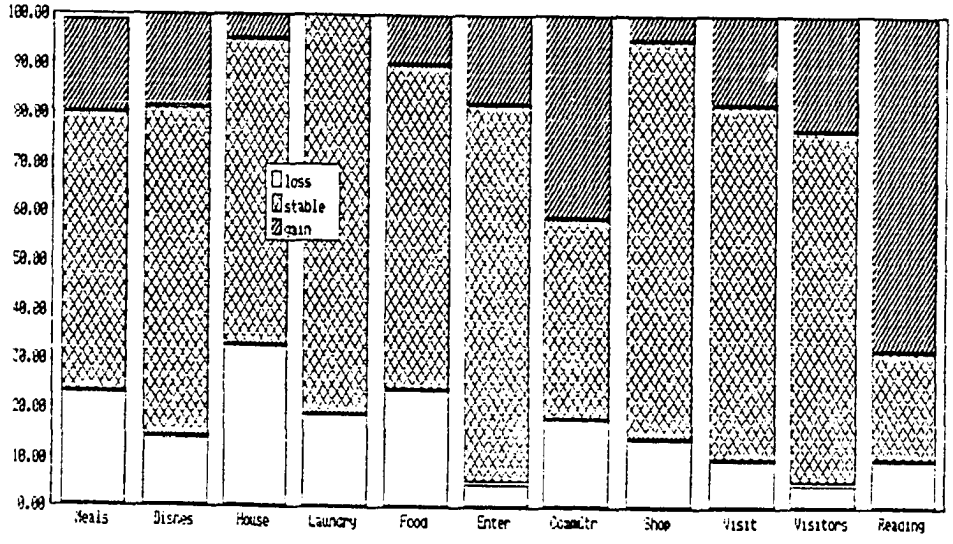

Figure 16. Productivity Changes for Men Living with Others: Disability and Handicap Concerns.

Perception of health plays a significant role in accounting for the losses experienced by this group. See Table 30. Of those items showing loss, 17% occur among men reporting poor health; another 57% of items indicating loss occur among men reporting fair health. The total accounts for nearly three-quarters (74%) of those particular items.

Men and Women Living in Institutions

Men and women who reside in institutional settings report minimal levels of productivity at the beginning of services (see Table 34). Except for visiting and having visitors, this group, as one would probably expect, presents few opportunities for independence. After the rehabilitation program is completed, skills associated with disability concerns (meal preparation, laundry, and food shopping, for example) show no gains; in fact, two issues show losses. None of these tasks is performed by anyone living in an institutional setting. However, handicap issues indicate sustained levels or some modest gains. Reading shows the most gain; 14% read once or more each week at entry, and 47% read once or more each week at exit.

Table 34

Reported Changes in Task Performance

Task	% Completing task once or more each week		
	Entry	Exit	Gain (loss)
Disability			
Meal Preparation	7%	0%	(7%)
Housecleaning	13%	0%	(13%)
Laundry	0%	0%	0%
Food Shopping	0%	0%	0%
Dishes	7%	0%	(7%)
Public Entertainment	21%	47%	28%
Handicap			
Community Center	29%	27%	(2%)
Shopping (not food)	14%	20%	6%
Reading	14%	47%	33%
Visitors	79%	73%	(6%)
Visit Others	43%	60%	17%

Changes in Perception of Health

Another measure of change may arise from shifts in perception of health. Fourteen percent of those beginning services report poor health; at exit, that report remains the same. However, 31% report fair health at entry, and 48% report fair health at exit. Finally, the

report of good health decreases from 54% at entry to 41% at exit. Figure 17 displays these shifts.

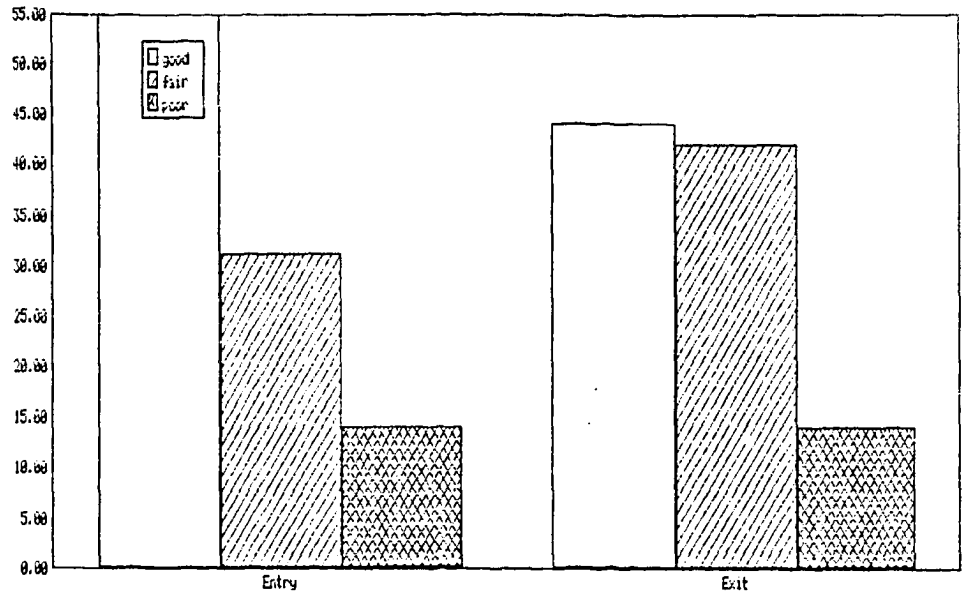

Figure 17. Perception of Health at Entry and Exit.

The second portion of this study deals with rehabilitation gains. Rehabilitation activities most frequently address disability (task performance) concerns; tasks that receive the most frequent attention include printing/writing, telling time, low vision, and identifying coins and currency. The greatest gains occur in low vision, printing/writing, signature, and telling time.

Women living alone, men living alone, women living with others, men living with others, and men and women

who reside in institutions represent five distinct groups that report differing levels of gain, stability, and loss in disability (task performance) and handicap (social integration) issues. Women living alone generally appear to be the most stable group, but men living alone report great gains and great losses primarily in disability issues. Of the five groups, greater gains consistently occur in handicap domains than in disability areas.

Concerns of the Family

The third research question in this study has to do with the concerns of the family members who are caregivers for a spouse or parent who is older and blind and how these concerns change after rehabilitation services have been provided. As noted above, family members are asked to complete a survey at entry and exit. The 40 individuals represented in this portion of the study comprise a separate group from the 112 individuals characterized earlier in this research; 14 of the sample of 40 (35%) are represented in the larger sample of 112. A limited amount of information is gathered about the caregivers.

Of the 40 individuals who participated, 21 (53%) are spouses, and 17 (43%) are adult children; only 2 (5%) are friends. Among these respondents in this study, one-third of the children live with the older blind parent,

and two-thirds live away. Finally, 10% of the spouses and 18% of the adult children indicate that they have quit their jobs as a result of their caregiving duties. In this analysis two groups are identified based on living arrangement: (1) spouses (21 individuals) and adult children who have a parent living with them (6 individuals) and (2) adult children who do not have a parent living with them (11 individuals).

Table 35 displays the percentage of spouses and adult children who indicated that a particular issue is an important or critical concern at the beginning of services. Clearly, safety is the issue that creates the greatest proportion of concern that all family members express. Eighty-three percent of the spouses and adult children who have a parent living with them indicate that safety is an important or critical concern. Among the adult children living away from home, 55% recognize safety as a major issue; yet this item raises the greatest concern of the 19 items surveyed. Seventy-one percent of the spouses and children who have a parent living with them acknowledge that transportation is a serious concern. By contrast, only 30% of the adult children who do not live with a parent perceive the gravity of this issue. The domestic tasks of housework and meal preparation are not serious concerns for spouses and children who have a parent living with them, scoring

27% and 28% respectively. While children who do not have a parent living with them are very concerned about meal preparation (54%), there is rather little concern for housework (22%). Knowing how to help (56%) and how much to help (67%) create serious concerns for the spouses and adult children who have a parent living with them. Only 18% of the children who do not have a parent living with them define these issues as concerns.

One would have expected that having enough time would be a serious concern for adult children living away from their parent, and indeed, it is for 45% of the respondents. Similarly, 48% of the spouses and adult children who have a parent living with them acknowledge that having enough time is a concern.

One would have suspected, as well, that children living away would identify family responsibility as a serious concern, and while it is for 27%, spouses and children who have a parent living with them provide a similar score of 27%. Similarly, getting other work done would likely be a concern for adult children living away from home, and it is for nearly half (45%) of that group. Twenty-six percent of spouses and children who have a parent living with them acknowledge a similar level of concern.

Table 35

Report of Family Concerns

	Family living with elder n=29		Children n=11		All n=40	
	Entry	Exit	Entry	Exit	Entry	Exit
Safety	83	50	55	45	77	46
Transportation	71	38	30	27	59	24
Housework	27	24	27	10	27	19
Meal Preparation	28	27	54	30	36	22
Depression	48	28	36	27	44	25
Pay Bills	38	19	22	10	36	17
Spend Time	62	31	36	50	51	34
Know When to Help	37	30	27	27	45	28
Know How to Help	56	30	18	18	47	25
Know How Much to Help	67	22	18	36	53	26
Frustration	44	41	27	45	39	43
In Public	33	4	0	10	24	5
Enough Time	48	15	45	27	47	20
Family Responsibility	27	12	27	27	24	19
Other Work	26	19	27	18	26	18
Leave 6-8 Hours	37	26	9	27	29	26
Leave over 8 Hours	60	44	27	27	50	41
Short Trips	19	15	0	18	14	15
Long Trips	27	20	9	27	19	21

Those items related to respite from caregiving roles (getting away for short [9%] or long periods [20%], or taking trips [0%]) are of little or no concern for adult children living away, as one might suspect. By contrast, 37% of spouses and adult children who have a parent living with them indicate that leaving for short periods of time is a concern, and 60% indicate that leaving for over eight hours (over a meal) is a concern. However, taking short trips (15%) and taking long trips (27%) do not create high levels of concern.

After rehabilitation services have been provided, family members overall report that the proportion of concern has diminished. Safety for all family members drops from 77% to 46%; knowing when to help is reduced from 45% to 28%, and knowing how to help drops from 47% to 25%. Knowing how much to help moves from 53% to 26%. Figure 18 displays these changes for all family members in a graphic representation.

The gains, however, differ markedly between the two categories of caregivers. Spouses and children who have a parent living with them report considerable gains. By contrast, children who do not have a parent living with them report little, if any, gain in most areas; indeed, some items show an increased proportion of concern.

Safety for spouses and children who have a parent living with them decreases from 83% to 50%, and for

children who do not have a parent living with them, the proportion of concern is reduced from 55% to 45%.

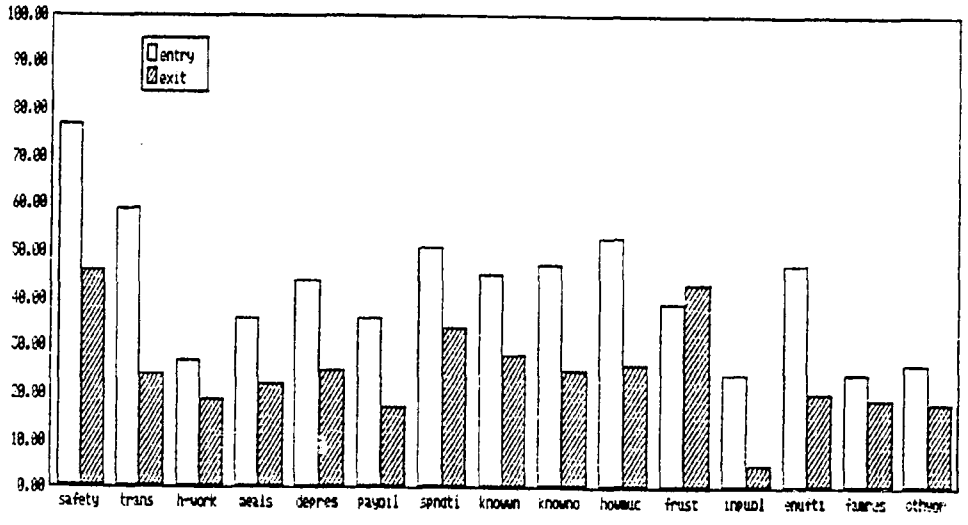

Figure 18. Concerns of All Family Members: Entry and Exit.

For spouses and children who have a parent living with them, the concern for meal preparation does not change, remaining at 27%. For children who do not have a parent living with them, meal preparation, the second greatest concern behind safety, decreases from 54% to 30%.

Transportation is initially a serious concern for 71% of the spouses and adult children who have a parent living with them, and this issue marks the second most serious issue for this group. At exit, 38% report that

transportation is an important or critical concern. For children who do not have a parent living with them, there is no change; only 30% report this issue to be serious, and at exit, only 27% report transportation to be an important or critical concern.

Knowing how, when, and how much to help drops for spouses and children who have a parent living with them. While knowing when to help shows a 7% drop (from 37% to 30%), knowing how to help indicates a 26% drop (from 56% to 30%), and knowing how much to help presents a gain of 45% (from 67% to 22%). By contrast, knowing when to help and knowing how to help (27% and 18% respectively) show no changes for children who do not have a parent living with them. And knowing how much to help shows an increased level of concern, from 18% to 36%. While the concern for family responsibilities drops for spouses and children who have a parent living with them (from 27% to 14%), it remains the same for children who do not have a parent living with them. Moreover, reported frustration shows no change for spouses and children who have a parent living with them, but it increases from 27% to 45% for the children who do not have a parent living with them.

The final portion of this research deals with a study of 40 family members of older people who are blind. Family members are divided into two groups: (1) spouses

and adult children who have parents living with them and (2) adult children who do not have a parent living with them. The research reveals that those family members who live with a person who is older and blind report much greater levels of concern than children who do not have an elder who is blind living with them. After rehabilitation services are provided, the reports of spouses and adult children who have parents living with them reveal diminished proportions of concern in most issues. By contrast, children who do not have a parent living with them report little, if any, change in levels of concern.

CHAPTER V

CONCLUSION

As America moves through the last decade of this century, the nation will be forced to confront realities unimagined by previous generations. Among the pressing issues before us will be the public policy and practice concerns of serving older people who become blind. The absolute number of older individuals experiencing severe vision impairment will probably double between 1980 and 2010, from about 2 million to nearly 4 million people. The numbers alone will begin to drive public policy, but numbers do not tell the entire story of human capacity and desire. The impact of aging and blindness is an intensely personal and private matter. It affects an older person's ability to perform tasks and establish relationships that are otherwise second nature to us all. And it may compromise the traditional roles that provide identity, self-esteem, and quality of life. We must be mindful of the profound implications of blindness for an older person. In addition, as blindness affects older individuals, it impacts upon their families and those who care for and about elders. Thus, blindness is not an isolated event, but one that ripples across the family,

support systems, and social structures designed to sustain dignity and independence.

The literature review for this research frames the importance of this study. Until recently there has been scant interest in the issue of aging and disability, and very little research has addressed on older people who are blind. It is clear that while aging does not cause disability, it certainly marks a time when disability becomes both more prevalent and more intense. Yet, given the prevalence of disabling conditions, most elders are able to preserve independence through their own perseverance, ingenuity, and support systems.

Census projections suggest that the numbers of elders will increase dramatically in the United States in the decades to come. This phenomenon will be experienced in Northern and Western Europe, Canada, and to some extent in Japan. As a part of this demographic trend, the numbers of people experiencing severe vision impairment and other age-related disabilities will soar.

These demographic shifts occur in the social context of families that are smaller and increasingly dispersed. As a result, the traditional caregiving system becomes increasingly taxed. Women who in the past assumed the traditional caregiving role are now caught in the middle as they attempt to work, care for their own families, and also care for an older person who is disabled. Moreover,

as more people live into their ninth and tenth decades, adult children in their 60s may be thrust into caregiving roles, or adults in their 40s may find both parents and grandparents dependent upon them.

It is clear that families are heroic and pivotal in their efforts to preserve independence. Families, chiefly wives, daughters, and daughters-in-law, are resilient, tolerant caregivers, providing 80 to 90% of the care necessary to sustain an older person at home; professionals provide the balance of care. Other research has shown, for example, that for every person in a nursing home, two others who are equally disabled are cared for at home. The chief reason that an elder is institutionalized is a collapse in the support system, not a sudden decline in the health of the older person. Consequently, people who are kinless are more vulnerable to institutionalization, and those who have families are much more disabled when institutionalization occurs. While families often provide critical levels of caregiving, little respite appears available that would allow them to sustain their caregiving activity.

While human experience occurs in a social context, it also happens in the context of public policy. Clearly, public policy has not kept pace with the massive demographic shifts of an aging population. Furthermore, part of this public policy is defined by the inadequacy

of measures to report the success or failure of rehabilitation programs designed to serve people who are older and disabled.

In recent years, the World Health Organization (1980) has developed the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) as a way to understand the issues of disablement. This model creates a distinction between disease and disability and the consequence of disease. Wood (WHO, 1980), for example, defined four planes of experience. In the first plane etiology gives rise to pathological changes that manifest themselves through symptoms and signs. At the second plane, an individual becomes aware of these changes and the pathology is exteriorized. Impairment is defined as "any loss or abnormality of psychological, physiological, or anatomical structure or function" (p. 27), and the concern of impairment focuses upon the organ level. Disability, then, is defined as "any restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being" (p. 28). Thus, disability is concerned about issues at the person level. Finally, handicap is defined as "altered behavior or performance" that places "the individual at a disadvantage relative to others, thus socializing the experience"(p. 28). Therefore, handicap is concerned about the person in society.

The ICIDH model becomes elegant because it distinguishes among these domains. And these distinctions allow for a clearer, more precise discussion of disablement as it impacts at the organ, person, and social levels.

The goal of rehabilitation is to allow people to sustain or increase independence. In some way, people should be better off as a result of a program designed to serve them. But measuring progress, especially among older people whose health and support systems may be fragile, is difficult, at best. Many organizations seek to create proxies to define success. For example, an organization may count the number of people served, units of service, or cost per unit of service. While these may become useful measures of efficiency, they do not portray a program's effectiveness.

The most critical thinkers in rehabilitation have attempted to define rehabilitation outcomes as a way to measure success. Such a model asks the basic question: Is an individual essentially better off as a result of service?

Methods

This study was concerned with describing the demographic characteristics and rehabilitation outcomes of 112 older people who are blind, and this sample ad-

dressed the first two research questions. This study also addressed the concerns of 40 family members who have a spouse or parent who is blind. This group comprised a separate group of individuals, although 35% of the 40 were contained within the sample of 112. This second group of individuals addressed the third research question. All of these individuals had received services through the Independent Living Rehabilitation Program of the Michigan Commission for the Blind. The data were compiled from aggregated information about these individuals. Instrumentation included client surveys, functional assessment devices, entry and exit surveys regarding productivity, and surveys administered to family members.

Three research questions provided the framework for this study.

1. What are the characteristics of a group of elders who are blind and who seek and receive rehabilitation services?

1A. What are the age, gender, ethnic characteristics, marital status, health concerns, and living arrangements of this group?

1B. What levels of productivity do these individuals report?

2. What are appropriate strategies for measuring rehabilitation gain among older people who are blind?

2A. What are strategies for presenting rehabilitation gain?

2B. In what areas do elders who are blind demonstrate rehabilitation gains after receiving rehabilitation services?

2C. What impact do gender, health, and living arrangements have upon rehabilitation outcomes?

2D. What impact does the completion of rehabilitation services have upon reported productivity measures?

3. What are the concerns of spouses and adult children regarding an older family member experiencing blindness?

3A. What are the concerns of spouses and adult children at the beginning of rehabilitation services?

3B. How do the concerns of spouses and adult children change after rehabilitation services?

Summary of Results

The demographic characteristics revealed that the average age of this group of 112 people was 76.5, ranging from 55-103. Sixty-seven percent of this sample were women. Twenty-two percent of the men and 58% of the women were widowed. In fact, 69% of the women had no spouse. Over three times as many women lived alone as men, and over half of this sample lived in cities with a

population greater than 50,000. Fourteen percent of the individuals in this sample were black, and the balance were white.

The causes of blindness among this sample were clearly associated with the age-related pathologies. Thirty-four percent reported macular degeneration, and 15% indicated diabetic retinopathy; 13% indicated glaucoma as a cause of blindness, and only 3% reported cataract. In addition, 19% indicated some combination of the above four pathologies. Thus, the four leading causes of blindness among elders--macular degeneration, diabetic retinopathy, glaucoma, and cataract--accounted for 87% of the cases of blindness that these 112 people reported at the beginning of service.

Eighty-seven percent of the people in this sample lost their vision after their 60th birthday. Indeed, 42% lost vision during their eighth decade, and 17% lost vision after age 80.

Reported impairments and diseases that are secondary to blindness showed greater prevalence rates than National Center for Health Statistics (Blake, 1984) data would suggest for these individuals. Sixty-one percent reported arthritis; 46% reported hypertension, and 38% showed heart disease. In addition, 32% reported hearing impairment, and another 5% indicated deafness. In fact, 59% of

the men in this sample reported hearing impairment or deafness.

Yet, despite significant reported secondary impairments, only 13% reported their health to be generally poor, and 30% reported health to be fair. The majority (53%) indicated that their health to be good or very good. Sixty-five percent reported that their health had not interfered with normal activities, and 10% indicated the poor health had prevented normal activity for 7 days or less during the preceding 90 days. Similarly, 63% indicated that they had not been inpatients in a hospital during the previous year, and 18% reported hospital stays of 9 days or less.

Productivity measures indicated that the women continue to perform domestic tasks of meal preparation and dishes, while men largely relinquished or simply did not perform those tasks. Moreover, this group was not involved with caring for children or supervising others; 86% did not perform this task at all.

As a group, this sample appears to be rather isolated socially. Fifty-four percent did not visit community centers, and 53% did not shop for items other than food. Sixty-three percent had visitors once a week or less. Yet, over three-quarters of the sample listened to radio or watched television daily.

Reports of rehabilitation outcomes indicated that the most frequently addressed skills were printing/writing (65%), signature (61%), pouring (58%), using clocks/watches (57%), and identifying coins (47%). Moreover, 44% received training in spot vision and reading, 41% identifying currency, and 38% received training in the use of the telephone.

Rehabilitation gain was measured on two scales, an independence scale reporting how a task is performed and a capacity scale measuring how well a task is performed. Gain was assessed on entry and exit only on those items where training occurred. The most significant gains on the independence (how) scale occurred in braille (64%), using tape recorders (60%), personal hygiene (60%), distance vision (59%), and sewing (58%). In addition, significant gains were made in locating items while shopping (57%), spot vision (51%), street crossings (50%), and printing/writing (44%).

The most significant gains on the capacity (how well) scale also reveal issues of skills training. The greatest capacity gains occurred in pouring (71%), spot vision (68%), printing/writing (68%), distance vision (67%), and using tape recorders (66%). Moreover, significant gains were reported in using clocks/watches (65%), buttering bread (63%), using doors/keys (60%), and writing a signature (59%).

Changes in productivity measures show considerable variation based on gender, living arrangement, health status, and task. In this study of productivity five groups were examined: women living alone, men living alone, women living with others, men living with others, and men and women living in institutions. Each group displayed differing levels of losses and gains, and particular patterns emerged. Women living alone, for example, reported moderate amounts of gain and modest losses in disability (task performance) issues. Those women showing stable levels of productivity comprised the bulk of this sample. Moderate gains and moderate losses occurred in handicap (social integration) issues. By and large, women living alone appeared to be a very stable group. By contrast, men living alone reported great losses and great gains in disability issues. Moderate gains and losses appeared in the handicap domain.

For women and men who live alone there is no one on the premises to assist with domestic tasks. Therefore, the imperative to continue to perform these tasks remains. Women are more successful than men in this regard; yet the importance of social integration has not diminished.

Women living with others reported modest gains and moderate losses in disability issues, but handicap concerns showed fewer losses and greater gains. Similarly,

men living with others reported moderate gains and moderate losses in disability, and more gain and stability among handicap issues.

It appears that men and women who live with others tended to relinquish domestic tasks but have increased socialization activities. Because someone else resides in the household, it may be possible for these individuals to relinquish some household tasks and rely upon that support system for increased socialization.

Men and women living in institutional settings reported very little or no productivity. Disability issues showed no gain, and modest gains occurred in handicap issues. Only the task of reading showed significant improvement. By their very nature institutions do not tend to expect people to perform independent living skills, but this small group did demonstrate the desire for socialization activities, especially having visitors.

The third portion of this research had to do with measuring the impact of blindness upon the family. A total of 40 individuals were surveyed, and two groups were examined: (1) spouses and adult children who have a parent living with them and (2) adult children who do not have a parent living with them. The research revealed that the initial concerns of family members differed markedly based upon living situation. Those adult children who had a parent living with them and spouses report-

ed important or critical concerns with safety (83%), transportation (71%), and knowing when (37%), how (56%), and how much (67%) to help.

Children who did not have a parent living with them reported much lower levels of concern. For example, 55% reported safety as an important or critical concern, while meal preparation (54%), and having enough time (45%) created significant levels of concern, but these issues did not match the levels reported by spouses or other children.

After rehabilitation services had been completed, the percentage of spouses and adult children who had parents living with them reported diminished levels of concern across a broad spectrum of issues.

At the beginning of service, 83% of spouses and adult children who have a parent living with them reported safety to be an important or critical concern. At the conclusion of service, only 50% reported concern for safety. Similar reductions were reported in transportation (71% to 38%), how to spend time (62% to 31%), and knowing when (37% to 30%), how (56% to 30%), and how much (67% to 22%) to help. Concern about getting away for eight hours dropped, as well, from 37% to 26%. Every item on this inventory showed decreased proportion of concern.

Adult children who did not have a parent living with them showed little or no change, and in some cases the proportion of concern increased. Safety decreased from 55% to 45%, and meal preparation decreased from 54% to 30%. Transportation showed virtually no change (30% to 27%), and knowing when (27%) and how (18%) to help remained unchanged. How time was spent increased from 36% to 50%; knowing how much to help increased from 18% to 36%, and frustration increased from 27% to 45%.

Discussion

As the nation ages and chronic disability becomes increasingly common, available resources and strategies to address disablement must replace the existing models that chiefly deal with diagnosis and treatment of acute disorders. The data presented in this study point to a situation that is much more fluid and dynamic and far more complex than policy makers and practitioners would--in all probability--suggest. These findings begin to define and validate a theory of aging and disability that has emerged in this and various scholarly discussions about elders and disablement.

Because there is no comprehensive, agreed upon model of rehabilitation, it is impossible to assert what the goals of rehabilitation are. As noted in the discussion of the open systems model, organizations tend to create

various proxies to measure results. Some organizations, for example, focus chiefly upon referrals and closures, and others may stress units of service, especially for billing purposes. Generally, these measures address the efficiency of programs, and often organizations strive to increase efficiency by reducing costs or other resources. But these measures avoid the more central question of how rehabilitation affects the lives of individuals. That is, discussions of how "effective" a program may be is largely avoided. Therefore, outcomes in terms of the life of the person--quality of life or productivity--must be identified and measured.

Throughout this research, strong emphasis has been placed upon discussing or creating models that address the issue of effectiveness. For example, the enriched open systems model of input-throughput-output-outcome reveal the relationship of effectiveness to efficiency. The Wood and Badley (1980) concept of the General Model of a Caring System reveals that rehabilitation initiatives do not occur in isolation, but they function in the very broad domain of public policy. The Wood and Badley model shows that no matter how worthwhile a program is, it must be able to communicate its activities into the public policy arena to gain public support. Finally, the ICIDH model, which so heavily influences this discussion, becomes a way of organizing central issues of disablement

in a logical fashion. The logic allows for discussion as well as the capacity to aggregate data.

These models become important in establishing an overarching framework for measuring and reporting rehabilitation outcomes, especially among elders who experience disability.

Moreover, the findings in this research begin to characterize central policy and practice issues that must be addressed as rehabilitation strategies for elders who are disabled are defined. From this research six characteristics emerge to temper public policy decisions in the context of defining and measuring rehabilitation outcomes for elders who are disabled. These dimensions include: (1) the heterogeneous character of elders, (2) the important distinction between disability and handicap, (3) the value of small gains, (4) the importance of sustained functional levels, (5) the importance of sustaining "active" life, and (6) the importance of the family. Fenderson (1986) wrote,

> In rehabilitation, the therapeutic goals and emphases shift from diagnosis and treatment to function and performance. The goals are not limited to physical performance alone. They encompass, as do those of the relatively new medical specialty of family medicine, an 'extended boundary' concept of the person in his/her environment. (p. 4)

The demographic discussion suggests what a remarkably heterogeneous population older people comprise. While

the average age of persons participating in this program was 76.5, the range was 55 to 103. A 55-year-old has little in common with someone 103 years old; in fact, a 55-year-old may not even perceive a 77-year-old as a peer. And clearly age and gender suggest widely differing resiliency and support systems. For people who are younger, health may be good, one's spouse may be alive, and adult children may be relatively young. For the older old, health may be fragile, and as the number of women suggests, many women face life as widows. Moreover, the adult children of someone over 80 may themselves be over age 60. Simply put: older people bring differing expectations, support systems, personalities, and resources to the experience of disablement. Being older and blind does little to describe this population, and this condition does nothing to predict rehabilitation needs or outcomes for a particular individual. Facile generalizations can be easily contradicted.

The International Classification of Impairments, Disabilities, and Handicaps (WHO, 1980) creates a powerful distinction between **disability** (task performance at the person level) and **handicap** (integration at the social level). This conceptualization underscores the importance of these two domains in rehabilitation practice. Emerging models of rehabilitation must balance the value of increased functional ability (task performance) with

the value of increased social integration (a quality of life issue). The skill of crossing a street, for example, has little value to the individual unless he or she has somewhere to go or someone to see. Rehabilitation activities that do not lead to an enhanced quality of life must be called into question.

Reports of productivity in this research reveal that handicap issues often show greater gain than the gains and losses displayed in disability (functional gain). While the relationship between disability and handicap cannot be asserted in this research, it is arguable that a rehabilitation intervention may not be able to successfully address every skill area, but if the service leads to a reduction of handicap, then the intervention must be judged a success.

Williams (1984) has cited the importance of small gains as they relate to quality of life and needless institutionalization. This research reveals that policy makers and practitioners must be mindful of these small gains and the importance they have for the individual. Crossing a street, reading one's mail, or even setting the thermostat involve a complex set of small gains; these gains provide the individual with control over life choices that leads to a fuller, more satisfying life. Policy and practice decisions cannot ignore the value of

one small gain or the aggregate of small gains in the quality of an individual's life.

Another characteristic of a rehabilitation model for elders concerns the ability to sustain one's functional level. While one goal of rehabilitation is to achieve gains, however small, a second, and equally valid, goal is to maintain function (S. J. Brody, 1986). Given the remarkably varied characteristics of older people who become disabled, achieving gains may be out of the question, but sustaining function may be equated to preserving quality of life and self-esteem. In this study many older people report sustained levels of productivity; this achievement becomes increasingly important in light of the fact that this group is old and becoming older. Age threatens productivity, but in many cases productivity has been sustained. For women who live alone, because of their vulnerability, sustaining functional ability may be essential in avoiding institutionalization.

The model of an active and dependent life proposed by Fulton and Katz (1986) provides another dimension to this discussion. The Katz-Fulton model suggests that the average 65-year-old should be able to enjoy 10 years of active life; indeed, the average 80-year-old should enjoy five years of active life. A goal of rehabilitation should be to preserve an active life for as long as

possible. If it is the impairment of blindness that threatens active life, then rehabilitation should provide the services that will assist individuals to preserve all of the years that a person should normally expect. There is no question that the moment may arise when the gravity and complexity of problems overwhelm an individual's ability to continue to live independently, but if the particular threat can be isolated and addressed, then continued active life may be possible. If, for example, vision impairment threatens the ability to cook, travel, and maintain one's environment, then skills may be taught to address those specific concerns.

The sixth dimension of a rehabilitation model has to do with the family. There is no question that the family is the most tolerant and resilient caregiver, and that the presence of the family preserves independence and dignity. This study points to the kinds of stress that family members experience. It reveals that the proportion of family members expressing concerns can be diminished even though services are provided directly to the person who is older and blind and not the family. Since research in gerontology has shown us that a collapse of the support system is the chief reason that elders are institutionalized, then it is imperative that strategies be developed to preserve the caregiving capacity of the family and not tax it unduly because of a lack of know-

ledge or a lack of rehabilitative services. If additional services can be provided to the family to reduce stress and provide respite, then those people who provide 80-90% of the care can continue to do so. Moreover, the reports of productivity in this study point to the role of family caregivers. For men and women who live with others, disability issues may increase, as people are less involved in meal preparation and other activities. But family support systems combined with the rehabilitation intervention may be factors that lead to greater socialization. Rehabilitation models must address and support the most fundamental institution in our society, the family.

Limitations of the Study

This study is limited by the nature and context of the research. The research was conducted within the confines of the operation of an established service delivery program, and any research conducted within the context of an ongoing program will experience constraints. Therefore, the study describes those participants who come to the program and receive services. It is not a random study of elders who are blind. One might expect that people who seek out and receive rehabilitation services may be different from the entire population of people who are older and blind.

In addition, this study did not use an experimental or even a quasi-experimental research design. Conducting a study within the context of a service delivery model does not allow one to create the controls or withhold services that would establish an experimental research design. Moreover, there are not enough controls to predict causality. One cannot say with certainty that specific rehabilitation interventions lead to particular outcomes. Clearly, changes occurred, but one cannot point to particular reasons for those changes.

In addition, while productivity reports and surveys of family concerns are characterized by an internal reliability, the validity and reliability of the assessment instruments cannot be accomplished within the context of a rehabilitation agency where issues of validity and reliability are not pressing concerns. Although the staff conducting assessments are highly trained, skilled, and experienced, one must expect that these instruments are reasonably reliable, but it is clear that assessments devices were not designed primarily with research goals in mind. Field research of this nature simply must rely upon the available data generated by established instruments. That constraint is not unlike other field research that is conducted in rehabilitation or social service programs.

Suggestions for Future Research

This research serves as a frame of reference to define additional areas of applied research affecting rehabilitation practice and public policy. The limitations of this research help to define those particular issues requiring further inquiry. For example, random studies need to be accomplished to better understand the characteristics of the entire population of elders who become blind. In addition, carefully controlled and much larger studies are needed to identify the impact of various rehabilitation strategies. What specific service components, for example, create the most rehabilitation gain?

In addition, future research needs to explore the relationship of rehabilitation services to shifts in disability and handicap. This study suggests that modest gains in disability areas may lead to greater gains in handicap. This suggestion needs to be tested in controlled studies with larger samples. Moreover, researchers need to better understand the older person's perceptions of these changes. Where, for example, do older people most desire for changes to occur? Would they rather learn additional skills or would they rather achieve greater social integration? Moreover, of the various skills addressed in rehabilitation models, which

ones lead to the greatest impact? Does learning to cross the street have greater impact than being able to read newspaper print with a low vision aid? Or is there a discrete core of services that provides the bulk of gain? If so, perhaps rehabilitation initiatives could focus on fewer skills in more depth knowing that the end result would equally be positive.

Additional research must address the validity and reliability of the ICIDH scales and test the utility of those scales for use in field settings. Strategies should be defined to demonstrate that assessment tools gather and aggregate data in ways that are useful to practitioners and policy makers. In addition, research needs to further test the utility of the scales. Should they be expanded, for example, in a manner to better report small gains?

The research with the family provides a rich area for additional study. Again, subsequent studies should be designed to include control groups. Are the two groups identified in this sample representative of the families of all older people who are blind? The aging literature implies that children who do not have a parent living with them would experience higher levels of concerns than this research reports; therefore, this issue needs to be explored. Moreover, the sample size needs to be expanded considerably so that more can be understood

about adult children who have a parent living with them. The sample size in this study was too small to draw specific conclusions about this discrete group. In addition, this group of 40 people is probably unrepresentative of families experiencing other kinds of disabilities, and more needs to be known about the relationship of these caregivers to other family members in caregiving roles. Are concerns different or more intense? More also needs to be known about the characteristics of these caregivers. What is their age? What health conditions and limitations do they experience? How much are they involved in caregiving? What support systems do they have? This research also suggests that service models should be designed around the concerns that not only clients but families express. If a variety of direct services could be also delivered directly to the family, would changes in client performance be different or much the same? Both quantitative and qualitative research is required in this arena.

The aim of this study is to assist in laying the foundation for these additional research questions that will address policy and practice issues of older Americans who are blind in the decades to come.

Appendix A

Survey for Rehabilitation Services

LABOR

SURVEY FOR REHABILITATION SERVICES
INDEPENDENT LIVING REHABILITATION PROGRAM

Michigan Department of Labor
Michigan Commission for the Blind

AUTHORITY: P.A. 260 of 1978, AS AMENDED. COMPLETION: VOLUNTARY. PENALTY: NONE	THE DEPARTMENT OF LABOR WILL NOT DISCRIMINATE AGAINST ANY INDIVIDUAL OR GROUP BECAUSE OF RACE, SEX, RELIGION, AGE, NATIONAL ORIGIN, MARITAL STATUS, HANDICAP, OR POLITICAL BELIEFS.

Name	Social Security No.	County Code

Birth Date Mo./Day/Yr.	Sex 1 ☐ Male 2 ☐ Female	Ethnic Origin 1 ☐ Black 2 ☐ Caucasian 3 ☐ Oriental 4 ☐ Hispanic 5 ☐ American Indian

Current Address	City	Zip	Telephone

Directions to the Home (Optional)

Geographical Area (Use city or township — check one)

1 ☐ Rural (Under 5,000) 2 ☐ 5,000 — 10,000 3 ☐ 10,000 — 30,000 4 ☐ 30,000 — 50,000 5 ☐ Over 50,000

Current Marital Status (Check only one)

1 ☐ Married 2 ☐ Divorced 3 ☐ Never Married 4 ☐ Widowed 5 ☐ Separated

Education	Veteran
_____ Number of years completed	1 ☐ Yes 2 ☐ No

Referred by	Referral Date

Resource Person (in case of emergency)
Name

Address

Current Doctor

Ophthalmologist

Physician

Eye Condition _____

At what age did your eye problem begin to interfere with your ability to perform daily activities? _____

Hearing Evaluation Requested 1 ☐ Yes 2 ☐ No	Braille Date _____	Mobility Date _____

General Health

A. Active Pathology (Mark if present)

☐ Arthritis ☐ Hypertension ☐ Cancer ☐ Diabetes ☐ Heart Disease
☐ Kidney ☐ Respiratory ☐ Seizure Disorder ☐ Other (Specify)

Comments: _____

B. Federal Reporting (Check if present)

1 ☐ Deafness	5 ☐ Cerebral Palsy	9 ☐ Mental Illness
2 ☐ Other Hearing Impairments	6 ☐ Polio	10 ☐ Epilepsy
3 ☐ Amputation or Absense of Limb(s)	7 ☐ Multiple Sclerosis	11 ☐ Stroke
4 ☐ Spinal Cord Injury	8 ☐ Mental Retardation	12 ☐ Head Injury

C. Medication _____

D. Current perceptions of physical health/illness:

1. In general, how has your health been for the past 3 months?
   1 ☐ Poor 2 ☐ Fair 3 ☐ Good or Very Good
2. During the past three months, how many days has your health kept you from doing those activities which are a part of your normal day?
   _____ days Comments _____
3. During the past 3 months, how many days has your health kept you in bed all or most of the day?
   _____ days Comments _____
4. During the past year, how many days were you an inpatient in a hospital?
   _____ days Indicate reason(s) _____

Ambulation/Mobility/Orientation: Check level of difficulty of applicable items

A. Ambulation

Difficulty			Type
Great	Some	No	
☐	☐	☐	Without Aid (0)
☐	☐	☐	Walker (1)
☐	☐	☐	Wheelchair (2)
☐	☐	☐	Orthopedic Cane (3)
☐	☐	☐	Quadcane (4)
☐	☐	☐	Person (5)
☐	☐	☐	Other (Specify) (6)

B. Present Method of Mobility

Difficulty			Type
Great	Some	No	
☐	☐	☐	Without Aid (0)
☐	☐	☐	Sighted Guide (1)
☐	☐	☐	Guide Dogs (2)
☐	☐	☐	White Cane (Long) (3)
☐	☐	☐	White Cane (Support) (4)

LABOR

SURVEY FOR REHABILITATION SERVICES
INDEPENDENT LIVING REHABILITATION PROGRAM
Michigan Department of Labor
Michigan Commission for the Blind

C. Orientation Within Living Space, Neighborhood, and Community.

Difficulty			Type
Great	Some	No	
☐	☐	☐	Within Home or Living Space
☐	☐	☐	Within Immediate Neighborhood
☐	☐	☐	Outside Immediate Neighborhood

D. Environmental Barriers 1 ☐ Yes 2 ☐ No

Living Arrangement (Check only one)

0 ☐ Lives alone
1 ☐ Lives with spouse, significant other, or children
2 ☐ Lives with friends/unrelated persons
3 ☐ Lives with other relatives
4 ☐ Lives in public institution
5 ☐ Lives in private institution
6 ☐ Lives in foster home
7 ☐ Other

Productivity

A. Household chores:

1. Are you responsible for physically performing household chores? 1 ☐ Yes 2 ☐ No

2. Indicate how frequently you engage in the following activities:

	(0) Not Done	(1) Once Per Week or Less	(2) A Few Times Per Week	(3) Daily
a. meal preparation	☐	☐	☐	☐
b. house cleaning	☐	☐	☐	☐
c. laundry	☐	☐	☐	☐
d. dishes	☐	☐	☐	☐
e. food shopping	☐	☐	☐	☐
f. supervision (children or dependent adults)	☐	☐	☐	☐
g. yardwork, snow shoveling, gardening, home repair (underline appropriate items)	☐	☐	☐	☐
h. Other _____	☐	☐	☐	☐

B. Vocational Status: 1 ☐ Retired 2 ☐ Full-time Employed 3 ☐ Part-time Employed 4 ☐ Unemployed

C. What would you like from this program? (Optional) _____

_____

D. Organizational Memberships

0 ☐ None

1 ☐ 1-2 organizations, regular attendance with either

2 ☐ 1-2 organizations, irregular attendance with both

3 ☐ 3 or more organizations, regular attendance with any one

4 ☐ 3 or more organizations, irregular attendance with all

E. Leisure Activities:

Indicate how frequently you engage in each activity.

	(0) Not Done	(1) Once Per Week or Less	(2) A Few Times Per Week	(3) Daily
a. Public entertainment (e.g., show, dinner, sporting event)	☐	☐	☐	☐
b. Community Center (e.g., church, bingo, cards, travelogue)	☐	☐	☐	☐
c. Shopping (other than for food alone)	☐	☐	☐	☐
d. Visiting friends or relatives	☐	☐	☐	☐
e. Watch television/listen to radio	☐	☐	☐	☐
f. Read newspapers, magazines, books, (TBM or tapes)	☐	☐	☐	☐
g. Have friends or relatives visit	☐	☐	☐	☐
h. Adult education, crafts/hobbies	☐	☐	☐	☐
i. Other, Specify _____	☐	☐	☐	☐

Financial Statement (Optional)

A. Financial Difficulties:

1. Are you currently having trouble meeting your bills? 1 ☐ Yes 2 ☐ No

2. Do you need more income to cover basic living needs? 1 ☐ Yes 2 ☐ No

Appendix B

Functional Assessment Report

FUNCTIONAL ASSESSMENT REPORT

INDEPENDENT LIVING REHABILITATION PROGRAM
MICHIGAN DEPARTMENT OF LABOR
MICHIGAN COMMISSION FOR THE BLIND

AUTHORITY: P.A. 260 of 1978 AS AMENDED COMPLETION: VOLUNTARY PENALTY: NONE	THE DEPARTMENT OF LABOR WILL NOT DISCRIMINATE AGAINST ANY INDIVIDUAL OR GROUP BECAUSE OF RACE, SEX, RELIGION, AGE, NATIONAL ORIGIN, MARITAL STATUS, HANDICAP, OR POLITICAL BELIEFS.
CLIENT NAME _____	CASE NUMBER _____
ENTRY DATE _____	EXIT DATE _____

SCALES FOR FUNCTIONAL ASSESSMENT

PERSONAL PERFORMANCE CAPACITIES

DEFINITION: If you had to do alone, how would you perform this task?

0— Normal Capacity—Client would perform task with satisfactory completion.

1— Diminished Capacity—Client would perform task but satisfactory completion is somewhat affected by problems with speed, pain, or confidence.

2— Reduced Capacity—Client would perform task but satisfactory completion is seriously affected by problems with speed, pain, or confidence.

3— Incapacity—Client cannot perform task with satisfactory completion.

9— No Score—Unable to obtain a reliable rating.

INDEPENDENCE

DEFINITION: How task is performed

A— Alone—Client performs task alone.

B— Aided Performance—Client requires aid or appliance for normal completion of task.

C- Assisted/Dependent Performance—Client performs task with human assistance.

D— Augmented Performance—Client requires both human assistance and aid or appliance.

E— Hired—Client hires task out to someone else, task is performed by a relative/friend or task is provided by facility.

F— No Desire—Client has no desire to perform task or have task performed by another person.

G— Unable—Task is impossible to achieve or sustain; assisted or augmented performance has safety or completeness of task concern.

FUNCTIONAL ASSESSMENT

ORIENTATION AND MOBILITY	ENTRY	EXIT
1. Walk one block/flat surface	____	____
2. Uneven terrain/up 20 stairs	____	____
3. Standing/sitting, lying position	____	____
4. Into/out of bus, public transportation	____	____
5. Ride distances	____	____
6. Street Crossing	____	____
7. Carry small package 1 block	____	____
8. To/from grocery store	____	____
9. Locating items/shopping	____	____
PERSONAL MANAGEMENT		
10. Dressing	____	____
11. Finding/organizing bathing items	____	____
12. Hygiene tasks	____	____
13. Using tub/shower	____	____
14. Selecting/matching clothes	____	____

MDL 259 (9-87) Previous editions obsolete

	ENTRY	EXIT
EATING		
15. Pouring from a pitcher	____	____
16. Dishing out food	____	____
17. Using cup or glass	____	____
18. Cutting meat	____	____
19. Buttering bread	____	____
20. Salt and peppering	____	____
21. Eating tasks	____	____
LOW VISION		
22. Spot reading	____	____
23. Continuous reading	____	____
24. Distance vision (TV, faces, street crossings)	____	____
25. Distinguishing colors	____	____
HEARING		
26. Hearing normal speech	____	____
27. Hearing during interview	____	____
28. Speaking/expressing	____	____
COMMUNICATIONS		
29. Printing/writing	____	____
30. Signature	____	____
31. Braille	____	____
32. Typing	____	____
33. Tape recording devices	____	____
34. Telephone	____	____
ADAPTIVE KITCHEN SKILLS		
35. Opening cans/containers	____	____
36. Slicing/chopping foods	____	____
37. Measuring dry/liquids	____	____
38. Mixing, beating, or kneading foods	____	____
39. Serving foods	____	____
40. Refrigerator/cupboard organization	____	____
41. Washing dishes	____	____
42. Kitchen cleanup	____	____
43. Stove/oven	____	____
44. Switches, plugs, faucets, or dials	____	____
HOME MANAGEMENT		
45. Vacuum cleaner	____	____
46. Laundry	____	____
47. Making Beds	____	____
48. Cleaning, dusting, or polishing	____	____
49. Doorlocks, keys, handles	____	____
50. Opening/closing doors	____	____
51. Sewing	____	____
52. Organize home	____	____
TIME AND MONEY		
53. Using clocks/watches	____	____
54. Identifying coins	____	____
55. Identifying currency	____	____
OTHER		
56. Performing tasks (lifting, reaching, bending stooping, pulling, pushing)	____	____
57. Personal safety	____	____

Appendix C

Family Entry Survey

FAMILY SURVEY

Independent Living Rehabilitation Program

Michigan Commission for the Blind

The Michigan Commission for the Blind is administering a federal grant to serve olde people who are blind. As a part of this program, the Commission wishes to involve th family to better serve blind individuals. By completing this survey, we can better serv you and individuals who are older and blind. Your assistance is much appreciated.

****

Client Name_____ Social Security Number_____

Date of Completion_____

****

1. Caregiver Name_____ 2. Age_____

3. Your relationship with client:
   ___Spouse (1) ___Sibling (2) ___Parent (3) ___Child (4)
   ___In-Law (5) ___Friend (6) ___Other (7) Specify_____

4. Do you live in the same household? ___Yes ___No

5. Did you know the client before he/she became blind? ___Yes ___No

6. Are you employed? ___Yes ___No

7. Has your employment status changed as a result of the client's blindness? ___Yes ___N

8. Do you have any physical problems that interfere with completing daily livin activities? ___Yes ___No

9. To what extent do you want to be involved in our client's independent livin rehabilitation training program?

1	2	3	4
Not at All	As little as Possible	Critical Time	As Much As Possible

10. Realistically, how much time will you be able to spare to participate in ou client's independent living training program?

1	2	3	4
Not at All	As little as Possible	Critical Time	As Much As Possible

11. Circle the number which best reflects your concerns about the client being blind

		No Concern	Some Concern	Important Concern	Critica Concern
a.	His/Her safety	1	2	3	4
b.	Transportation to places	1	2	3	4
c.	Doing housework	1	2	3	4
d.	Preparing meals	1	2	3	4
e.	He/She is depressed, overly anxious, etc.	1	2	3	4
f.	Paying bills	1	2	3	4
g.	How to spend his/her time	1	2	3	4

12. Circle the number which best reflects the current concerns about how the client' blindness affects you.

		No Concern	Some Concern	Important Concern	Critica Concern
a.	Knowing <u>when</u> to help the client do things	1	2	3	4
b.	Knowing <u>how</u> to help the client do things	1	2	3	4
c.	Knowing <u>how much</u> help is needed	1	2	3	4
d.	Frustration over situation	1	2	3	4
e.	Uncomfortable when out in public with client	1	2	3	4
f.	Having enough time available to help the client	1	2	3	4
g.	Taking time away from other family members	1	2	3	4
h.	Getting other work done	1	2	3	4
i.	Leaving for short periods of time (6-8 Hours)	1	2	3	4
j.	Leaving for long periods of time (8 hours or longer)	1	2	3	4

					3
		No Concern	Some Concern	Important Concern	Critica Concern
k.	Taking short car trips with the client	1	2	3	4
l.	Taking overnight trips with the client	1	2	3	4

13. Circle the number in which the client's blindness affected the way these task are accomplished.

		Same as before	Slightly Different	Completely Different	Not Applicable
a.	Meal preparation	1	2	3	4
b.	Snack preparation	1	2	3	4
c.	Child care	1	2	3	4
d.	Lawn/yard care	1	2	3	4
e.	Grocery shopping	1	2	3	4
f.	Arranging for home repair	1	2	3	4
g.	Banking and finance	1	2	3	4
h.	Leisure time	1	2	3	4
i.	Visiting friends/relatives	1	2	3	4
j.	Having friends/relatives visit	1	2	3	4
k.	Eating out	1	2	3	4
l.	Household chores	1	2	3	4
m.	Reading labels/print near seeing	1	2	3	4
n.	Seeing faces, TV distance seeing	1	2	3	4

14. Circle the number in which you think the client can perform the following task by him/herself.

		Cannot do without help	Can/ Extreme Difficulty	Can/ Some Difficulty	Can do Very Well
a.	Crossing Streets	1	2	3	4

4

		Cannot do without help	Can/ Extreme Difficulty	Can/ Some Difficulty	Can do Very Well
b.	Grocery shopping	1	2	3	4
c.	Opening cans	1	2	3	4
d.	Pouring liquids	1	2	3	4
e.	Using knives—cutting, chopping, peeling, etc	1	2	3	4
f.	Using stove/oven	1	2	3	4
g.	Washing dishes	1	2	3	4
h.	Personal care (dressing, hygiene)	1	2	3	4
i.	House cleaning	1	2	3	4
j.	Laundry	1	2	3	4
k.	Selecting/matching clothes	1	2	3	4
l.	Dialing telephone	1	2	3	4
m.	Writing notes/messages	1	2	3	4
n.	Writing signature	1	2	3	4
o.	Identifying coins/currency	1	2	3	4
p.	Telling time	1	2	3	4
q.	Reading pring (labels, newspaper)	1	2	3	4
r.	Seeing faces (distance tasks)	1	2	3	4

15. Has the client's loss of vision had any affect on your personal relationship with:

Friends:

3	2	1	0	1	2	3
Relationships Are Much Worse	Somewhat Worse	Little Worse	No Change	Little Better	Somewhat Better	Relationships Are Much Better

5

Immediate Family Members:

3	2	1	0	1	2	3
Relationships Are Much Worse	Somewhat Worse	Little Worse	No Change	Little Better	Somewhat Better	Relationships Are Much Better

Other Relatives:

3	2	1	0	1	2	3
Relationships Are Much Worse	Somewhat Worse	Little Worse	No Change	Little Better	Somewhat Better	Relationships Are Much Better

16. Are there things that you would like to do but don't because the client is no visually impaired? ___Yes ___No

If yes, describe what those things may be (e.g., vacations, eating out, visitin friends or relatives)

_____

_____

17. List any information you would find helpful in better understanding or copin with the client's blindness.

_____

_____

_____

Appendix D

Family Exit Survey

FAMILY EXIT SURVEY

Independent Living Rehabilitation Program

Michigan Commission for the Blind

The Michigan Commission for the Blind is administering a federal grant to serve olde people who are blind. As a part of this program, the Commission wishes to involve th family to better serve blind individuals. By completing this exit survey, we can bette serve you and individuals who are older and blind. Your assistance is much appreciated.

****

Client Name_____ Social Security Number_____

Date of Completion_____

****

1. Caregiver Name_____

2. Circle the number which best reflects your current concerns about the clien being blind.

		No Concern	Some Concern	Important Concern	Critica Concern
a.	His/Her safety	1	2	3	4
b.	Transportation to places	1	2	3	4
c.	Doing housework	1	2	3	4
d.	Preparing meals	1	2	3	4
e.	He/She is depressed, overly anxious, etc.	1	2	3	4
f.	Paying bills	1	2	3	4
g.	How to spend his/her time	1	2	3	4

3. Circle the number which best reflects the current concerns about how the client' blindness affects you.

		No Concern	Some Concern	Important Concern	Critica Concern
a.	Knowing when to help the client do things	1	2	3	4
b.	Knowing how to help the client do things	1	2	3	4

2

		No Concern	Some Concern	Important Concern	Critica Concern
c.	Knowing how much help is needed	1	2	3	4
d.	Frustration over situation	1	2	3	4
e.	Uncomfortable when out in public with client	1	2	3	4
f.	Having enough time available to help the client	1	2	3	4
g.	Taking time away from other family members	1	2	3	4
h.	Getting other work done	1	2	3	4
i.	Leaving for short periods of time (6-8 Hours)	1	2	3	4
j.	Leaving for long periods of time (8 hours or longer)	1	2	3	4
k.	Taking short car trips with the client	1	2	3	4
l.	Taking overnight trips with the client	1	2	3	4

4. Has the rehabilitation program improved the way the following responsibilitie are accomplished?

		No/Little Improvement	Some Improvement	Great Improvement	Not Applicable
a.	Meal preparation	1	2	3	4
b.	Snack preparation	1	2	3	4
c.	Child care	1	2	3	4
d.	Lawn/yard care	1	2	3	4
e.	Grocery shopping	1	2	3	4
f.	Arranging for home repair	1	2	3	4
g.	Banking and finance	1	2	3	4

		No/Little Improvement	Some Improvement	Great Improvement	3 Not Applicable
h.	Leisure time	1	2	3	4
i.	Visiting friends/relatives	1	2	3	4
j.	Having friends/relatives visit	1	2	3	4
k.	Eating out	1	2	3	4
l.	Household chores	1	2	3	4
n.	Reading labels/print-near seeing	1	2	3	4
m.	Seeing faces, TV-distance seeing	1	2	3	4

5. Circle the number that best reflects how well do you think the client can perfor the following tasks by him/herself.

		Cannot do without help	Can/ Extreme Difficulty	Can/ Some Difficulty	Can do Very Well
a.	Crossing Streets	1	2	3	4
b.	Grocery shopping	1	2	3	4
c.	Opening cans	1	2	3	4
d.	Pouring liquids	1	2	3	4
e.	Using knives—cutting, chopping, peeling, etc	1	2	3	4
f.	Using stove/oven	1	2	3	4
g.	Washing dishes	1	2	3	4
h.	Personal care (dressing, hygiene)	1	2	3	4
i.	House cleaning	1	2	3	4
j.	Laundry	1	2	3	4
k.	Selecting/matching clothes	1	2	3	4
l.	Dialing telephone	1	2	3	4
m.	Writing notes/messages	1	2	3	4

	Cannot do without help	Can/ Extreme Difficulty	Can/ Some Difficulty	Can do Very Well
n. Writing signature	1	2	3	4
o. Identifying coins/currency	1	2	3	4
p. Telling time	1	2	3	4
q. Reading print (labels, newspaper)	1	2	3	4
r. Seeing faces (distance tasks)	1	2	3	4

6. Our rehabilitation services are intended to allow older blind individuals t function more independently in the home and community. Circle the number tha best reflects your general perception of changes that have occurred in th following ways as a result of the rehabilitation program.

	Much Worse Than Before	Worse Than Before	About The Same As Before	A Little Better Than Before	Much Better Than Before
a. Physical Independence: Client is able to do personal tasks such as preparing meals, going places, telling time.	1	2	3	4	5
b. Social Independence: Client gets out of the home to shop, visit friends/relatives, eat out.	1	2	3	4	5
c. Resources/Benefits: Your understanding of resources and benefits available for blind individuals.	1	2	3	4	5
d. Do you feel more relaxed with the situation of how blindness has affected your family member?	1	2	3	4	5
e. You have enough available time for other responsibilities now.	1	2	3	4	5

7. At the beginning of this program, we asked if there were things you wanted to do but didn't because the client is visually impaired. Are there things that yo are doing now (for example, vacations, eating out, visiting, etc.) that thi program has enabled you to do or helped you feel more comfortable about doing?

Thank you very much for completing this form. It will help us better serv others. If there is anything that you would like to share with us, please us the space below to relate successes or concerns. We take your comment seriously, and use them to shape and refine our program.

Appendix E

Exit Survey for Rehabilitation Services

LABOR

SURVEY FOR REHABILITATION SERVICES
INDEPENDENT LIVING REHABILITATION PROGRAM

Michigan Department of Labor
Michigan Commission for the Blind

AUTHORITY: P.A. 260 of 1978, AS AMENDED. COMPLETION: VOLUNTARY. PENALTY: NONE	THE DEPARTMENT OF LABOR WILL NOT DISCRIMINATE AGAINST ANY INDIVIDUAL OR GROUP BECAUSE OF RACE, SEX, RELIGION, AGE, NATIONAL ORIGIN, MARITAL STATUS, HANDICAP, OR POLITICAL BELIEFS.
Name	Social Security No.

Living Arrangement (Check only one)

0 ☐ Lives alone
1 ☐ Lives with spouse, significant other, or children
2 ☐ Lives with friends/unrelated persons
3 ☐ Lives with other relatives
4 ☐ Lives in public institution
5 ☐ Lives in private institution
6 ☐ Lives in foster home
7 ☐ Other

Current perceptions of physical health/illness:

1. In general, how has your health been for the past 3 months?

1 ☐ Poor 2 ☐ Fair 3 ☐ Good or Very Good

Orientation Within Living Space, Neighborhood, and Community.

Difficulty			Type
Great	Some	No	
☐	☐	☐	Within Home or Living Space
☐	☐	☐	Within Immediate Neighborhood
☐	☐	☐	Outside Immediate Neighborhood

Productivity

Household chores:

1. Are you responsible for physically performing household chores? 1 ☐ Yes 2 ☐ No

2. Indicate how frequently you engage in the following activities:

	(0) Not Done	(1) Once Per Week or Less	(2) A Few Times Per Week	(3) Daily
a. meal preparation	☐	☐	☐	☐
b. house cleaning	☐	☐	☐	☐
c. laundry	☐	☐	☐	☐
d. dishes	☐	☐	☐	☐
e. food shopping	☐	☐	☐	☐
f. supervision (children or dependent adults)	☐	☐	☐	☐
g. yardwork, snow shoveling, gardening, home repair (underline appropriate items)	☐	☐	☐	☐
h. Other _____	☐	☐	☐	☐

Leisure Activities:

Indicate how frequently you engage in each activity.

	(0) Not Done	(1) Once Per Week or Less	(2) A Few Times Per Week	(3) Daily
a. Public entertainment (e.g., show, dinner, sporting event)	☐	☐	☐	☐
b. Community Center (e.g., church, bingo, cards, travelogue)	☐	☐	☐	☐
c. Shopping (other than for food alone)	☐	☐	☐	☐
d. Visiting friends or relatives	☐	☐	☐	☐
e. Watch television/listen to radio	☐	☐	☐	☐
f. Read newspapers, magazines, books, (TBM or tapes)	☐	☐	☐	☐
g. Have friends or relatives visit	☐	☐	☐	☐
h. Adult education, crafts/hobbies	☐	☐	☐	☐
i. Other. Specify _____	☐	☐	☐	☐

Appendix F

Changes on Independence Scale

Appendix F

Changes on Independence Scale

Skill	n	%	Entry	Exit	% gain
1. Walk One Block	29	26	46	76	30
2. Up 20 Steps	19	17	37	63	26
3. Standing/Sitting	9	8	78	100	22
4. Into/Out of Bus	10	9	60	70	10
5. Ride Distances	4	4	75	75	0
6. Street Crossing	21	19	23	73	50
7. Carry Packages	6	5	67	83	17
8. To/From Grocery	8	8	0	38	38
9. Locate Items Shopping	15	13	14	71	57
10. Dressing	6	5	33	67	34
11. Organize Bath Items	5	5	80	60	-20
12. Hygiene	6	5	0	60	60
13. Tub/Shower	6	5	67	67	0
14. Select Clothing	27	24	30	70	40
15. Pouring	65	58	71	95	24
16. Serving Food	8	7	75	62	-13
17. Cup/Glass	23	21	87	96	9
18. Cutting	16	14	56	81	25
19. Butter Bread	19	17	63	90	27
20. Salt/Pepper	25	22	88	100	12
21. Eating	6	5	83	100	17
22. Spot Vision	49	44	43	94	51
23. Reading	49	44	50	77	27
24. Distance Vision	36	32	31	89	58
26. Hear Normal Speech	20	18	85	100	15
27. Hear During Interview	17	15	65	100	35
28. Speaking/Expressing	5	4	100	100	0
29. Printing/Writing	73	65	44	88	44
30. Signature	68	61	53	97	44
31. Braille	11	10	0	64	64
32. Typing	13	12	54	69	15
33. Tape Recorder	35	31	26	86	60
34. Telephone	43	38	61	81	20
35. Opening Cans	9	8	67	89	22
36. Slicing/Chopping	22	20	64	91	27
37. Measuring	23	21	65	96	31
38. Mixing	8	7	75	88	13
39. Serving Foods	8	7	63	75	12
40. Organize Cupboards	16	14	56	75	19
41. Washing Dishes	10	9	40	80	40
42. Kitchen Cleanup	9	8	67	67	0

Skill	n	%	Entry	Exit	% gain
43. Stove/Oven	41	37	54	93	39
44. Switches/Plugs	42	38	83	95	12
45. Vacuum Cleaner	3	3	33	33	0
47. Making Beds	4	4	25	50	25
48. Cleaning	4	4	75	75	0
49. Doorlocks/Keys/Handles	10	9	50	90	40
50. Opening Doors	4	4	100	100	0
51. Sewing	31	28	29	87	58
52. Organize Home	4	4	50	75	25
53. Clocks/Watches	64	57	58	98	40
54. Identify Coins	53	47	49	87	38
55. Identify Currency	46	41	46	83	37
56. Lifting	6	5	33	67	34
57. Safety	10	9	40	80	40

Appendix G

Changes on Capacity Scale

Appendix G

Changes on Capacity Scale

Skill	n	%	Entry	Exit	% Gain
1. Walk One Block	29	26	41	79	38
2. Twenty Steps	19	17	32	74	42
3. Standing/Sitting	9	8	44	67	23
4. Into/Out of Bus	10	9	40	70	30
5. Ride Distances	4	4	75	100	25
6. Street Crossing	21	19	29	71	42
7. Carry Packages	6	5	50	83	33
8. To/From Grocery	8	8	50	75	25
9. Locate While Shopping	15	13	40	73	33
10. Dressing	6	5	83	100	13
11. Organize Bath Items	5	5	60	100	40
12. Hygiene	5	5	60	80	20
13. Tub/Shower	6	5	60	100	40
14. Select Clothing	27	24	44	93	49
15. Pouring	65	58	28	99	71
16. Serving Food	8	7	50	100	50
17. Cup/Glass	23	21	48	100	52
18. Cutting	16	14	50	100	50
19. Butter Bread	19	17	37	100	63
20. Salt/Pepper	25	22	72	100	28
21. Eating	6	5	83	100	17
22. Spot Vision	49	44	12	80	68
23. Reading	49	44	5	55	50
24. Distance Vision	36	32	3	70	67
27. Hear During Interview	17	15	59	88	29
28. Speaking/Expressing	5	5	100	100	0
29. Printing/Writing	73	65	25	93	68
30. Signature	68	61	38	97	59
31. Braille	11	10	0	36	36
32. Typing	13	12	23	62	39
33. Tape Recorder	35	31	17	83	66
34. Telephone	43	38	37	67	30
35. Opening Cans	9	8	44	67	23
36. Slicing/Chopping	22	20	41	82	41
37. Measuring	23	21	44	87	43
38. Mixing	8	7	75	63	-12
39. Serving Foods	8	7	63	63	0
40. Organize Cupboards	16	14	38	69	31
41. Wash Dishes	10	9	70	70	0
42. Kitchen Cleanup	9	8	78	56	-22
43. Stove/Oven	41	37	27	85	58
44. Switches/Plugs	42	38	55	93	38
45. Vacuum Cleaners	3	3	0	0	0

Skill	n	%	Entry	Exit	% gain
46. Laundry	7	6	57	86	29
47. Making Beds	4	4	25	25	0
48. Cleaning	4	4	75	75	0
49. Doorlocks/Keys/Handles	10	9	30	90	60
50. Opening Doors	4	4	100	100	0
51. Sewing	31	28	29	81	52
52. Organize Home	4	4	50	75	25
53. Clocks/Watches	64	57	30	95	65
54. Identify Coins	53	47	49	94	44
55. Identify Currency	46	41	41	89	48
56. Lifting	6	5	50	33	-17
57. Safety	10	9	60	80	20

Appendix H

Approval Letter From the Human Subjects
Institutional Review Board

Human Subjects Institutional Review Board

Kalamazoo, Michigan 49008-3899

WESTERN MICHIGAN UNIVERSITY

Date: October 23, 1989

To: John E. Crews

From: Mary Anne Bunda, Chair Mary Anne Bunda

This letter will serve as confirmation that your research protocol, "Demographic Characteristics, Family Concerns, and Rehabilitation Outcomes of a Group of Older People Who Are Blind: A Descriptive Study", has been approved under the exempt category of review by the HSIRB with no requirement for Consent Form since extant data without identifiers are being used to address the research question. The conditions and duration of this approval are specified in the Policies of Western Michigan University. You may now begin to implement the research as described in the approval application. You must seek reapproval for any changes in this design.

The Board wishes you success in the pursuit of your research goals.

xc: P. Kobrak, Public Administration

HSIRB Project Number 89-10-09

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