U.S. Department of Housing and Urban Development
Office of Policy Development and Research

Evaluation of the HOPE for Elderly Independence Demonstration Program

Second Interim Report

Evaluation of the HOPE for Elderly Independence Demonstration

Second Interim Report

Prepared for:
Office of Policy Development and Research
U.S. Department of Housing and Urban Development

Prepared by:
Westat, Inc.
Rockville, MD

Contract HC-5907

August 1996

The contents of this report are the views of the contractor and do not necessarily reflect the views or policies of the U.S. Department of Housing and Urban Development or the U.S. Government.

Foreword

The HOPE for Elderly Independence Demonstration Program (HOPE IV), established by Congress through Section 803 of the National Affordable Housing Act in 1990, combines Section 8 rental assistance with case management and supportive services to help frail elderly, very low-income renters enhance their quality of life while remaining in an independent living environment when home and community based options are appropriate.

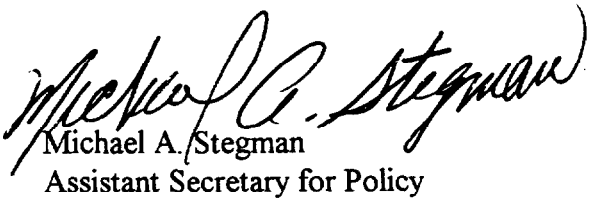
This report is the second in a series of reports from an evaluation which focuses on 16 public housing authorities (PHAs) that received HOPE IV grants in the initial funding round in February 1993. The first interim report described the early program implementation; this report describes the baseline characteristics of program participants and those of a comparison group composed of frail elderly recipients of Section 8 rental assistance who are not receiving HOPE IV supportive services. It also presents the HOPE IV participants' initial views of the program and its services.

Two years into the program, PHAs continue to have difficulties finding candidates not in assisted housing who are sufficiently frail to qualify for HOPE IV. Only one-third of the number of people expected to be available to participate in the program are currently enrolled. The HOPE IV participants are frail at a relatively young age. They are much frailer than non-institutionalized elderly persons in the general population, but they are considerably less frail than persons in community based programs for nursing home eligible or persons in nursing home.

Even though most HOPE IV participants are considered very frail, with many adverse health conditions, they actively participate in activities outside the home and enjoy social contact. Over half of the participants report they are satisfied with their lives, like their neighborhoods and living arrangements, have good appetites, have control over their activities, and have few worries. Almost all say that the HOPE IV program is integral to keeping them independent.

At the outset, the comparison group is remarkably similar to the HOPE IV participants except that they do not receive a package of tailored supportive services. Instead, comparison group members obtain services on their own through community organizations. Comparisons on levels of frailty, frequency and patterns of informal support, and receipt of services will be made in two years to assess the impact of the HOPE IV program on key outcomes such as institutionalization and life satisfaction.

This research will help the Department develop cost-effective policies that meet the intricate and varied needs of America's growing aged population who need help to live independently outside of institutions.



Michael A. Stegman
Assistant Secretary for Policy
Development and Research

Westat Research Team

Stephen K. Dietz, Corporate Officer in Charge

Robert C. Ficke, Project Director and Co-Principal Investigator

Susan G. Berkowitz, Deputy Project Director and Co-Principal Investigator

Cynthia Thomas, Chair, Expert Panels

Mark Matulef, Senior Research Analyst

Gregg Van Ryzin, Senior Research Analyst

Paul Zador, Senior Statistician

David Judkins, Senior Statistician

Rotraut Bockstahler, Survey Operations Manager

Brent Partello, Senior Systems Analyst

Janice Machado, Survey Development Specialist

Michelle Kiser, Research Analyst

Shirley Sandborne, Survey Training

Patricia Davis, Research Analyst

Joyce Powell, Systems Analyst

Shirley Parker, Interviewer Supervisor

Annmarie Howard, Administrative Assistant

Marsha Leizman, Administrative Assistant

Nancy Merrill, Administrative Assistant

Sharon Proctor, Administrative Assistant

Patricia Thayer, Administrative Assistant

TABLE OF CONTENTS

TABLE OF CONTENTS
(Continued)

TABLE OF CONTENTS
(Continued)

List of Appendices

List of Figures

List of Tables

TABLE OF CONTENTS
(Continued)

List of Tables
(Continued)

EXECUTIVE SUMMARY

This is the second report on the HOPE for Elderly Independence Demonstration (HOPE IV) program evaluation conducted by Westat, Inc., for the U.S. Department of Housing and Urban Development (HUD).[1] HOPE IV, a new program that allows considerable flexibility in local implementation, combines HUD Section 8 rental assistance with provision of case managed supportive services to low-income elderly persons (62 and older) with limitations in three or more personal care and home management activities (e.g., bathing, dressing, housekeeping). The purpose of HOPE IV, administered by local Public Housing Agencies (PHAs), is to help participants avoid nursing home placement or other restrictive settings when home and community-based options are appropriate. In addition to rental assistance, HUD pays 40 percent of the supportive services costs, the grantees pay 50 percent, and participants, except for those with very low incomes, pay 10 percent. During the first round of funding (February 1993), the focus of this evaluation, HUD awarded grants to 16 agencies for projects ranging from 25 to 150 persons for a five-year demonstration period. The grants collectively total $9.9 million for the supportive services component and an additional $29.6 million for rental assistance.

This report presents findings from the second phase of the evaluation, covering the baseline surveys of HOPE IV program participants and comparison group members. It primarily describes the HOPE IV participants, including their demographic and housing characteristics, health status, levels of frailty, mental health, and patterns of receipt of informal assistance and social support. It also presents the participants' views of HOPE IV and its services shortly after entering the Program. In addition, the report compares the responses of HOPE IV participants with those of a comparison group of frail elderly recipients of Section 8 rental assistance who are not receiving HOPE IV supportive services. These comparisons cover a few selected domains of particular importance to the success of the study's quasi-experimental design -- levels of frailty, frequency and patterns of receipt of informal assistance, and receipt of services. In two years, the full range of both groups' responses to follow-up surveys will be compared to assess HOPE IV program impact on the key outcomes of interest (e.g., premature or inappropriate institutionalization and life satisfaction). These analyses will be presented in the final report on the HOPE IV evaluation.

[1] Westat was awarded a five-year contract in July 1993 to evaluate the HOPE IV program.

Overview of Findings

- Because of its newness and complexity, the HOPE IV program had difficulty getting started, and by the end of the baseline survey, which was two years after the grants were awarded to the 16 PHAs, only about one third of the participants who were expected to enroll in the program were in place.

- The vast majority of HOPE IV participants are widowed, white females, consistent with the profile of frail elderly Americans overall. In addition, approximately half are age 75 and over, have less than a high-school education, and receive incomes under $8,000 per year.

- Over half of the participants, however, are between 62 and 74 years old, but with few exceptions and in spite of their relatively young age, these persons have similar levels of frailty as their counterparts above age 75.

- Most HOPE IV participants have at least three factors that are highly correlated with frailty and risk of institutionalization in national studies - low-income, low-level of education, and living alone. Advanced age, very low-income, and minority status are the other factors associated with risk, all of which can be found in some of the HOPE IV population.

- HOPE IV participants are much frailer than non-institutionalized elderly persons in the general population, and they are considerably less frail than elderly persons in community based programs for nursing home eligibles or persons receiving nursing home care.

- Levels of frailty, however, vary considerably among participants, confirming the need for case management to tailor supportive services to individual participant requirements.

- Compounding the risks of frailty and need for HOPE IV services, only about half of the participants have someone who could take care of them for any length of time during a protracted illness, and just one quarter say this person could help out indefinitely.

- The majority of participants described their overall health as fair or poor, and over one third said their health had worsened during the past year. In addition, most participants reported multiple chronic health conditions, including arthritis, hypertension, heart disease, and respiratory problems.

- Even though HOPE IV participants are considered very frail and reported having many medical conditions that they say worsened in the past year, more than half report they are satisfied with their lives, like their neighborhoods and living arrangements, are confident, have good appetites, have control over their activities, and have few worries.

- Many HOPE IV participants are not isolated, participate in activities outside the home, and enjoy their social contact. However, the patterns of both in-person and telephone contact showed that most participants have either a great deal of contact or little contact at all, with surprisingly few cases in between.

- Almost all of the HOPE IV participants are able to get help quickly in case of an emergency, but only half can count on sustained help during an illness or other emergency.

- Consistent with the Section 8 program, overall, about one third of the participants moved as a function of the HOPE IV program, either to meet Section 8 Housing Quality Standards or the rental housing requirement.

- Nearly all HOPE IV participants like the program. They are satisfied with the services, feel the service coordinator is helpful, and say that the HOPE IV program is integral to keeping them independent.

The report which follows consists of five chapters, presenting the scope, methodology, findings, and conclusions from the baseline survey of HOPE IV participants and comparison group members. Chapter one provides a description of the HOPE IV demonstration and a summary of the evaluation design. Chapter two presents the demographic and housing characteristics of those participating in the program. Chapter three describes the frailty, health status, emotional well-being, and cognitive functioning of the participants. Chapter four identifies the nature and intensity of participants' social supports, formal and informal systems of care, and initial satisfaction with the HOPE IV program. Chapter five presents the conclusions and implications of the participants and comparison group findings for the follow-up survey and impact analysis. The appendices contain copies of the screening instruments and the baseline participant survey questionnaire.

1. INTRODUCTION

While most elderly persons continue to live independently in their own homes, the rising number of persons throughout the United States who are reaching advanced age heightens the need for provision of assistance with many personal care and home management activities, such as bathing, dressing, and meals preparation. This increase in the numbers of frail elderly creates demands on various community agencies to develop new forms of assistance geared to the special needs of this population. For Public Housing Agencies (PHAs), adapting the Section 8 rental assistance program to the needs of frail elderly tenants means providing a range of services that goes well beyond affordable housing.

1.1 The HOPE for Elderly Independence Demonstration Program

The HOPE for Elderly Independence Demonstration (HOPE IV) program is designed to explore how the U.S. Department of Housing and Urban Development (HUD) can support the needs of a frail, low-income elderly population by combining Section 8 rental assistance with case management and supportive services, to enhance the quality of life and avoid unnecessary or premature institutionalization. To be eligible for HOPE IV, a person must be at least 62 years of age, have an income that generally does not exceed 50 percent of the area's median,[2] reside in or be willing to move to a rental dwelling meeting HUD's Section 8 Housing Quality Standards, not be a current participant in Section 8 or other housing assistance programs, and be frail, according to HUD's definition.

For HOPE IV program purposes, frailty is defined as needing assistance in at least three of the following activities: 1) eating (may need assistance with cooking, preparing or serving food, but must be able to feed self); 2) bathing (may need assistance in getting in and out of shower or tub, but must be able to wash self); 3) grooming (may need assistance in washing hair, but must be able to take care of personal appearance); 4) dressing (must be able to dress self, but may need occasional assistance); and 5) home management activities (may need assistance in doing housework, grocery shopping, laundry, or getting to and from one location to another, but must be mobile, alone or with the aid of assistive devices such as a wheelchair). A Professional Assessment Committee (PAC), in conjunction with a Service Coordinator, determines eligibility, develops a case plan for services, and regularly monitors each participant's condition and care.

---

[2] The median income is adjusted according to family size.

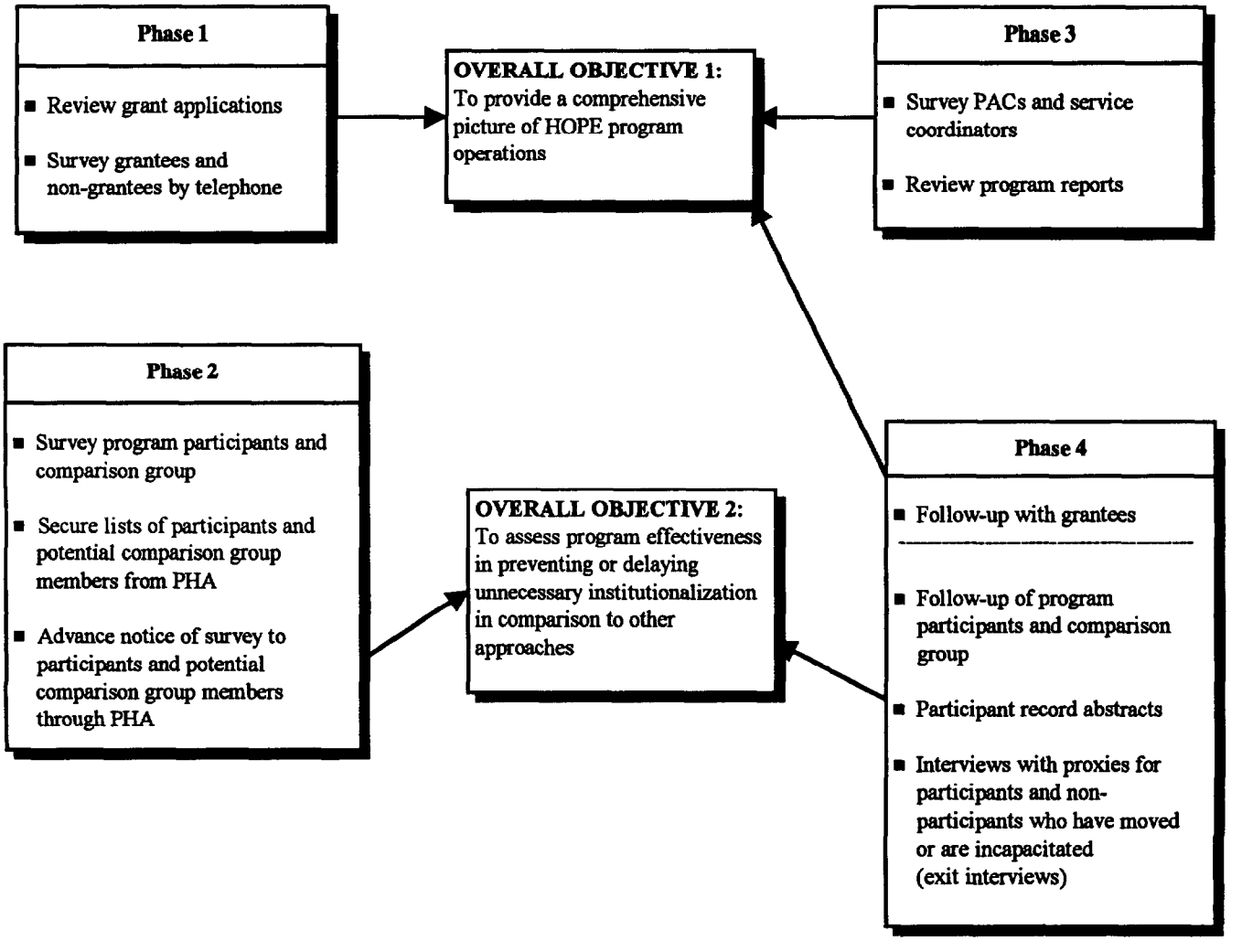
The ultimate goal of the HOPE IV program, administered by local Public Housing Agencies (PHAs), is to demonstrate how PHAs and others can effectively help the frail elderly avoid nursing home placement or other restrictive settings when home and community-based options are appropriate and available. HUD pays 40 percent of the program costs, the grantee pays 50 percent, and the participant pays 10 percent, except where this exceeds 20 percent of the person's income. This report, and the evaluation on which it is based, focuses on the first round of funding, during which HUD awarded grants to 16 grantee agencies for projects ranging in size from 25 to 150 persons for a five-year demonstration period. Collectively, these first-round grants total about $10 million for the supportive services component and approximately $30 million for rental assistance.

1.2 Purpose and Scope of the HOPE IV Evaluation

HOPE IV embraces what for many grantee PHAs is a new Section 8 tenant population. To even begin to meet the special challenges of serving a frail elderly constituency, most HOPE IV grantees have had to adapt their normal Section 8 operating procedures and initiate an array of new services and linkages with other agencies in the community. Beyond specifying minimum age, income, and frailty requirements, HOPE IV allows considerable flexibility in local implementation. This means that relatively little is known in detail about who the first Program participants are. Therefore, the primary purpose of this report is to present a brief portrait of the HOPE IV participants, including their demographic and housing characteristics, health, frailty, mental health, and patterns of receipt of informal assistance and social support. It also describes the participants' initial views of various aspects of the HOPE IV program, including the process of entering the Program, services received, satisfaction with the Program to date, and perceptions of HOPE IV program benefits.

This is the second in a series of reports on the results of a five year evaluation of the HOPE IV program. It presents findings from the second phase of the HOPE IV evaluation, covering the baseline surveys of HOPE IV program participants and comparison group members. The overall evaluation design, as shown in Figure 1-1, occurs in four phases that combine a process evaluation of Program implementation at the 16 HOPE IV grantee sites with a quasi-experimental design to assess Program impact.

Figure 1-1. Overview of Evaluation Plan

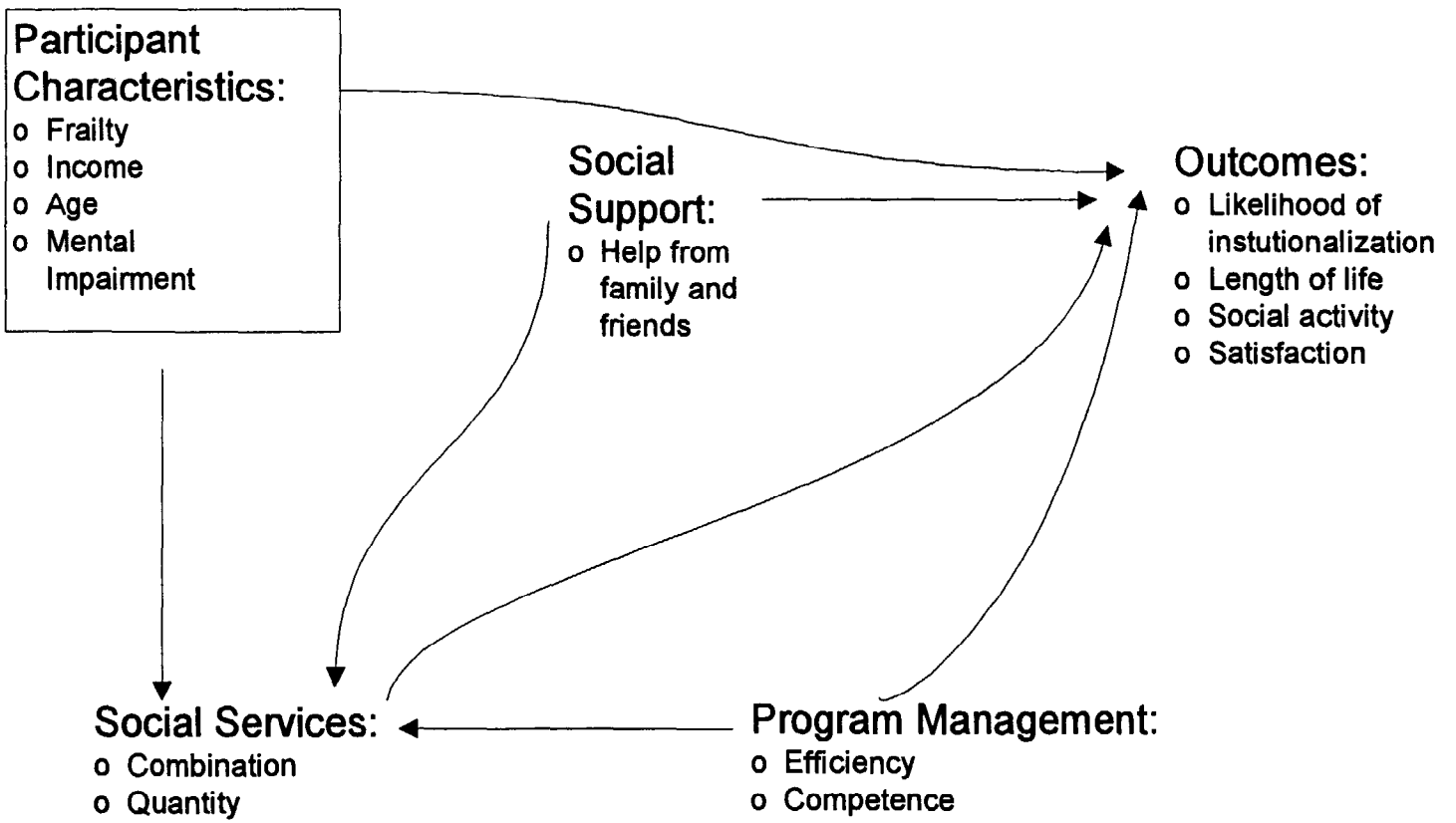


Phase 1, Analysis of Program Design, which began in late 1993, consisted of abstracting grantee applications and surveying the 16 first-round HOPE IV grantee agencies. The aim was to describe the PHA grantees, participant recruitment, services, case management procedures, and the organizational and demographic environment in which the grantees operate. Phase 1 also included a survey of PHAs that did not apply for HOPE IV to determine their reasons for non-participation. The results of this phase are summarized in the first Interim Report, released by HUD in March 1995.

Phase 2, Baseline Participant and Comparison Group Surveys, the focus of the present report, marks the beginning of the evaluation of HOPE IV program impact. The conceptual framework for the quasi-experimental design, illustrated in Figure 1-2, is based on the assumption that the ability of frail elderly people to live independently can be enhanced with certain basic supportive services. These services can and often are delivered informally by family, friends and neighbors, but formal delivery of services by community-based agencies may be needed. By helping to provide a variety of community-based support services, HOPE IV aims to reduce inappropriate or premature institutionalization, increase the length of the participants' lives, and promote their quality of life and life satisfaction. According to this conceptual framework, the outcomes of the demonstration are likely to be influenced by participant demographic characteristics (frailty, income, age), the combination and volume of services delivered to participants, the efficiency and competence of program operations, and the quantity and quality of informal social support received from family and friends.

To test this model and thus assess the impact of HOPE IV program participation on the outcomes of interest, a comparison group was selected of frail, low-income, elderly Section 8 tenants who are not receiving supportive services through the HOPE IV Program. The idea was that the basic comparison would be between HOPE IV participants receiving a combination of Section 8 rental assistance and an individualized, case-managed package of supportive services, and a similar group of frail, low-income elderly receiving Section 8 housing but not HOPE IV supportive services. These comparison group members came from the grantees and other, similar PHAs located in the same states. Comparison group selection procedures, however, only allowed for screening comparison group respondents on reported frailty and age. This left open the possibility that some comparison group members might be receiving supportive services similar to those provided by HOPE IV under other auspices, such as Area Agencies on Aging or other community service agencies.

Figure 1-2.
Conceptual Framework For Impact Evaluation



Consequently, in addition to presenting a portrait of this first group of HOPE IV participants, a secondary purpose of this Second Interim Report is to compare the participants and comparison group in selected domains most germane to establishing the viability of the evaluation's quasi-experimental design. These include, most centrally, basic demographic and housing characteristics, levels of frailty, receipt of informal social support, and receipt of supportive services, any or all of which could importantly affect the ability to discern Program benefits according to the conceptual model presented above. Knowing the degree to which the two groups are alike on these characteristics at baseline will help to guide the analysis of HOPE IV program impact in two years.

Phase 3 of the evaluation, the **Analysis of Service Coordination and Professional Assessment**, began in December 1995, and focuses on telephone surveys of Professional Assessment Committee (PAC) members who determine participant functional status and the Service Coordinators who arrange for and oversee service delivery.

Phase 4, the Follow-up Survey to Ascertain Program Impact, will start in August 1996, and will consist of follow-up surveys of participants and comparison group members approximately two years after the first interviews, to show relative changes in functional status, quality of life and care, and living arrangements, such as nursing home placement. In addition, exit interviews will be carried out with proxy respondents or the Service Coordinator for persons no longer in the program. This final phase will also entail abstracting participant service records. Abstracts of program and financial reports to HUD and a follow-up survey of grantees also will be carried out to ascertain the full implementation of the program.

Phases 1-3 all involve a separate analysis of findings, followed by an integrative final report in Phase 4. Accompanying the final report will be documented data sets from the survey activity to facilitate subsequent analysis and comparison with other programs.

1.3 Phase 2 Methods and Objectives

For Phase 2 of the HOPE IV evaluation, Westat conducted telephone surveys of the 543 HOPE IV program participants who had been recruited and placed by grantee PHAs as of August 1995, and 522 comparison group members selected from among current elderly Section 8 tenants in the grantee agencies and other similar PHAs. We had originally hoped to conduct roughly twice that number of interviews, based on an assumed total of 1,255 first-round HOPE IV participant units. However, the

543 participants interviewed represent all, or very nearly all, the HOPE IV participants in the program, as of early August 1995, when we had to complete this phase of the evaluation.

To provide an early profile of the HOPE IV program, this report presents findings from the first 793 interviews, 388 with HOPE IV participants and 405 with comparison group respondents, representing all surveys completed as of May 31, 1995. Table 1-1 shows the number of these interviews conducted for each of the grantee sites. Table 1-2 lists the agencies supplying the comparison group names. Selection of May 31, 1995, for the cut-off date allowed for timely analysis and presentation of information on the characteristics of the first-round Program participants for this report. However, the follow-up survey and impact analysis to be conducted in two years will use data from all 543 participant and 522 comparison group Phase 2 interviews.

We achieved an overall response rate of 96 percent for participants and 94 percent for the comparison group. Nineteen percent of the interviews conducted with HOPE IV participants, and 20 percent of those carried out with comparison group members, were completed by proxies. Proxies were used when the frail elderly respondent had physical health or mental acuity problems that made it difficult or impossible to conduct the interview, or when respondents specifically requested that a proxy be used. Most proxies were the respondent's child. Although less than five percent of all the interviews were carried out in Spanish, about 10 percent of proxy interviews were in Spanish.

Before we could administer the full telephone survey to comparison group respondents, we had to screen from the larger pool of persons 62 and older whose names had been provided by the comparison PHAs. Although a few of the 16 grantee PHAs could supply some names of elderly Section 8 tenants not in the HOPE IV program, to ensure a sufficient number of comparison group respondents, it was necessary to develop a list of about 60 comparison PHAs, chosen for their geographic proximity and demographic similarity to the 16 HOPE IV sites. These PHAs supplied names, addresses, telephone numbers, and basic demographic information on persons 62 and older receiving Section 8 rental assistance, but could not provide information on frailty. Therefore, we administered a screener designed to select comparison group members with levels of frailty similar to those of HOPE IV program participants. The screener consists of eleven questions on limitations in various activities related to the HOPE IV eligibility regulations, each of which has a numeric score. Those scoring above a certain threshold on the screener, who represented about 1 out of every 5 persons on the larger list, were selected into the comparison group and administered a full comparison group survey. A copy of the screener appears in Appendix A.

Table 1-1. Participant and Comparison Group Agencies and Interviews

Grantee PHA Name	Number of Participant Interviews 5/31/95	Number of Comparison Group Interviews 5/31/95*
City of Mesa Housing Authority, AZ	74	63
City of Tucson Community Services Department, AZ	23	23
Housing Authority of the City of Redding, CA	41	65
Jefferson County Housing Authority, CO	59	44
Waterloo Housing Authority, IA	14	15
Housing Authority of Jefferson County, KY	5	10
Somerville Housing Authority, MA	0	0
Housing Authority of the City of Westbrook, ME	18	9
New Hampshire Housing Finance Authority, NH	57	59
New Jersey Department of Community Affairs, NJ	0	0
Fayette Metropolitan Housing Authority, OH	38	27
Oklahoma City Housing Authority, OK	10	5
Miami Housing Authority, OK	10	5
Fayette County Housing Authority, PA	4	5
Housing Authority of the City of El Paso, TX	10	30
Housing Authority of the City of Richland, WA	25	15
TOTAL	**388**	**405**

* The comparison group consisted of elderly Section 8 tenants, not in the HOPE IV program, who were screened for frailty and came from a total of 52 PHAs, including the HOPE IV grantees and others in the same states with similar demographic characteristics.

Table 1-2. Comparison Group Sites

Arizona	New Hampshire
City of Mesa Housing Authority*	New Hampshire Housing Finance Authority*
Maricopa County Housing Division, Phoenix	Berlin Housing Authority
Tempe Housing Authority, Tempe	Claremont Housing Authority
City of Tucson Community Services Department*	Franklin Housing Authority
	West Lebanon Housing Authority
California	**Ohio**
Housing Authority of the City of Redding*	Fairfield Metro Housing Authority, Lancaster
Yuba County Housing Authority, Marysville	Greene Metro Housing Authority, Xenia
Housing Authority of the City of Eureka and the County of Humboldt	Pickaway Metro Housing Authority, Circleville
Housing Authority of the County of Butte, Chico	
Shasta County Housing Authority & Community Action Agency, Redding	
Colorado	**Oklahoma**
Jefferson County Housing Authority*	Oklahoma City Housing Authority*
Housing Authority of the City of Englewood	Housing Authority of the City of Shawnee
Littleton Housing Authority	Housing Authority of the City of Norman
Sheridan Housing Authority	Miami Housing Authority, Oklahoma*
Longmont Housing Authority	Shawnee Housing Authority
Housing Authority of City and County of Denver	Housing Authority of the Delaware Tribe, Chelsea
Aurora Housing Authority	Housing Authority of the City of Norman
Boulder County Housing Authority	Oklahoma Housing Finance Authority, Oklahoma City
Housing Authority of Brighton	
Iowa	**Pennsylvania**
Cedar Falls Housing Authority	Fayette County Housing Authority, Uniontown*
Iowa City Housing Agency	Washington County Housing Authority
Charles City Housing Commission	Housing Authority of Greene County, Waynesboro
Davenport Housing Commission	
Sioux City Housing Authority	
Kentucky	**Texas**
Housing Authority of Jefferson County*	Housing Authority of the City of El Paso*
	Laredo Housing Authority
	McAllen Housing Authority
Maine	**Washington**
Portland Housing Authority	Housing Authority of the City of Richland *
Auburn Housing Authority	Housing Authority of the City of Kennewick
	Housing Authority of Grant County
	Housing Authority of the City of Pasco and Franklin County

* Also a HOPE IV grantee site.

The primary source of information for this report comes from administration of an approximately hour-long telephone survey instrument covering demographic information, housing characteristics, physical health, activities of daily living, mental health and mental acuity, informal assistance and social support, service utilization, and, for participants only, HOPE IV program participation. The baseline survey of participants and comparison group members, a copy of which is presented in Appendix B, was designed to address the following research questions and objectives:

- *To describe program participants and comparison group members* -- including demographic characteristics, level of frailty and functional status, general state of physical health, state of mental health, life satisfaction, mental acuity, and housing characteristics.

- *To study the informal assistance and social support received by HOPE IV participants and comparison group members* -- including who provides informal help, how often, types of help provided, accessibility and availability of help in an emergency, and, for HOPE IV participants, how this compares to help and support received before entering HOPE IV.

- *To investigate the HOPE IV participants' and comparison group members' receipt of supportive services* -- including specific services received through HOPE IV and other sources, frequency and length of receipt, satisfaction with services, and, for participants, utilization of services prior to entering HOPE IV.

- *To examine various aspects of the participants' experience with the HOPE IV program to date* -- including how participants were recruited, their perceptions of their service coordinators, Program features participants regard as most important to their continued independence, and the participants' overall assessment of Program benefits to date.

1.4 The Organization of this Report

Following the Executive Summary and Introduction, Chapter 2 presents data on the demographic and housing characteristics of the participants from the 14 (of the 16) HOPE IV grantees that had placed participants at the time of the survey. This includes age, gender, race/ethnicity, income, marital status, living arrangements, and educational attainment. These characteristics describe the participants in this new demonstration and identify persons with particular risk factors, such as very low levels of education, extreme poverty, and living completely alone. In addition, this chapter describes the types of housing that participants occupy, whether they had to move to meet HUD Housing Quality Standards, and their levels of satisfaction with housing. Comparison group respondents are compared to the HOPE IV respondents to establish baseline similarities.

Chapter 3 presents the most important indicators of service needs using measures of functional status, health, mental health, and cognitive status. These indicators relate to the HOPE IV eligibility

criteria and provide a baseline for assessing program impact over time. Comparing measures of frailty for the participants and comparison group is also important to establish the viability of the quasi-experimental design.

Chapter 4 describes the frequency and kind of informal assistance and social support participants receive from family and friends, and compares this to the support received by the comparison group. As discussed above, the availability of informal and other non-HOPE IV support ultimately may be germane to explaining outcomes related to preventing or delaying unnecessary institutionalization. This chapter also compares the participants' and comparison group respondents' perceptions of the quality and adequacy of their social activities and the availability of help in emergencies. As indicated in the conceptual model, the nature and frequency of social interaction and social support may itself prove to be an important outcome measure. Finally, the chapter gives the participants' initial views and impressions of different aspects of the HOPE IV program.

Chapter 5 summarizes our conclusions from this second phase of evaluation activities.

2. DEMOGRAPHIC AND HOUSING CHARACTERISTICS OF THE HOPE IV PARTICIPANTS

2.1 Demographic Characteristics

HOPE for Elderly Independence, as a new service for many Public Housing Agencies, brings frail elderly tenants and an accompanying system of case management and supportive services into Section 8 rental assistance programs. To be eligible for HOPE IV, participants must meet the program's age, income, and frailty guidelines, but within these criteria there are many other possible combinations of demographic characteristics. Of particular interest are those factors that prior research shows are highly correlated with risk of institutionalization and need for services. While the disability measures in Chapter 3 are the most predictive in this regard, demographic characteristics are important as well. These include advanced age, living alone, very low income, minority status, and low levels of educational attainment.

2.1.1 Age, Race/Ethnicity, and Gender

The baseline survey found that the vast majority of HOPE IV participants are white females, many of whom are of advanced age. Table 2-1 shows that nearly half of the participants are at least 75 years of age, and more than 15 percent are over the age of 85. Of particular interest, however, is the fact that over half of the participants are under the age of 75, a group not often at high risk of institutionalization. For example, only 16 percent of elderly nursing home residents are less than 75 years of age.[3]

Table 2-1.
Demographic Characteristics:
Age, Race/Ethnicity, and Gender

Characteristics	Participants *(n-388)* (%)	Comparison Group *(n=405)* (%)
Age		
62-74	52	48
75-84	33	32
85 and over	15	20
Race		
White	95	84
Black	2	8
Other	2	2
Don't know	1	4
Hispanic origin*	7	13
Gender		
Female	80	83
Male	20	17

*Hispanics can be of any race.

[3] National Center for Health Statistics, 1985 National Nursing Home Survey, *Vital and Health Statistics*, Series 13, No. 97, Table 27.

During interviews with the HOPE IV grantees, the Service Coordinators, who have major responsibility for outreach and recruitment, stated that scattered site rental housing, even with case management and supportive services, required participants to be far less frail than the nursing home population. These Service Coordinators also saw the HOPE IV program serving an elderly population who had fewer needs than persons in many other community-based, long-term care programs, such as those operated under various Medicaid waivers as alternatives to nursing home placement. For example, of those participating in the Long Term Care Channeling Demonstrations, a home- and community-based, long-term care alternative for persons who are nursing-home eligible, only 27 percent were under the age of 75.[4] These HOPE IV participant age characteristics are also consistent with the program regulations, which set a level of frailty, for eligibility purposes, that are far less severe than for either nursing home residents or those participating in home and community-based alternatives. We also found, when analyzing HOPE IV participant data on frailty according to age, as discussed in Chapter 3 below, that the youngest group reported rates of limitation in activities of daily living that were similar for those over age 75. We also found that this age profile varied somewhat among grantees. For example, the percentage below age 75 ranged from 30 percent to 75 percent, but the relatively small numbers of participants at some grantees requires analysis of participant data as a whole..

Unlike age, the race and Hispanic origin of participants was often a function of the overall characteristics of the grantee location. For example, the majority of first round HOPE IV grantees were not in locations with high concentrations of minority elderly. This was especially true for those grantees that had recruited a substantial number of their participants in time for inclusion in the baseline survey. There were exceptions, however, for some HOPE IV sites had few if any black or Hispanic participants, despite sizable numbers of these groups among the overall elderly population in the grantee's locale.

Nearly all the participants were white (95 percent), while only 4 percent came from other racial groups. Those of Hispanic origin, who can be of any race, comprise seven percent of participants, virtually all from a single grantee PHA in an area with a high concentration of Mexican American elderly. As a caveat, these figures come from only the first one third of HOPE IV participants the grantees hope to ultimately recruit. Many of the areas that had only just begun placement and services under HOPE IV are also locations with high concentrations of minority elderly, both black and Hispanic. For this reason, the percentage of minority participants will likely rise with full implementation of the program.

---

[4] Mathematica Policy Research, The Evaluation of the Long Term Care Demonstration: Final Report, U.S. Department of Health and Human Services, 1986, p.41.

Over three-quarters of the participants were female, mirroring the profile of America's population of low-income, frail elderly, overall. This pattern generally held across all the grantee sites. Federal statistical agency data show that most poor, frail elderly in this country are female, and the HOPE IV participants reflect this national trend. For example, according to the Census Bureau, of persons age 65 and over who are below the poverty threshold and have a severe disability, 78 percent are women and 22 percent are men.[5]

Table 2-1 also shows considerable similarity between the participant and comparison groups regarding age, for each of the three cohorts. Concerning race/ethnicity, the black and Hispanic rate differences should mitigate as grantees in areas with high concentrations of minorities increased their enrollment and the remaining baseline interviews (approximately 150) incorporate this change. These race/ethnicity percentages are based on very small numbers and, therefore, subject to substantial change with continued program implementation. Given that most frail elderly are, in fact, women, screening solely on the basis of frailty and age yielded a gender profile of participant and comparison group members that is nearly the same.

2.1.2 Marital Status and Living Arrangements

Most of the participants have been widowed for many years and are living alone. As Table 2-2 shows, less than 10 percent of participants were married at the time of the survey, while over 60 percent were widowed and another 30 percent were divorced, separated, or never married. Of all participants, over 36 percent had been widowed for more than 10 years, and nearly half for more than five years. Only 7 percent had been widowed during the past two years. Consistent with these figures, the vast majority of participants (87 percent) lived alone. Only 11 percent lived with one other person, and virtually none were in households with more than two persons. Consistent with HOPE IV's focus, persons who are frail and live alone are at considerable risk, relying on outside help for assistance they may need in performing activities of daily living.

[5] McNeil, J.M., Americans with Disabilities: 1991-92, U.S. Bureau of the Census, Current Population Reports, P70-33, U.S. GPO, Washington, D.C., 1993, Tables 13 and 14.

Approximately one third of the participants moved as a function of the HOPE IV program, either to meet Section 8 Housing Quality Standards or the rental housing requirement. Many HOPE IV applicants lived in rental housing not meeting Section 8 requirements; in some cases, the applicants owned their residences. These individuals either chose to forego enrollment in the HOPE IV program by not moving, or they relocated into qualifying housing as HOPE IV participants. Conversely, nearly 60 percent of participants already lived in rental housing meeting HUD Housing Quality Standards.

Table 2-2.
Demographic Characteristics:
Marital Status and Living Arrangements

Characteristics	Participants *(n=388)* (%)	Comparison Group *(n=405)* (%)
Marital status		
Widowed	61	56
Divorced	23	25
Married	9	10
Separated	4	4
Never married	3	4
Years widowed		
Not widowed	39	44
1 to 2 years	7	4
3 to 4 years	5	5
5 to 10 years	13	23
Over 10 years	36	24
Living arrangements		
living alone	87	79
2 persons	11	17
More than 2 persons	1	2
Unknown	1	1
Moved to qualify for HOPE IV		
Yes	33	NA
No	60	NA
Unknown	8	NA

Figures on moving are important for several reasons. First, studies of the elderly show that changing residence can be a traumatic experience that exacerbates, rather than alleviates, the problems of frailty that HOPE IV is attempting to address. Second, as interviews with Service Coordinators and other HOPE IV staff revealed, locating adequate housing was a substantial barrier to implementation of the program. The rental units not only had to meet Section 8 Housing Quality Standards, but also had to appeal to the frail elderly, in terms of accessibility, safety, and proximity to community services. In this regard, there were problems of housing availability. For example, Service Coordinators reported that after being on a Section 8 waiting list for several years, some HOPE IV participants had to place themselves on waiting lists for private rental housing for the elderly in their community in order to obtain a suitable apartment.

Table 2-2 also confirms that the marital status and living arrangements of the participant and comparison groups are nearly the same. This table also shows there is a high level of consistency regarding many other demographic factors when selecting comparison group members solely on the basis of age and frailty.

2.1.3 Education, Income, and Housing Costs

Many studies of the elderly show that age, alone, is a poor predictor of service needs, except at the far end of the spectrum, such as over 85 years. Other factors, such as education and income, however, are highly correlated with frailty and risk for loss of independence. Table 2-3 presents information on the education, income, and rental payments of HOPE IV participants. *Nearly half of those in the program have not completed high school, and while all are poor, there is substantial variation within this low-income group.* For example, nearly 20 percent have annual incomes under $6,000 and almost half receive less than $8,000. Monthly tenant contribution to rent (including utilities), which varies as a function of income, is quite low. More than half of the participants pay less than $200 a month in rent, and over three-quarters pay less than $300.

Table 2-3.
Demographic Characteristics:
Education, Income, and Tenant Contribution to Rent

Characteristics	Participants *(n=388)* (%)	Comparison Group *(n=405)* (%)
Education level		
No formal schooling	4	8
Not a high school graduate	44	56
High school graduate	31	20
Some college	14	12
College graduate	5	4
Unknown	3	2
Income		
Less than $6,000	19	25
$6,000 to $8,000	31	40
$8,001 to $10,000	24	21
More than $10,000	23	14
Unknown	3	0
Monthly tenant contribution to rent		
Less than $100	16	8
$100 to $200	37	66
$201 to $300	24	17
More than $300	13	7
Unknown	9	2

Table 2-3 shows that the comparison group also had substantial numbers with less than a high school education, low incomes, and low tenant contribution to rent. The rates for these items, however, were somewhat higher than for participants in the HOPE IV program.

2.2 Housing Characteristics and Satisfaction

This section describes the homes and neighborhoods in which the HOPE IV participants live and the attitudes of these persons about their environment. For those participants who moved within the past

year, either to qualify for HOPE IV or in response to the new housing choices the program provided, this section also compares participant feelings about the old and new neighborhoods.

2.2.1 Satisfaction and Safety

Participants not only were quite satisfied with their current living environment but also felt safe most of the time. Table 2-4 shows that nearly 70 percent of participants indicated they were very satisfied with their living arrangements, while another 21 percent reported they were just somewhat satisfied. Only 5 percent stated they were somewhat or very dissatisfied with their current living environment. Concerning safety, 88 percent reported they feel safe most of the time, while 10 percent felt safe only some of the time or rarely. As a program model that is often new to both public housing agencies and a frail elderly tenant population, HOPE IV participant satisfaction and perception of safety are extremely important indicators for continuation and expansion of the concepts embodied in the demonstrations. The comparison group reported similar rates of satisfaction and feelings of safety, despite having lived in their neighborhoods far longer than participants (see Table 2-7).

Table 2-4.
Housing Characteristics:
Satisfaction and Safety of Current Living Environment

Characteristics	Participant *(n=388)* (%)	Comparison Group *(n=405)* (%)
Satisfaction:		
Very Satisfied	69	64
Somewhat satisfied	21	25
Neither satisfied nor dissatisfied	4	3
Somewhat or very dissatisfied	5	8
Unknown	1	0
Safety:		
Feel safe most of the time	88	85
Feel safe some of the time	8	10
Feel safe rarely or never	2	4
Unknown	2	1

2.2.2 Physical Features

With the physical features of buildings, we begin to see some differences between the participants and comparison group that may be a function of length of time receiving Section 8 assistance. Table 2-5 shows that over two-thirds of the HOPE IV participants live in a building with more than one floor versus about 50 percent for the comparison group. Section 8 rental assistance allows flexibility in the type of

rental housing; thus some HOPE IV participants and comparison group members live in a single-family home, such as a rented house with more than one story. This is the exception, however, for 98 percent of the participants and 96 percent of the comparison group members have all their rooms on one floor.

Concerning accessibility, 42 percent of participants and 47 percent of the comparison group must climb at least one stair to enter their building. Also, approximately 8 percent of participants and the comparison group reported living in a rental unit above the first floor without a working elevator in their building.

Table 2-5.
Housing Characteristics:
Physical Features

Characteristics	Participants *(n=388)* (%)	Comparison Group *(n=405)* (%)
More than one story building	68	49
Stairs required for entry	42	47
Unit is above first floor	35	25
Unit above first floor without working elevator	8	8
All rooms are on same floor	98	96
Interior modifications made	16	16
Difficult to enter home	13	17
Difficult to get around home	8	12

According to the grantees, an issue of considerable importance during implementation of the HOPE IV program was locating rental units that not only met Section 8 Housing Quality Standards but also were relatively free of physical barriers, given the tenant's level of frailty. Modifications were made to units; 16 percent of participants reported interior modifications to their housing units, including installation of grab bars and modifications to the bath and shower to facilitate use by persons with disabilities. Concerning the consequences of physical barriers, 13 percent of the participants reported difficulty entering their home, while 8 percent said it was difficult to get around inside their unit.

2.2.3 Participant Use of Community Services within Walking Distance of Home

Participants reported that the services within walking distance of their homes that they most frequently used were dry cleaners or laundromats (24 percent), grocery stores (22 percent), drug store or pharmacy (17 percent), and beauty parlor or barber shop (17 percent), as Table 2-6 shows. Less than one quarter of the participants, however, use these essential services within the proximity of their own home, suggesting that they require transportation and escort services to other locations. These figures provide

some context for the supportive services information presented in Table 4-7, below. For example, transportation is the second most frequently used service for both participants and the comparison group, after housekeeping.

Table 2-6.
Housing Characteristics:
Participant Use of Community Services within Walking Distance of Home

Community Services	Participants *(n=388)* (%)
Dry cleaners/laudromats	24
Grocery stores	22
Drug store/pharmacy	17
Beauty parlor/barber shop	17

2.2.4 Length of Time in Current Home

Nearly half of the participants had moved into their current home within the past year, either in conjunction with the HOPE IV program, or for other reasons. In contrast, only 7 percent of the comparison group had lived in their current home for less than one year (Table 2-7). Nearly 30 percent of participants had lived in their home from one to four years, and almost one quarter had been there at least five years. Only 11 percent of participants had lived in their homes for more than 10 years, versus 29 percent for the comparison group.

Participants who had moved within the past year identified their reasons for relocating. The evaluation includes this information to help determine if participants felt they had to move in order to enroll in the HOPE IV program, or if other factors explained why they relocated. HOPE IV is a combination of two types of benefits, the first consisting of Section 8 rental assistance, and the second covering supportive services. Given the long waiting periods for receiving Section 8, in many cases more than two years, grantee locales had a substantial unmet demand for affordable rental housing. At the same time, given the requirements of HOPE IV, applicants may have had to choose between staying in their current home and foregoing HOPE IV services, or giving up their residence in order to meet the rental housing and housing quality standards of Section 8, which also apply to HOPE IV. For these reasons, the study sought to distinguish between participants who moved primarily as a function of HOPE IV program requirements and those who reported another primary reason. Of the 46

Table 2-7.
Housing Characteristics:
Length of Time in Current Home

Characteristics	Participants *(n=388)* (%)	Comparison Group *(n=405)* (%)
Less than 6 months	29	3
6-11 months	17	4
1-4 years	29	30
5-10 years	14	34
More than 10 years	11	29

percent of participants who had lived in their home for less than one year, about half said they moved as a function of HOPE IV, with the other half reporting different reasons, such as proximity to children, safety, and cost. Given the benefits of remaining in place for this population, the impact analysis will explore the relationship between housing stability and various outcome measures, such as nursing home placement and life satisfaction.

2.2.5 Characteristics of New Neighborhood

When asked to compare their old and new neighborhoods, participants who had moved within the past year reported their present location to be the same or more favorable than their previous neighborhood in terms of convenience to transportation and services, safety, visitation by family and friends, and noise levels. Less than half, however, said they knew as many or more neighbors in their new area than the old one, possibly as a function of how recently they moved.

Table 2-8.
Housing Characteristics:
How Does Present Neighborhood Compare to Previous Neighborhood?

Characteristics	Participants *(n=178)* (%)
New neighborhood is the same or more convenient to transportation and services	64
Feel as safe or safer in new neighborhood	83
Visited the same or more often in new neighborhood	74
New neighborhood is as quiet or quieter	83
Know as many or more neighbors in new neighborhood	48

3. FUNCTIONAL STATUS AND HEALTH

3.1 Frailty of HOPE IV Participants

HOPE IV regulations require that participants not only qualify for Section 8 rental assistance by virtue of their low-income, but also need assistance in basic life activities, as defined in 1.1, above. These activities cut across two primary measures of frailty frequently used in research: limitations in *Activities of Daily Living (ADL)* and *Instrumental Activities of Daily Living (IADL)*. ADLs include five very basic activities essential to independent living: eating, dressing, bathing, transferring (between bed and chair), and toileting (getting to and using the toilet as opposed to continence).[6] IADLs go beyond ADLs in level of complexity and include handling personal finances, meal preparation, shopping, traveling about the community, doing housework, using the telephone, and taking medications.[7]

To ensure consistency with the considerable body of prior research on the frail elderly, the HOPE IV study design collected data in terms of these standard ADL/IADL measures, as well as the additional activities in the HOPE IV regulations. By doing so, this report can present a functional profile of the HOPE IV participants relative to both the HUD program regulations and other studies of frailty among the elderly, especially in relation to participants in other community-based, long-term care programs. The following tables and accompanying narrative begin with the traditional ADL/IADL measures and end with a presentation and discussion of frailty in terms of the HOPE IV program regulations.

3.1.1 Activity of Daily Living Limitations

Table 3-1 identifies the number and percent of HOPE IV participants reporting difficulty in performing each of the five ADLs, including those who are unable to do so, as well as those who have some or a lot of difficulty. In addition, the table shows how many report multiple ADL difficulties, as a composite indicator of frailty. *Nearly 80 percent of the participants reported difficulty performing at least*

---

[6] Katz, S., and C.A. Apkom, A measure of primary sociobiological functions. International Journal of Health Sciences 6:493-508, 1976.

[7] Lawton, M.P. and E.M. Brody, Assessment of older people: Self-maintaining and instrumental activities of daily living. *Gerontologist* 9:179-186, 1969.

one ADL, with individual activity limitation rates ranging from a high of 51 percent for transferring between bed and chair to a low of 12 percent for feeding oneself.

Measures of frailty are of greatest importance in confirming the viability of the comparison group, given the extensive weight that HOPE IV regulations and local recruitment practices place on these criteria. Table 3-1 shows there is considerable similarity between the participant and comparison groups in both the individual and multiple measures of ADL performance difficulty. The participants, however, report somewhat lower rates than the comparison group in having at least one ADL limitation (79 percent versus 90 percent), or in two ADL limitations (19 percent versus 26 percent). Statistical techniques can correct for any differences when the impact analysis occurs after the two-year follow-up interviews.

Table 3-1.
Frailty Characteristics:
Activity of Daily Living (ADL) Limitations

Activities	Participant *(n=388)* (%)	Comparison Group *(n=405)* (%)
Limitation in		
Bathing	41	45
Dressing	43	47
Bed/chair transfer	51	64
Using toilet	29	22
Feeding self	12	13
Multiple ADL limitations		
One or more	79	90
None	21	10
One	22	23
Two	19	26
Three	20	21
Four	13	15
Five	5	5

When analyzing participant data across the 14 of 16 grantee sites that had recruited and placed participants at the time of the survey (see Table 1-1), the average number of ADL limitations ranges from 0.8 to 3.0. The mean number of ADL limitations for all participants is 1.9. Given the small number of participants at some sites, the analysis in this report focuses on participants, overall, and within broad demographic and functional categories.

Given the large percentage (approximately half) of participants who were under the age of 75, it is reasonable to ask if this group reported a relatively low level of ADL limitations. When analyzing HOPE IV participant measures of frailty as presented in Table 3-1, however, the percentage reporting multiple Activity of Daily Living limitations was similar for the three age cohorts: less than 75 years, 75 to 84 years, and 85 and above. The exception was for those reporting a limitation in all five ADLs, where the activity limitation rates for the oldest age group were more than three times higher than the youngest cohort (10

percent versus 3 percent). Those reporting difficulty with all five ADLs, however, comprise only about five percent of all participants.

HOPE IV participants are considerably more frail than the elderly population as a whole, in terms of the ADL difficulty criteria in Table 3-1. Measures of ADL difficulty address very basic life activities essential for independent living, affecting a relatively small percentage of the overall elderly population. For example, among all non-institutionalized elderly age 65 and over, only 11 percent reported a limitation in at least one ADL, ranging from about 9 percent for dressing to approximately one percent for feeding oneself.[8] By contrast, nearly 80 percent of HOPE IV participants report difficulty performing at least one ADL.

When describing physical frailty, other community-based, long-term care surveys or programs often identify the number of persons receiving (or needing) help from another person to perform the activity, as opposed to just having a difficulty or a limitation. These studies use the term ADL dependencies to describe this measure, which identifies a more severe limitation than simply reporting difficulty performing the activity. Using this constructured definition, approximately 44 percent of HOPE IV participants reported receiving help from another person for at least one of the five ADLs. For comparison purposes, only about 8 percent of the total household population age 65 and over reported receiving such help from another person in performing at least one of these five ADLs.[9]

While HOPE IV participants are considerably more frail than the elderly population overall, they are much less frail than persons who receive, or are eligible for, nursing home care. Approximately 92 percent of nursing home residents age 65 and over had at least one ADL dependency, in this case involving the assistance of another person among six activities, including continence (e.g., using a catheter or bedpan), ranging from a high of 91 percent for dressing to a low of 40 percent for eating.[10] Involving a similar clientele needing skilled nursing care, the recent Program for All-Inclusive Care for the Elderly (PACE) demonstrations focus on elderly persons who are eligible for nursing home care but

---

[8] Agency for Health Care Policy and Research, 1987 National Medical Expenditure Survey, Research Findings 4.

[9] Wiener, J.M., et al, "Measuring the Activities of Daily Living: Comparisons across National Surveys," *Journal of Gerontology: SOCIAL SCIENCES, Vol. 45, No. 6 (1990).*

[10] National Center for Health Statistics, 1985 National Nursing Home Survey, *Vital and Health Statistics*, Series 13, No. 97, Table 27.

choose to receive services in the community. Between 79 percent and 95 percent of participants in the PACE program had at least one ADL dependency.[11] Also targeting a nursing home eligible elderly population, The Long Term Care Channeling Demonstration program participants had an ADL dependency rate of approximately 84 percent.[12]

Table 3-2.
Frailty Characteristics:
Comparing HOPE IV with Other Long Term Care Programs for the Frail Elderly

Program	Persons With at Least One ADL Dependency* (%)
Household population 65+	8
HOPE IV	44
Channeling demonstrations	84
PACE demonstrations	79-95
Nursing home residents 65+	92

*ADL dependency means receiving help from another person to perform an activity of daily living.

The purpose of these ADL comparisons, as summarized in Table 3-2, is to show where the HOPE IV participants lie along a continuum, from the elderly household population in general, through those who receive or qualify for nursing home care.

3.1.2 Instrumental Activities of Daily Living Limitations

Consistent with the functional profile of most HOPE IV participants, the Instrumental Activities of Daily Living (IADL) scale focuses on a higher level of functioning than do the ADL measures. IADL limitations cover many of the frailty and eligibility criteria in the HOPE IV regulations, including need for assistance in preparing meals, shopping, doing housework, and managing money. In terms of these four IADLs, 91 percent of the HOPE IV participants reported difficulty performing at least one, ranging from a high of 83 percent for light housework to a low of about 29 percent for managing money, as Table 3-3 shows. The important IADL difficulty rates in Table 3-3 are almost identical for the participants and comparison groups and address the relatively complex domains of functioning that HOPE IV participants require for independent living in scattered site rental housing, albeit with case management and supportive services.

---

[11] Branch, L.G., et al, "The PACE Evaluation: Initial Findings," *The Gerontologist*, Vol. 35, No. 3 (1995).

[12] Kemper, P., et al, *The Evaluation of the National Long Term Care Demonstration: Final Report*, Mathematica Policy Research, Inc., Princeton, NJ, 1986, p. 41.

To put these figures in perspective, 18 percent of the total household population, age 65 and over, reported at least one IADL limitation, in this case from a list of six activities including the above four, as well as using the telephone and getting around the community.[13] Also, by way of comparison, virtually all nursing home residents and participants in the PACE and Channeling demonstrations had at least one IADL difficulty, consistent with the relatively high level of physical and cognitive functioning IADLs require.

Table 3-3.
Frailty Characteristics:
Instrumental Activity of Daily Living (IADL) Limitations

Activities	Participants *(n=388)* (%)	Comparison Group *(n=405)* (%)
Reports difficulty in:		
Preparing meals	54	56
Doing light housework	83	82
Shopping	73	73
Managing money	29	33
Total IADL limitations:		
One or more	91	93
None	9	7
One	16	17
Two	26	22
Three	30	33
Four	19	21

3.1.3 Analysis of HOPE IV Eligibility

During interviews with HOPE IV grantees, the Service Coordinators and others stated they had considerable difficulty interpreting the eligibility criteria that participants be "deficient in at least three activities of daily living," as the program regulations define them. Also, for eligibility determination purposes, all but one of the 16 first round grantees used their own existing local assessment instruments and procedures to collect and cross walk traditional ADL and IADL information to the HUD criteria for the purposes of HOPE IV eligibility screening and developing a plan for supportive services. The grantees used their own judgment in translating their assessment results according to HOPE IV eligibility criteria.

For the purposes of analyzing grantee adherence to the HOPE IV eligibility criteria, the evaluation defined the five HUD ADL items as: 1) eating, including meals preparation, 2) bathing, including getting in and out of tub or shower, 3) grooming, including washing one's hair, 4) dressing, and 5) home management, including housekeeping, shopping, managing money, and various activities associated with moving about one's environment, such as transferring between bed and chair, and getting to and using the toilet room. Defining each of the five activities in this way, 97 percent of participants reported difficulty with at least

[13] Agency for Health Care Policy and Research, 1987 National Medical Expenditure Survey, *Research Findings*, 4.

one of the five, and almost 70 percent reported difficulty performing at least three (see Table 3-4). When counting all 12 of the activities mentioned in the HOPE IV regulations and included in the participant survey instrument, 96 percent report difficulty performing at least one, and 80 percent report difficulty performing at least three. (See Table 3-5.)

The activity of daily living difficulty information in Tables 3-4 and 3-5, suggests that between 20 and 31 percent of the participants have fewer than three ADL difficulties, contrary to the HOPE IV program regulations. As one explanation for this disparity, prior research in measuring ADL difficulties shows that frail elderly persons, especially women, self report fewer difficulties than occurs during professional assessments of the same individuals. For example, in their work with the *Women's Health and Aging Study*, sponsored by the National Institute on Aging through Johns Hopkins University, Westat researchers found that frail elderly women in the community under report their level of ADL difficulties compared to the functional assessments and physical performance tests conducted by study team professional staff. In addition, this study found that such under reports of functional capacity come, in part, from various adaptive behaviors on the part of frail elderly (e.g., changing how they approach an activity) to compensate for a limitation in functioning. The study also found that respondents were quite unaware that this decline in functioning had occurred, which may explain some of the under reporting. These findings are consistent with others in the literature on frailty among the elderly.[14]

Table 3-4.
Frailty Characteristics:
HUD ADL Difficulties (5 activity categories)

Activities	Participants *(n=388)* (%)	Comparison Group *(n=405)* (%)
Difficulty:		
Eating/meals preparation	55	59
Bathing/in & out of tub/shower	76	86
Grooming/washing hair	57	65
Dressing	43	47
Home management	92	96
Total limitations:		
None	3	2
One	13	5
Two	15	15
Three	20	24
Four	23	25
Five	26	29

[14] Rubenstein, et al., "Systematic Biases in Functional Status Assessment of Elderly Adults: Effects of Different Data Sources." *Journal of Gerontology*, 1984, 39:686-69.

As another possible explanation for under reporting, the high level of participant satisfaction with the HOPE IV program and fear of losing the benefits, as Chapter 4 discusses, may discourage participants to report ADL limitations. Participants may be unwilling to admit difficulties that either suggest criticism of the HOPE IV program (for not meeting all their needs) or that imply they need nursing home or other restricted forms of care that participants want to avoid.

Table 3-5.
Frailty Characteristics:
HUD ADL Difficulties (12 activity categories)

Activities	Participants *(n=388)* (%)	Comparison Group *(n=405)* (%)
Reports difficulty:		
Feeding self	12	13
Preparing meals	54	56
Washing self	41	45
Getting in and out of shower/ tub	68	74
Using toilet	29	22
Personal grooming	28	29
Washing hair	52	61
Dressing	43	47
Bed/Chair transferring	51	64
Housework	83	82
Shopping	73	73
Managing money	29	33
Total limitations:		
None	4	2
One	9	4
Two	7	5
Three	8	8
Four	10	12
Five	12	14
Six or more	50	55

In addition, as the first interim report on the HOPE IV evaluation states, grantees showed considerable variation in how they interpreted the program eligibility requirements and measured ADL difficulties using their own assessment instruments and procedures. For example, one PHA staff person stated during the grantee interviews that persons with two ADL imitations and a portion of a third were particularly difficult to assess for eligibility. In this case, the HOPE IV applicant had an ability to perform some aspects of an ADL but also had difficulty with other components of it. Also, consistent with the design of the Westat participant questionnaire, most grantee assessments categorized ADL difficulty according to several levels, ranging from inability to perform an activity at all to just having some difficulty with it. Some grantees assigned numeric scores depending on the particular activity and the level of difficulty, and they used these as a basis for determining HOPE IV eligibility. These procedures varied from site to site, which may explain some of the inconsistency between the evaluation survey findings and local practice in ascertaining HOPE IV eligibility. This also confirms the need for the standard frailty measures in the evaluation's survey instruments to ensure consistent data for this study.

3.1.4 Functional Limitations

Moving beyond ADL and IADL limitations in degree of complexity, functional limitations provide yet another measure of frailty among the elderly. For persons who must live independently in the community, especially when personal care workers are not present for considerable periods throughout the day and night, measures of functional limitation are extremely important indicators of physical ability. These include such activities as getting around inside the home, climbing stairs, bending, reaching, grasping, going in and out of the house, getting in and out of a car, seeing, and hearing. Table 3-6 lists these activities with the number and percent of HOPE IV participants reporting difficulty in performing them. *The most severe functional limitations were in climbing stairs, bending down to pick up clothing, reaching up for light objects, and getting in and out of a car.* Also, 42 percent of participants reported difficulty seeing ordinary newspaper print even with glasses or contact lenses, and 41 percent had difficulty hearing a normal conversation. The functional limitation rates are similar between the participant and comparison groups, with the latter reporting somewhat higher rates than the former in walking up or down stairs (88 percent versus 78 percent), bending down (74 percent versus 62 percent), and going in and out of the home (46 percent versus 34 percent). To put these figures in perspective, the corresponding rates from the total household elderly population are 16 percent with difficulty seeing words and letters, 14 percent with difficulty hearing a normal conversation, and 31 percent who have difficulty climbing stairs.

Table 3-6.
Frailty Characteristics:
Functional Activity Limitations

Activities	Participant *(n=388)* (%)	Comparison Group *(n=405)* (%)
Walking up or down stairs	78	88
Bending down to pick up clothing	62	74
Reaching up for light objects	56	62
Getting in and out of a car	54	59
Seeing ordinary newspaper print	42	45
Hearing a normal conversation	41	50
Walking between rooms	36	41
Going in and out of home	34	46
Grasping faucets/knobs/stove pots	26	32
Confined to a wheelchair	7	6

Regardless of the particular criteria, be they ADL, IADL, or functional limitations, these data show that the HOPE IV participants are considerably more frail than the elderly household population as a whole

and substantially less frail than persons residing in or otherwise qualifying for nursing home care as part of home and community-based alternatives to institutionalization.

3.2 Health Status

This section describes the self-reported health status of the HOPE IV participants using a variety of indicators. Some of these indicators relate to acute medical conditions and care, including overall health status, hospital stays, and doctor visits. They also cover chronic, or long term, conditions such as heart disease, arthritis, and diabetes. Equally important are the consequences of one's health status and conditions, such as the number of days participants are confined to a bed or chair. While the frailty measures above are the primary basis for HOPE IV eligibility, there is a high correlation between chronic activity limitation and overall health status. For this reason, HOPE IV participants are likely to report numerous health problems.

3.2.1 Self-Assessed Health Status

Table 3-7 confirms the relatively poor overall health on the part of both participants and the comparison group. It presents a profile of the self-reported health status according to five categories, poor to excellent. For interpretation purposes, the National Center for Health Statistics often summarizes this information into two categories: good to excellent or fair to poor health. In these terms, *less than 40 percent of participants and the comparison group reported good to excellent health, while over 60 percent of the participants and comparison group members stated their health was fair to poor.* Concerning changes in health status over the past year, participants reported they were better off than a year ago in only 20 percent of the cases, while 45 percent stated their health was the same. Particularly important is the fact that over one third of the participants and more than 40 percent of the comparison group indicated their health was worse now than it was a year ago.

Also showing the correlation between frailty and poor health, of all participants who said their health was excellent, less than one quarter (24 percent) reported 3 or more ADL limitations (as defined in

Table 3-1). At the same time, of all participants who said their health was poor, over half (52 percent) reported three or more ADL limitations.

More than 40 percent of the HOPE IV participants said they had gained or lost a lot of weight during the past year without trying to do so. Also, about one quarter of both the participants and comparison group said they had eaten fewer than two meals per day at least once during the past week. Substantial gain or loss of weight by the elderly is often an indication of health or emotional problems. For example, in its recent review of the literature on malnutrition among the elderly, the Administration on Aging found that skipping meals was indicative of a high risk of many problems, beyond malnutrition and weight loss, including chronic medical conditions and general food insecurity, such as inability to afford, shop for, and prepare meals.[15] A national study by the Urban Institute, *Hunger Among the Elderly*, found that unintended weight loss is a strong predictor of poor health and nutrition, disease, and mortality among the elderly.[16] Living alone, a characteristic common among HOPE IV participants, is also highly correlated with skipping meals, poor quality diets, and overall inadequate

Table 3-7.
Health Characteristics:
Self-Assessed Health Status

Characteristics	Participants *(n=388)* (%)	Comparison Group *(n=405)* (%)
Current health status:		
Excellent	5	4
Very Good	11	13
Good	23	18
Fair	35	37
Poor	23	26
Unknown	3	2
Change in past year:		
Better	19	14
Same	45	42
Worse	36	42
Unknown	1	1
Gained or lost a lot of weight during past year without trying	43	38
Ate fewer than two meals per day at least once during past week	24	26

[15] Codispoti, M.S. and Barlett, B.J., *Food and Nutrition for Life: Malnutrition and Older Americans*, (Administration on Aging, U.S. Department of Health and Human Services, Washington, D.C., 1995).

[16] Burt, M.R., *Hunger Among the Elderly: Local and National Comparisons, Final Report of a National Study on the Extent and Nature of Food Insecurity among American Seniors*. Washington, D.C.: The Urban Institute, 1993.

nutritional intake. For example, the Institute of Medicine found that social isolation and malnutrition were strongly interrelated, with one contributing to the severity of the other.[17]

Information on skipping meals is significant, even in the presence of HOPE IV, because in-home services that deliver meals and assist with food preparation often cover only one meal per day, with no service on the weekends. The follow-up survey will identify the extent to which these indicators of nutritional well being show increases or decreases among HOPE IV participants, relative to the comparison group.

3.2.2 Health Conditions

Consistent with their overall health status, participants and the comparison group reported having had many chronic medical conditions. Table 3-8 shows the range of these health conditions (based on what their doctor or other health professional had told them) and the extent to which at least one had worsened during the past year. Seventy percent of participants reported having had arthritis and more than half said they had high blood pressure. Forty-five percent of participants indicated having had a heart condition, and 42 percent reported having had pneumonia or other respiratory disease. About half of the participants said they had other conditions, the most frequent of which were a digestive disease, bone or joint problems, and cancer. Nearly fifty percent of participants said that at least one condition had worsened during the past year, most frequently arthritis and respiratory conditions.

Table 3-8.
Health Characteristics:
Health Conditions

Conditions	Participants *(n=388)* (%)	Comparison Group *(n=405)* (%)
Arthritis	70	81
Hypertension	52	56
Heart Disease	45	48
Respiratory	42	45
Osteoporosis	24	24
Diabetes	19	24
Stroke	18	18
Arteriosclerosis	14	14
Broken hip	11	12
Parkinson's Disease	3	1
Other	51	51
Worsened in past year	47	55

[17]Berg, R.L. and Cassells, J.S. (eds.), *The Second Fifty Years: Promoting Health and Preventing Disability*, (Institute of Medicine, National Academy Press, Washington, D.C., 1990).

3.2.3 Frequency of Falls

HOPE IV requires that, despite their frailty, participants must be able to live independently in the community, given the tenant-based nature of their rental assistance. Even with the case management and personal assistance provided by the Service Coordinator and supportive services, participants will spend considerable time alone in their home. For a frail elderly population, the risk of falls is always present and a potential source of injury. As Table 3-9 shows, over 40 percent of participants reported having fallen during the past year. Of all participants, 18 percent said they fell once in the last year, while over one fifth reported falling more than once during this period. Among all participants, 9 percent sustained a broken bone, and 6 percent received a head injury. Twenty-three percent sought medical care as a result of falling, and 9 percent were hospitalized for more than one day due to a fall. The comparison group rates were nearly identical for all these items, confirming the similarity of the two groups in this area as well.

Table 3-9.
Health Characteristics:
Frequency of Falls

Characteristics	Participants *(n=388)* (%)	Comparison Group *(n=405)* (%)
Fallen during past year	42	42
Number of times:		
Once	18	16
Twice	8	9
More than two	14	16
Unknown	3	1
Type/degree of injury:		
Broken bone	9	8
Head injury	6	8
Sought medical care	23	25
Hospitalized over 1 day	9	6

3.2.4 Medical Care Access and Use

Despite their high level of frailty and overall poor health, the majority of the HOPE IV participants, at baseline, were not confined to bed or a chair during the past month, saw a doctor fewer than four times during the past year, and did not need to use a hospital emergency room or stay in a hospital overnight at all during the last 12 months. As of baseline, however, nearly half of the participants had used a hospital emergency room at least once, and over 40 percent had stayed overnight as a hospital in-patient over the past year. The latter is a rate twice that for the elderly household population as a whole.[18]

[18] U.S. Bureau of the Census, Current Population Reports, Series P-70, No. 8, *Disability, Functional Limitation, and Health Insurance Coverage:* 1984/85, U.S. Government Printing Office, Washington, D.C., 1986.

Nearly 30 percent of participants saw a medical doctor once during the past year, another 36 percent saw a doctor two to four times, and 18 percent saw one more than four times. Just eight percent of participants, however, stayed at least one night in a nursing home during the past year.

Disability days, that is the number of days a person stayed in bed or a chair most of the time due to a health problem, represent a common health status measure. *Sixty percent of the participants reported no disability days at all, and virtually all the participants (95 percent) reported having a usual source of health care.* However, 36 percent of participants stayed in bed or a chair most of the day at least once during the past month due to a health problem, including 4 percent for 1 to 3 days, 6 percent for 4 to 9 days, and 8 percent for 10 to 29 days. Of particular importance is that nearly one fifth (18 percent) of participants reported staying in bed or a chair most of the time for the entire month prior to the survey due to a health problem. This group reported lower levels of well-being regarding other measures as well. For example, they had a mean of 2.9 ADL limitations, compared to 1.9 for participants overall (using the measures in Table 3-1), and nearly 80 percent of this group reported fair to poor health, compared to 58 percent for all the HOPE IV participants.

Table 3-10.
Health Characteristics:
Access to and Utilization of Medical Care

Characteristics	Participants *(n=388)* (%)	Comparison Group *(n=405)* (%)
During past year:		
Used hospital emergency room	48	41
Was overnight hospital patient	42	34
Stayed in a nursing home	8	6
Saw a doctor:		
Did not see a doctor	15	15
Once	28	31
2 to 4 times	36	36
More than 4 times	18	15
Don't know	3	3
During past month:		
Stayed in bed or chair most of the time due to health problem:		
No days	60	59
1 to 3 days	4	8
4 to 9 days	6	7
10 - 29 days	8	7
30 days	18	16
Don't know	4	3
Has usual source of medical care	95	94

For nearly every health indicator, as Tables 3-7 through 3-10 present, the participant and comparison group profile is almost identical. Prior research shows the consistently strong correlation

between frailty and various other measures of health status. Having only screened comparison group members for similarity with participants based on age and limitations in activities of daily living, it is not surprising that other measures, such as health status, are similar as well.

3.2.5 Mental Health, Quality of Life, and Cognitive Status

While the physical functioning measures presented thus far can effectively assess one's capacity for self-care and independent living, they say little about the quality of a person's life. Indeed, a major purpose of programs that prevent or delay inappropriate institutionalization is to enhance the many domains of mental, emotional, and social well-being. While the physical focus of the HOPE IV eligibility criteria is quite appropriate for selecting participants, an important impact measure is the extent to which this demonstration improves (or lessens the decline) in quality of life, relative to a comparison group over time.

Table 3-11.
Measures of Life Satisfaction

Quality of Life Measures	Participants *(n=388)*	Comparison Group (n=405) (%)
Life satisfaction:		
Very satisfied	38	33
Somewhat satisfied	41	46
Not satisfied	20	18
Unknown	1	3
Amount of choice:		
A great deal	59	52
Some	31	36
None	8	11
Unknown	1	2
Confidence:		
Very confident	52	50
Somewhat confident	41	42
Not confident	6	5
Unknown	1	2
Amount of worry:		
A lot	18	17
Some	33	32
Not at all	47	50
Unknown	1	1
Appetite:		
Good	53	55
Fair	31	33
Poor	15	12
Unknown	1	0

In spite of their poor health and frailty, most of the participants report the quality of their lives to be relatively high, although, this was not the case for all. Table 3-11 presents five measures of life satisfaction. Nearly 40 percent of the HOPE IV participants responded that they were, in general, very satisfied with the way their life is going, and over 40 percent indicated they were somewhat satisfied with life. Almost one fifth, however, said they were not satisfied. Most participants (59 percent) said they had a great deal of choice about what they do and when they do it, and over half reported they were very confident about their ability to deal with daily living. However, 18 percent said they worry at lot of the time about not knowing who to turn to for help, and 45 percent said their appetite was fair to poor. Consistent with the patterns in physical measures presented thus far, the comparison group reports similar rates of life satisfaction for all these items.

Participants describe themselves as generally happy, peaceful and calm, and many said they were full of life most or all of the time. However, only a few participants reported having lots of energy, and many felt worn out or tired most or all the time. Table 3-12 provides several measures of depression using positive and negative indicators about participant feelings. Forty percent of participants said they felt full of life most or all the time during the past 30 days, and about 60 percent said they were a happy person or felt calm or peaceful most or all of the time during that period. Few of the participants (14 percent) felt so down in the dumps that nothing could cheer them up, and a similar number (13 percent) felt downhearted or low most of the time. Over one quarter of the HOPE IV participants, however, stated they had been a nervous person during the

Table 3-12.
Measures of Depression

During the past 30 days ...	Percent responding "all or most of the time"	
	Participants *(n=388)* (%)	Comparison Group *(n=405)* (%)
1. Did you feel full of life?	40	33
2. Have you felt calm or peaceful?	57	55
3. Did you have a lot of energy?	20	20
4. Have you been a happy person?	61	61
5. Have you been a very nervous person?	27	22
6. Have you felt so down in the dumps that nothing could cheer you up?	14	13
7. Have you felt downhearted or low?	13	13
8. Did you feel worn out?	32	34
9. Did you feel tired?	39	40

past month, and only 20 percent said they had a lot of energy. For most of these measures, the comparison group responses were nearly the same.

Cognitive functioning is an important determinant of risk for institutionalization and ability to function independently in a community-based, long-term care program such as HOPE IV. Generally, participants and comparison group members had few incorrect responses to questions that served as indicators of mental status. Table 3-13 presents the rates of incorrect responses to six questions, as a measure of cognitive status: the current year, season, date, day of the week, state of residence, and county of residence. Sixty-three percent of the participants and 64 percent of the comparison group members answered all items correctly, while 31 percent of participants and one quarter of the comparison group made one incorrect response, virtually all of which was reporting the incorrect date. The remaining 6 percent of participants and 12 percent of the comparison group had either two or three incorrect responses.

Table 3-13.
Cognitive Status

Number of incorrect responses	Participants *(n=326)* (%)	Comparison Group *(n=321)* (%)
None	63	64
One	31	25
Two	5	10
Three	1	2

Excluded from this analysis were all proxy responses, resulting in 326 participants and 321 comparison group members. While this may eliminate persons with the most severe cognitive impairment, virtually all proxy cases were a function of preference by the participant rather than a decision by the interviewer due to inability of the person to respond. Follow-up interview data analysis will avoid mixing proxy and frail elderly tenant responses when determining change in cognitive status.

Measures of mental health and cognitive status are extremely difficult to interpret, and researchers are only beginning to develop methods for scoring and aggregating responses to such questions to ascertain overall well-being.[19] The major application of these measures occurs when analyzing data from the follow-up interviews to determine changes over time, between the participants and comparison group members.

[19] Ware, J.E., *SF-36 Physical and Mental Health Summary Scales: A User's Manual*, The Health Institute, New England Medical Center, Boston, 1994.

4. INFORMAL ASSISTANCE, SOCIAL SUPPORT, AND PROGRAM PARTICIPATION

This chapter treats two main topics: the extent, sources, and patterns of informal assistance and social support received by the HOPE IV participants, and their initial experiences with and views of the HOPE IV program. The first part of the chapter, focusing on social support, compares the frequency with which HOPE IV participants and comparison group members see or speak on the telephone with relatives, friends, and neighbors. It also describes the HOPE IV participants' and comparison groups' satisfaction with the amount and quality of their social activity, as well as the availability and accessibility of help in emergency situations.

Informal assistance, social support and sociability are important aspects of an older person's quality of life that also tend to correlate with measures of mental health and life satisfaction. In addition, the quality and level of social support received, independent of other factors, can affect a frail elderly person's risk of institutionalization. Consequently, the HOPE IV participants' and comparison groups' informal social interactions are important to the HOPE IV evaluation for several related reasons: 1) the amount and quality of informal assistance and support received may independently affect the risk of institutionalization for both the participants and the comparison group; 2) informal social support may enhance life satisfaction, itself an outcome variable in the conceptual model guiding the quasi-experimental design; and, 3) prior research has examined whether and how receipt of formal services influences the amount and type of informal assistance that elderly persons receive, and how, this, in turn, affects outcomes such as institutionalization. While these issues can not be directly addressed until after the follow-up interviews, this report establishes a baseline profile as a starting point for discerning the long-term effects of HOPE IV program participation in these critical areas.

The second part of the chapter concentrates on the HOPE IV participants' initial perceptions of and early experiences with the HOPE IV program, including their views on entering HOPE IV and various Program requirements; perceptions of their service coordinators; specific services received and satisfaction with them; and overall assessment of the HOPE IV program to date. Since most of the participants were interviewed shortly after entering HOPE IV, the focus is on describing first impressions and experiences that are likely to change between now and the follow-up survey, when the participants will have been in the HOPE IV program for a full two years.

4.1 Informal Assistance and Social Support

To ascertain the level and kinds of social support they receive, HOPE IV participants and comparison group respondents were asked about the frequency and patterns of their informal social contacts with relatives, friends, and neighbors. In the follow-up surveys, these questions will be asked again and the two groups' responses will be compared to determine differences in social support that may have developed due to Program participation. To establish a baseline comparison for this crucial social support dimension, this sub-section presents the findings for both HOPE IV participants and comparison group members.

4.1.1 Frequency and Nature of In-Person Social Contacts

On the whole, both the frequency and pattern of social contacts as reported at baseline are remarkably similar for HOPE IV participants and comparison group members. Eighty-one percent of both the HOPE IV and comparison group respondents report seeing another person -- whether a family member, friend or neighbor -- on a regular basis at least once a month. Nineteen percent of both groups see no one monthly except for service personnel or others living in their households.

The average frequency of social contacts is only slightly higher for comparison group members than for HOPE IV participants; the comparison group reports somewhat more frequent contact with children and other relatives. However, both groups see someone, on average, almost every day in a month. As presented in Table 4-1, most HOPE IV respondents and comparison group members show a bi-modal pattern and see a child either less than once a month or several times a week or more. For example, forty-five percent of HOPE IV and 48 percent of comparison group respondents see a child less than once a month. By contrast, twenty-five percent of HOPE IV respondents see a child three or more times a week, and 12 percent see a child on a daily basis. The same figures for the comparison group are 18 percent and 18 percent, respectively. Thus, the main, relatively minor difference between the two groups is that a slightly higher percentage of comparison group members than HOPE IV participants see a child every day. This may reflect that HOPE IV is targeted to frail elderly who may have limited support available from family members or others living in close proximity.

Table 4-1.
Monthly Frequency of Different Types of In-Person Social Contacts for HOPE IV and Comparison Group Respondents*

	Participants (n=388)				Comparison Group (n=405)			
Times per month regularly sees ...	Child (%)	Other relative (%)	Friend or neighbor (%)	Anyone (%)	Child (%)	Other relative (%)	Friend or neighbor (%)	Anyone (%)
Less than once (0)	45	72	58	19	48	69	54	19
A few times (1-3)	5	8	4	3	7	6	4	4
Once or twice a week (4-7)	13	7	5	12	10	7	5	8
Several times a week (8-27)	25	9	12	29	18	11	15	26
Every day (28+)	12	4	20	36	18	7	22	43

*Percentages are rounded up and may not total exactly 100%.

Neither group has frequent contact with relatives other than children: 72 percent of HOPE IV respondents and 69 percent of comparison group members report seeing a relative other than a child once a month or less. At the opposite end, somewhat more comparison group members (7 percent) than HOPE IV respondents (4 percent) see such a relative every day. For both groups, the distribution of in-person contact with friends and neighbors is somewhat more skewed than it is for contact with children. While 58 percent of HOPE IV and 54 percent of comparison group respondents do not see a friend or neighbor at least once a month, 20 percent of the former, and 22 percent of the latter, do so every day.

While the overall pattern of contact is quite similar for the two groups, comparison group members appear to have slightly more intensive informal contacts than HOPE IV participants. Although 19 percent of both respondent groups report no regular in-person informal monthly contact, 43 percent of comparison group members and 36 percent of HOPE IV participants see someone on a daily basis. Again, what deserves emphasis is not the differences but the striking similarities between the two groups.

In a question designed primarily with the follow-up survey in mind, HOPE IV participants were also asked if the frequency of their in-person contacts had changed since they entered HOPE IV. For obvious reasons, no similar question was posed to the comparison group. Since most respondents had been in HOPE IV for just a brief while (a few months at most) at the time of the baseline interview, it seemed unlikely we would notice any change. As shown in Table 4-2, for the most part HOPE IV participants indicated no change in frequency of contacts since they began in the HOPE IV program: 65 percent of contacts with children, 70 percent of those with another relative, and 58 percent of contacts with friends and neighbors had remained the same. However, as Table 4-2 shows, for the smaller percentage of cases for which changes were reported, there were more increases than decreases in contact. Thus, at least in the very short run, entering HOPE IV does not appear to have lessened the frequency of informal contact. It is too soon to tell whether there will be any longer-term effects in either direction.

Table 4-2.
Changes in Frequency of In-person Contacts Since Entering HOPE IV Program

	Since entering HOPE IV, percentage of contacts that have ...		
Contacts with ...	Decreased (%)	Stayed the same (%)	Increased (%)
Child	11	65	24
Other family member	9	70	21
Friend/neighbor	12	58	30
Overall	11	63	26

Frequency of contact is only one ingredient of social support; it is also important to know how the time together is spent. Some researchers have suggested that one beneficial outcome of an elderly parent's receipt of formal in-home help with household and personal care activities is that it frees children to spend more "quality" time with their parents. Time that might previously have been occupied running errands for their parents or taking care of household chores can now be spent sitting and talking. This provides benefits to the elderly parent by enriching the quality of their visits with their children, and also lessens the children's caregiver burden. Thus, HOPE IV participants were also queried about what they usually do when their children, other relatives, friends and neighbors come to visit. Their answers covered a broad span of activities, from helping with housework to running errands, eating out, or attending social functions together. *There does seem to be a clear division of activities according to the type of visitor.* When a child visits, the most frequently named activities by far are that the child 1) helps with household activities, 2) shops or runs errands for the participant, followed by 3) talks about business affairs. When other relatives pay a call, they most frequently 1) attend a social function with the participant, 2) watch television together, or 3) perform personal

caretaking activities for the participant. By contrast, participants most often 1) play games, or 2) spend time informally talking and visiting with friends and neighbors.

Not surprisingly, given their very limited tenure in the Program, HOPE IV participants reported very little change since entering HOPE IV in the nature of their activities with visitors. In two years, the answers to this question will be more useful in addressing the long-term effects on the frequency and the quality of time spent with visitors.

4.1.2 Telephone Contact

In an increasingly mobile society, when elderly persons may live far from family and friends, keeping in touch by telephone is another important form and source of social contact. *The frequency of telephone contact with relatives and friends at baseline is also very similar for HOPE IV participants and comparison group respondents.* Seventy-five percent of the HOPE IV participants, and 77 percent of the comparison group respondents, speak to someone on the phone on a regular basis.

Again, as with in-person contacts, the pattern of telephone contacts is only slightly different for the two groups. Concerning interaction with their children, participants have slightly more frequent telephone contact and comparison group members have slightly more frequent in-person contact. Perhaps more frequent telephone contact serves to compensate for less frequent in-person contact, especially when physical distance makes it impossible for a child to make frequent in-person visits to an elderly parent. Another possibility is that shifts in patterns of contact occurred as a result of the moves many participants had made in order to enter the Program. For everyone, but children, the pattern is reversed, in that comparison group respondents have slightly more frequent phone contact both with other relatives and with friends and neighbors than do participants.

Both HOPE IV and comparison group respondents show a bi-polar pattern of either no monthly telephone contact or rather frequent phone contact (from several times a week to every day), with relatively little in between. As shown in Table 4-3, about one-quarter of both HOPE IV and comparison group respondents report no regular phone contact with anyone in a month. However, 40 percent of both groups speak on the phone with someone every day. With respect to frequency of telephone contact with a child, slightly more than half of HOPE IV participants and comparison group respondents speak to a child on the phone less than once a month. However, fewer than one-quarter of

HOPE IV participants and comparison group respondents speak to a child daily, while another 14 percent of HOPE IV and 16 percent of comparison group respondents do so at least several times a week. Although we would not expect phone contact to be as affected by participation in the HOPE IV program as in-person contact, we will see whether these patterns remain similar across the two groups after two years.

Table 4-3.
Monthly Frequency of Telephone Contacts for HOPE IV and Comparison Group Respondents*

	Participants (n=388)				Comparison Group (n=405)			
Times per month regularly speaks with ...	Child (%)	Other relative (%)	Friend or neighbor (%)	Anyone (%)	Child (%)	Other relative (%)	Friend or neighbor (%)	Anyone (%)
Less than once (0)	53	70	67	26	55	64	64	24
A few times (1-3)	3	6	4	5	3	7	2	3
Once or twice a week (4-7)	6	7	5	8	7	8	6	10
Several times a week (8-27)	14	10	9	22	16	11	11	23
Every day (28+)	24	7	15	40	20	11	16	40

*Percentages are rounded up and may not total exactly 100%.

4.1.3 Level of Satisfaction with Social Activities

Because of varying perceptions of what constitutes a satisfactory level of social contact, different individuals may express rather different degrees of satisfaction with the same frequency of visits and telephone calls. For example, some elderly respondents may feel quite satisfied with seeing a child once or twice a month, whereas others may be unhappy with anything less than daily visits. Similarly, getting out of the house twice a month may be quite satisfactory for some, but not nearly enough for others. To gauge this more subjective aspect of social support and sociability, HOPE IV participants and comparison group respondents were asked about the quality of their social ties and how they assess their present level of social activity.

Considering their frailty, both HOPE IV participants and comparison group respondents seem to enjoy fairly full social lives, with which most are reasonably, but not completely, satisfied. Forty percent of HOPE IV respondents and 37 percent of comparison group members had participated in some kind of social activity outside their home in the two weeks prior to the interview. About forty percent of both participants and comparison group members are satisfied with their current level of social activity, but about half of both groups would like to be doing more socially. About half of both HOPE IV participants and comparison group members say they see their relatives and friends about as often as they want, and another third of both groups is only somewhat unhappy about how little they see relatives and friends. Just eleven percent of participants and an even smaller percentage (8%) of comparison group members say they are very unhappy with the frequency of their social contacts, and only a small number of participants (barely 1%) report they have no one to see.

Along a slightly different dimension, neither HOPE IV nor comparison group respondents report high levels of loneliness, and almost all in both groups have at least one confidante. Although 21 percent of the HOPE IV respondents and 16 percent of comparison group members say they feel lonely quite often, 39 percent of both groups say they feel this way sometimes and another 39 percent of HOPE IV respondents and 42 percent of the comparison group almost never feel lonely. The vast majority of both groups -- about 86 percent of HOPE IV respondents, and 91 percent of comparison group members -- report having someone they trust and in whom they can confide.

The HOPE IV respondents and comparison group members are quite alike in having a confidant and feelings of loneliness. HOPE IV participants indicate feelings of loneliness or social isolation to a greater extent than do the comparison group members, although the rates for both groups are small. As above, this admittedly small difference between participants and comparison group members may reflect that more of the participants have only recently moved to their present residences, and so may not have had the time or opportunity to establish contacts with neighbors. In addition, fewer participants may live in close proximity to a child or other close relative. However, what bears greatest emphasis is again the degree of similarity between the HOPE IV participants and comparison group respondents, now and at the follow-up.

4.1.4 Getting Help in an Emergency

Enjoying reasonably frequent social contact, not feeling lonely very often, and having a confidante, do not necessarily mean that HOPE IV participants or comparison group members can be reached quickly during an emergency, or that someone is available to take care of them during protracted illness or convalescence. The surveys also addressed this important issue of accessibility and availability of help in emergencies. For somewhat less than half of HOPE IV respondents and comparison group members a relative, most often a child, would be the first person they would call in case of an emergency. For an even higher 48 percent of participants and 54 percent of comparison group respondents, a relative -- again, overwhelmingly, a child -- would be the second person they would call under these circumstances. About a third of both groups indicated the first number called would be 911, but only about half as many HOPE IV participants and a third as many comparison group members said 911 would be the second number they would call in an emergency. For both groups, calling a friend or neighbor is the third, albeit much less frequent response, for both the first and second person they would call. All other answers are spread thinly over several categories, including physician, nurse, apartment manager, HOPE IV service coordinator and others.

As shown in Table 4-4, in terms of how long it would take the first person they called to reach their home in an emergency, *about four-fifths of the participants reported that someone could be there within fifteen minutes, and 95 percent that someone could get to their homes within 30 minutes. For comparison group respondents, an even higher percentage (nearly 90%) can be reached in 15 minutes or less, while just about everyone can be reached within 30 minutes.* These relatively small differences between the two groups may again reflect the fact that HOPE IV applicants who are most in need of services may not have close relatives available to support them.

Table 4-4.
Time Required to Reach HOPE IV Participants' and Comparison Group Members' Homes in an Emergency

Amount of Time	Participants (n=329) (%)	Comparison Group (n=356) (%)
1 - 15 minutes	81	88
16 - 30 minutes	14	11
31 - 45 minutes	1	--**
46 minutes to 1 hour	2	--**
Over one hour*	2	--
Total	100%	99%

* Includes responses ranging from 2 hours to 2 days.
**Only one person each in each category.

Although the vast majority of HOPE IV participants and comparison group members can be reached relatively quickly in an emergency, only about one quarter of the participants and one third of the comparison group respondents have someone who could provide sustained help during an illness or other emergency. Slightly less than half (47%) of the HOPE IV and more than half (52%) of comparison group respondents say they have someone who could take care of them or help them at home if they were sick or needed assistance. However, just over one-quarter of HOPE IV participants and one-third of comparison group members indicate this person could help as long as needed. Most of the others replied that the person would be able to assist just for a week or less, or only "now and then."

4.2 Program Participation and Service Utilization

This second main section of the chapter describes various aspects of the HOPE IV participants' initial views of and experiences with the HOPE IV program to date. It describes how participants first heard about and were assessed for eligibility to enter HOPE IV; their perceptions of their service coordinator; the services they receive through the HOPE IV program and other sources; their

satisfaction with services, views on specific aspects of the HOPE IV program, and overall assessment of Program benefits.

4.2.1 Entering the HOPE IV Program

Table 4-5 shows the distribution of the participants' initial source of information on the HOPE IV Program. Nearly half of the respondents first found out about HOPE IV either from their local Area Agency on Aging or the housing authority. Another 19 percent first heard about HOPE IV from relatives, especially their children. Friends and neighbors accounted for another ten percent of respondents' sources. One interesting, somewhat unexpected finding is that eight percent got their first information on HOPE IV from a physician or hospital discharge worker. Table 4-5 shows that only about six percent of respondents first heard about the Program from impersonal sources such as ads, radio announcements, or brochures. This confirms the idea (as presented in the First Interim Report) that some form of "word-of-mouth" is the key to the recruitment process.

Table 4-5.
Initial Sources of Information on the HOPE IV Program (n=370*)

Source	Participants (%)
Area Agency on Aging or other local agency	25
Housing authority	24
Relative	19 (11% - child)
Friend or neighbor	10
Hospital/physician	8
Service worker	6
Newspaper article or radio announcement Brochure or flyer	6
Landlord	2

* Eighteen respondents who gave no source were eliminated from the denominator.

Respondents, on the whole, found the process of entering the HOPE IV program fairly easy. Eighty-five percent agreed that it was easy to provide the necessary financial information for entering the Program, 86 percent indicated that the program and its requirements were clearly explained to them, and eighty percent of the respondents reported having actively participated in deciding which services they would receive. ADL assessment was the one area for which there was a slightly lower level of satisfaction: 70 percent disagreed, and 23 percent agreed with the statement that the process used to determine the need for assistance was complicated.

The participants' perception that entering the HOPE IV program was a relatively easy process should be seen in relation to the enormous efforts grantee PHAs and service coordinators expended in recruiting and assessing applicants. The First Interim Report discussed how grantee PHAs had to adapt standard Section 8 procedures to fit the needs of the frail elderly HOPE IV applicants. Service coordinators, especially, assumed a variety of unanticipated functions in recruitment and assessment, including helping applicants find housing, assisting with moves, and making multiple home visits for completion of paperwork. Thus, program personnel may have done this part of their jobs so well they made entering HOPE IV that much easier for the participants. In addition, participants' children, many of whom were reportedly instrumental in encouraging their parents to enter the Program, may also have shouldered some of the paperwork burden.

4.2.2 How HOPE IV Participants View Their Service Coordinators

The HOPE IV service coordinator plays a pivotal role vis-à-vis the participants as the person who helps to assess eligibility and facilitate entry into the Program, develops an individualized service plan in conjunction with the participants and the Professional Assessment Committees (PACs), and monitors and coordinates the smooth delivery of services. However, the First Interim Report showed that many service coordinators had quickly become overburdened as they took on a variety of unanticipated functions. Some felt torn between devoting time and energy to "front end" tasks like marketing or recruitment, and performing the kind of individualized case management required by a frail elderly clientele with shifting needs. Knowing this, it is interesting to see how the service coordinators and their functions are perceived by the HOPE IV participants.

Just under half of all HOPE IV participants, or, as shown in Table 4-6, 73 percent of the 256 respondents who answered this question,[20] reported seeing their HOPE IV service coordinator once a month or more since entering the Program. These respondents were about evenly split between those reporting contact once a month and those indicating they see their service coordinator twice or more a month.

[20] A total of 132 (out of 388) or roughly a third of respondents were eliminated from the denominator in determining these percentages, mainly for "don't know" or "not ascertained" responses.

On the other hand, a total of 27 percent of these 256 respondents, or 18 percent of all HOPE IV participants, reported contact less than once a month, ranging from several times a year to once a year. In addition, six percent of all (388) respondents reported never having seen their service coordinator and another one-quarter of all respondents had "don't know" or "not ascertained" responses. However, since most participants were interviewed within a month or two of entering the HOPE IV program, this response set is probably not indicative of longer term patterns of contact between participants and their service coordinators.[21]

Table 4-6.
Frequency of In-Person Contact with Service Coordinator (n=256)

Amount of time	Participants (%)
2 or more times/month	37
1 time per month	36
4-11 times/year	7
2-3 times/year	13
Once a year	7
Total	100%

Forty-four percent of the HOPE IV respondents indicated that their service coordinator usually initiates contact with them, 31 percent said they usually contact their service coordinator if they need something, and about 15 percent reported that it works both ways. The remaining respondents gave "don't know" or "not ascertained" responses.

The HOPE IV participants' volunteered statements about what their service coordinator does for them that are consistent with the service coordinator acting primarily as a case manager. In addition, the respondents' views of their service coordinators' primary functions are obviously influenced by their relatively recent entry into the Program. The respondents' five most frequent answers to the open-ended question about what their service coordinator does for them are:

1) Helps to obtain, schedule and organize services (213 mentions);

2) Helps to get housing/rental assistance (105 mentions);

3) Helps persons to qualify for the HOPE IV program (96 mentions);

---

[21] We considered the possibility that proxy respondents might be contributing disproportionately to the "don't know" and "not ascertained" responses, but this was not the case. We also explored the possibility that a disproportionate share of the respondents who indicated never having seen their service coordinator came from one grantee site in which many participants experienced a significant delay between moving into their Section 8 housing and beginning to receive supportive services. Again, the evidence failed to confirm this hypothesis. Rather, analysis of the responses by site indicates that participants who reported never having seen their service coordinator are spread over seven of the fourteen HOPE IV sites represented among respondents to this question, roughly in proportion to the total number of participants served at a given site. Moreover, none of these respondents were from the first site in question.

4) Provides information and explains services (63 mentions); and,

5) Monitors needs and checks in on the respondent (57 mentions).

Other miscellaneous, somewhat idiosyncratic responses included bringing the participant things (16), helping the participant perform activities (16), and providing emergency financial assistance (3). About 16 percent of respondents reported either that their service coordinator does nothing for them (5 percent) or they did not know or could not say what she or he does (11 percent).

Of the 292 (75 percent) of all respondents who answered the question concerning which of the service coordinator's activities is most beneficial to them, the largest number (110 respondents) named helping to obtain and schedule services, followed by helping to get housing and rental assistance (66 respondents), and helping to qualify for the HOPE IV program (33 respondents). Only about one-quarter of the HOPE IV participants indicated they would like anything more from their service coordinator: the largest number of these respondents expressed a desire for more contact with their service coordinator (19 mentions), more services in general (17 mentions), or more cleaning services, in particular (17 mentions).

A high percentage of HOPE IV participants (81 percent) are very satisfied with their service coordinator, another nine percent somewhat satisfied. Only four respondents report active dissatisfaction with their service coordinators, with an additional six percent saying they do not know.

Overall, HOPE IV participants are very satisfied with their service coordinators. The relatively few who desire more from their service coordinators mostly want increased contact or additional services. The participants view as most important and beneficial the service coordinators' help in obtaining, coordinating and scheduling services and in getting housing and rental assistance. About half of HOPE IV participants report seeing their service coordinators once a month or more, while somewhat less than one-quarter indicate having had contact with their service coordinators only a few times a year or less or not at all.

4.2.3 Services Received by HOPE IV Participants and Comparison Group Respondents at Baseline

This subsection compares HOPE IV participants and comparison group respondents as to: the specific supportive services they receive; how long they have been getting each service; how often they receive it; and how satisfied they are with the service. In addition, it examines the extent to which comparison group members are receiving some type of formal or informal case management. Since comparison group selection did not permit screening out frail elderly Section 8 tenants who might be receiving services similar to those provided under HOPE IV, this comparison is potentially important to the quasi-experimental study design.

Table 4-7 presents the supportive services received by HOPE IV participants and comparison group respondents as reported in their survey responses, along with the number and percentage of each group getting each type of service. The service categories are defined as follows in the survey instruments:

housekeeping services, such as help with laundry, dishes, running errands or housecleaning;

transportation services, such as providing a car, van or escort to take the respondent shopping or to appointments;

home-delivered meals, or sending someone to prepare meals in the respondent's home;

in-home health services, such as a nurse or health aide who checks on the respondent's health, provides medications or bathes the respondent;

personal care services, including assistance with grooming, dressing, eating, toileting or getting around in the home;

meals at a senior center or other site;

recreational services, such as participating in activities at a senior center or having someone conduct friendly visits with the respondent in her home; and,

counseling services, or help from a professional with mental health or emotional issues. An example would be provision of counseling on loss of a spouse.

The highest percentage of both groups receive housekeeping (81 percent for participants and 50 percent for comparison group members) and transportation services (46 percent and 32 percent), and the lowest percentage for both groups is counseling (6 percent and 4 percent). Apart from somewhat different relative rankings for other services, the main difference between groups is that *a higher percentage of HOPE IV participants receive each type of service except personal care.* However, although percentage differences between the two groups are quite high for certain services, such as housekeeping and home-delivered meals, for other services (e.g., in-home health, counseling), the differences are negligible.

Table 4-7.
Services Received by HOPE IV Participants and Comparison Group Members (in order of relative frequency)

Participants (n=388)		Comparison Group (n=405)	
Service	**% receiving**	**Service**	**% receiving**
Housekeeping	81	Housekeeping	50
Transportation	46	Transportation	32
Home delivered meals	42	In-home health	27
In-home health	31	Personal care	25
Personal care	23	Home delivered meals	24
Meals at senior center	16	Recreational services	10
Recreational	13	Meals at senior center	10
Miscellaneous others (food stamps, emergency beeper)	11	Miscellaneous others (food stamps)	10
Counseling	6	Counseling	4

Comparison group respondents who do receive services have been getting them for a longer period than the HOPE IV participants (see Table 4.8 and 4.9). With respect to the frequency with which services are received, HOPE IV participants and comparison group respondents who get two of eight categories of services -- home-delivered meals and transportation -- do so with roughly the same average frequency of just under 7 times a month for transportation, and about 21-22 days a month for home-delivered meals. However, comparison group respondents receive personal care, in-home health services, housekeeping, and recreational services with greater average frequency than HOPE IV participants. The only services participants receive more often than the comparison group, on average,

are meals at senior centers (13.8 versus 11.2 times a month) and counseling (3.3 versus 1.7 times a month). It is also noteworthy that a similarly high percentage of both groups indicates a very high level of satisfaction with their services, for all but one category of service (counseling).

Table 4-8.
HOPE IV Participants: Length of Receipt, Average Monthly Frequency of Receipt, and Satisfaction with Specific Services (n=388)

Service	% Receiving	For How Long (%)			Average Frequency (days per month)	% Very Satisfied
		Less than 6 months	6 months - 1 year	Over 1 year		
Transportation	46	41	26	33	6.8	73
Home delivered meals	42	60	25	18	21.6	68
Meals at senior center	16	45	28	27	13.8	73
Personal care services	23	68	21	11	12.9	88
In-home health	31	61	17	22	7.6	84
Housekeeping	81	61	21	18	8.1	79
Counseling	6	38	17	46	3.3	71
Recreational services	13	44	24	32	9.9	81

Table 4-9.
Comparison Group: Length of Receipt, Average Monthly Frequency of Receipt, and Satisfaction with Specific Services (n=405))

Service	% Receiving	For How Long (%)			Average Frequency (days per month)	% Very Satisfied
		Less than 6 months	6 months - 1 year	Over 1 year		
Transportation	32	9	10	81	6.5	75
Home delivered meals	24	15	17	67	21.2	77
Meals at senior center	10	7	7	85	11.2	83
Personal care services	25	18	15	67	15.7	83
In-home health	27	20	20	60	8.4	90
Housekeeping	50	15	17	68	10.9	77
Counseling	4	25	6	69	1.7	40
Recreational services	10	12	5	83	10.3	79

In other words, the situation at baseline does not indicate a totally "clean" distinction between participants and comparison group respondents with respect to receipt of services. *Although a larger overall percentage of HOPE IV participants receive services, comparison group respondents who do get services receive them, on average, more often than HOPE IV participants.* Moreover, relatively high percentages of comparison group respondents also indicated that some person or agency currently helps them arrange for and obtain services (43 percent) and provides information about services and how to access them (44 percent). These responses suggest that many comparison group members are also receiving some type of informal or formal case management in addition to the supportive services described above. However, it is not clear that having a person to help arrange for and obtain services is necessarily equivalent to the type and level of individualized, professional case management provided by the HOPE IV service coordinator.

It remains to be seen whether these patterns of formal service utilization will persist over time. At the time of the follow-up, HOPE IV participants will have spent two years in a case-managed program that will adjust the intensity and types of services they receive to fit their changing individual needs. Comparison group members may not continue to get services, and if they do, their services may not be tailored to their changing requirements in the same way or at the same intensity as those provided to HOPE IV participants. Either or both of these factors could make a difference in the ultimate outcomes for the two groups. Nevertheless, the possibility remains that these patterns of utilization will persist, and in two years we will be faced with the challenges of detecting HOPE IV program benefits when a significant portion of the comparison group is getting a combination of Section 8 housing and supportive services very much like that received by Program participants. Section 5.2 of the concluding chapter discusses analytic strategies that will be used to address this challenge, should the need arise.

4.2.4 Views of HOPE IV Program Benefits

The vast majority of the HOPE IV participants are happy with the amount and type of services they are receiving. Table 4-10 presents the one service participants consider most important in allowing them to continue to live in their own homes. Housekeeping services head the list, noted as most important by 42 percent of the respondents who answered this question. Housekeeping is followed by rental assistance (21 percent), home health aide services (15 percent), and Meals on

Wheels (12 percent) -- all core in-home services designed to maximize the participants' ability to remain independent.

Apart from indicating their level of satisfaction with individual services, HOPE IV participants were also asked if they needed more of any of their current services, or felt they could use services they are not now getting. About four-fifths of HOPE IV participants indicated not needing any more of their current services. Of the one-fifth who would like more of their present services, the greatest number (38) expressed a desire for more housekeeping services, followed by a few (13) who said they wanted more transportation or escort services. Similarly, over three-fourths of the HOPE IV respondents report they do not need any services other than those they are now getting. Transportation, housekeeping, and personal care services rank highest on the list of additional services desired among the one-quarter of HOPE IV participants who would like additional services.

Table 4-10.
Service Seen as Most Helpful for Maintaining Independence (n=369*)

Service	(n)	Percentage of Participants
Housekeeping	(155)	42
Rental assistance	(77)	21
Home health aide	(57)	15
Meals on wheels/meals program	(43)	12
All help equally	(13)	4
Miscellaneous others (e.g. transportation, food stamps)	(24)	6

*"Don't know" (7) and "not ascertained" (12) responses eliminated from denominator.

Paying for HOPE IV Supportive Services

HOPE for Elderly Independence program regulations state that HOPE IV participants should contribute ten percent of the cost of their supportive services, unless this exceeds twenty percent of their adjusted monthly income. However, telephone interviews conducted in the Fall of 1993 and 1994 revealed that HOPE IV program personnel at some grantee sites were reluctant to press the payment issue with participants, most of whom they felt were too poor to be asked to contribute. In this light, it is interesting that *43 percent of HOPE IV participants pay nothing above rent toward the cost of HOPE IV program services*. Thirteen percent of those who pay a portion of their service costs (roughly 7% of all HOPE IV respondents) say this has presented a problem for them since entering the HOPE IV Program.

When considering all the services they currently receive, through HOPE IV and any other source, excluding rent, 35 percent of the HOPE IV participants pay nothing, 35 percent pay between $1 and $25 per month, eleven percent between $25 and $50 a month, and ten percent pay over $50 for supportive services.[22] In terms of how this amount compares to what they paid prior to entering the HOPE IV program, about half of the respondents indicated they previously received no such services, and another 13 percent gave "don't know" answers. Of those 37 percent of respondents who answered the question, 42 percent said what they pay now is a lot less (32%) or a little less (10%) than before, 24 percent that the amount is about the same, and 33 percent that they are now paying somewhat (15%) or a great deal (18%) more. It is not clear to what extent greater or lesser monthly costs reflect differences in the types and amounts of services received before and after entering HOPE IV.

When asked a hypothetical question regarding their willingness to contribute more money each month for their current services should HOPE IV rules be changed to require this, participants currently paying for services were relatively evenly divided between those noting they would not (51%) and would (43%) be willing to do so. The vast majority (86%) of the latter indicated they would pay no more than $1-$25 more per month. Fifty-two percent of the participants not now paying for their HOPE IV services report they would be unwilling to pay anything. However, 36 percent of those currently paying nothing for support services say they would be willing to contribute something, with over four-fifths of the latter giving the amount at between $1 and $25 per month. It should be noted that even though it was posed hypothetically in an effort to allay fears about losing program benefits, some respondents may still have interpreted the question as a test of loyalty to the program. Consequently, these responses should be interpreted cautiously.

Participants' Overall Assessment of HOPE IV

On the whole, participants are enthusiastic supporters of the HOPE IV program, giving about equal weight to the housing and services components in terms of what they like most about it. Participants would change little, if anything, about HOPE IV, and consider the Program essential to helping them remain in their own homes. An overwhelming 84 percent of HOPE IV participants are very satisfied, and 10 percent somewhat satisfied, with the HOPE IV program. Only one respondent

---

[22] HOPE IV respondents can be receiving and paying for services from sources other than the HOPE Program. This could account for the apparent discrepancy that 43 percent of respondents report not paying anything above rent for HOPE IV services on a monthly basis, whereas 35 percent say they pay nothing at all for services (from whatever source) per month. That is, eight percent of the respondents may be paying for non-HOPE services.

indicated active dissatisfaction with the Program, while a very few were uncertain or did not say. Table 4-11 presents what respondents said they like most about HOPE IV. Not surprisingly, the highest percentages named help with housing and rent (31%) and receipt of specific services (29%). Interestingly, 17 percent indicated that the humane, caring attitude of program and service personnel is what they like most about HOPE IV, while 16 percent felt they could not really choose among the various aspects of the HOPE IV program, because "everything about it is good." About 85 percent of the respondents would make no changes to the HOPE IV program; most of the few who could think of something they would change indicated they would want the Program to provide more housekeeping services or improve the quality of existing services. Ninety percent of the respondents indicated that HOPE IV has been very important for allowing them to continue living in their own homes, eight percent felt the Program has been somewhat important, and only a few answered that the Program has made no difference one way or the other.

Table 4-11.
Single Thing Participants Like Most About HOPE IV Program (n=366)*

	(n)	Percentage of Participants
- Help with rent/housing	(114)	31
- Specific services (e.g., housekeeping, meals, home health aide)	(105)	29
- Humane/caring attitude	(61)	17
- Everything/services in general	(58)	16
- Enabling independent living	(17)	5
- Miscellaneous (safer environment, lowering financial burden)	(11)	3

*"Don't know" (18) and "not ascertained" (4) responses excluded.
**Percentages are rounded, so may not total exactly 100%.

5. CONCLUSIONS

This section summarizes the general findings on the characteristics of the HOPE IV participants, identifies some consistent patterns, and discusses the implications of the participants' and comparison group's responses which will be used to conduct the program impact analysis after the two-year follow-up survey.

5.1 Characteristics of the HOPE IV Participants

Consistent with the HOPE IV regulations, the majority of program participants are quite frail. For example, HOPE IV participants reported a basic level of frailty that was over seven times greater than the elderly household population as a whole. According to the five-item Activity of Daily Living scale (used in Table 3-1), 80 percent for HOPE IV participants reported difficulty performing at least one activity, compared to only 11 percent for all elderly in the community.

Compared to the nursing home population and participants in various home care programs for nursing home eligibles, the HOPE IV participants were much less frail. For example, when measuring frailty based on receiving assistance from another person to perform an activity, as opposed to just having difficulty with it, approximately 44 percent of the HOPE IV participants reported getting such help; the corresponding figure for all elderly (65+) in the community is about 8 percent. This compares to 92 percent for nursing home residents, 84 percent for the Long Term Care Channeling Demonstration program, and between 79 and 95 percent for the PACE programs that provided home care to frail elderly eligible for nursing home placement. This shows that HOPE IV participants have a level of ADL dependency roughly half that of those receiving or in need of nursing home care and about five times greater than all elderly persons living outside of institutions.

Beyond frailty, participants also reported many other factors that place them at risk for loss of independence. For example, almost 60 percent said their overall health was either fair or poor, and they had many diagnosed chronic medical conditions, including arthritis, high blood pressure, and heart disease. About 40 percent had experienced a fall during the past year, and an equal number found it necessary to use a hospital emergency room at least once during that same period.

Further intensifying the risk for institutionalization posed by these health and disability factors, virtually all participants live completely alone, nearly half are over the age of 75, and approximately 50 percent have less than a high school education and annual incomes below $8,000.

Despite a substantial level of poor health and frailty, the participants reported a relatively high level of satisfaction with many aspects of their lives. For example, almost 70 percent were very satisfied with their living arrangements, and about 60 percent reported feeling calm, peaceful, and being a happy person most or all of the time during the past month. Nearly 60 percent felt they had a great deal of choice in what they do and when, and only 11 percent said they were very unhappy with the frequency of their social contacts.

However, some participants do report a number of negative aspects in the quality of their lives and identify additional services they need. This is not surprising given that, by design, the HOPE IV program targets persons with limitations in activities essential for independent living. For example, one-fifth are not satisfied with life, and nearly 50 percent report having a fair to poor appetite. One quarter said they rarely if ever felt full of life and an equal number reported they were a very nervous person most or all of the time during the past month. About half of the participants said they would like to be doing more socially, and about 20 percent expressed a need for additional services, most notably housekeeping and transportation.

These data show that while certain characteristics dominate the participant profile, such as gender (nearly 80 percent are women) and specific measures of life satisfaction (almost 70 percent are very satisfied), there is considerable variation among participants in many factors such as multiple ADL limitations. For example, 21 percent of participants reported no ADL limitations, while 38 percent reported at least three, the latter an indication of considerable frailty. As discussed in Chapter 3, there are several ADL limitation scales. The one referenced here is based on the scale developed by Sidney Katz, as referenced in Section 3.1., above, and constitutes a more restrictive activity list than appears in the HOPE IV regulations. This variation in levels of frailty suggests a participant group that is far from homogeneous, confirming the need for individual case management, tailoring an appropriate mix and level of supportive services in response to each participant's needs. At the same time, this heterogeneity has significant implications for the impact analysis, for we are likely to see substantially different outcomes, depending on the degree of frailty, in conjunction with age, education, and other factors. For this reason, the impact analysis cannot treat the participants as a single group, and these data will help identify logical sub-groups for analytical purposes after the follow-up interviews.

In spite of their high level of disability, a number of participants do not appear to meet the HOPE IV definition of frailty. For example, when analyzing all activities referenced in the HOPE IV regulations, at least 20 percent of participants did not report a limitation in performing at least three. However, this may be a function of frail elderly tending to underreport their ADL limitations, relative to professional assessments. It also may be due to differences among the grantees in measurement of ADL limitations and interpretation of the HOPE IV regulations.

5.2 Comparison Group Design

While many studies have evaluated the benefits of case management and services for a frail elderly population in the community, this research focuses specifically on comparing two groups of Section 8 tenants, one participating in the HOPE IV program and the other receiving whatever support might otherwise occur in the absence of the HOPE IV demonstration.

The hypothesis underlying the quasi-experimental design is that the addition of a formal program of case management, personal care, and home management support to Section 8 rental assistance can prevent or delay unnecessary institutionalization and otherwise enhance the quality of lives of frail, low-income elderly persons. By comparing the status of the participant and comparison groups at two points in time, the evaluation can identify outcome differences and determine the impact of HOPE IV. Therefore, the viability of the study's approach depends, in large part, on having a comparison group that is similar to the HOPE IV participants in several key regards, especially in their level of frailty. This baseline description of participants and the comparison group members provides a basis for establishing the similarity of the two groups so essential for the success of the quasi-experimental design.

Given the HOPE IV eligibility criteria, which focus almost exclusively on frailty, similarity between the two groups in these functional domains is critical. We have seen that, in terms of the ADL, IADL, and functional limitations, the two groups are indeed quite similar. By design, the study employed a screening instrument (Appendix A) to help ensure that the level of frailty of the comparison group was similar to that of the participants. The figures in Tables 3-1 and 3-3 show that this screener succeeded very well. Beyond this, the considerable similarity between the HOPE IV participants and comparison group members in domains not directly a function of the comparison group screening

criteria further enhances the potential effectiveness of the impact analysis that will occur after a two-year follow-up survey. These include remarkably similar baseline responses to various demographic, health, and quality of life questions, as well as questions concerning frequency of receipt of informal assistance and social contact. For example, both participants and the comparison group are heavily female, and reported similar rates of satisfaction with their current living environment, as well as similar health status, overall life satisfaction and frequency of in-person and telephone contact with children, other relatives, friends, and neighbors.

Consistent with our assumptions, the participant group reported receiving more services than the comparison group. Somewhat surprisingly, however, the comparison group receives more services than might have been expected. For example, both groups reported the same rates for receipt of personal care (23 and 24 percent, respectively), but participants exceeded the comparison group rates in housekeeping (81 versus 50 percent, respectively); transportation (46 versus 32 percent), and home delivered meals (42 versus 27 percent). In addition, all participants benefit from HOPE IV's important case management component; by comparison, just under half of comparison group members report receiving some kind of informal or formal case management.

A relatively high level of receipt of services by the comparison group is itself an important finding suggesting that, at a given point in time, a certain segment of frail elderly Section 8 tenants in locations similar to those of the HOPE IV grantees receives substantial service support. The comparison group may have had to be receiving relatively high levels of personal care and other services in order to continue to live independently in Section 8 scattered site rental housing as frail elderly tenants. HOPE IV is but one of many community-based, long-term care programs available for the frail elderly, and the services of Area Agencies on Aging and others may be supporting frail elderly Section 8 tenants at a relatively high level. Another factor that might help to account for this comparatively high level of formal support among comparison group members is that they have lived in their current homes much longer than the HOPE IV participants: nearly one third of the comparison group members have lived in their residence over 10 years, compared to just about 10 percent of the participants. Having been in their communities for a long time may have allowed the comparison group to develop linkages with community resources that ensured a considerable level of formal services support.

This relatively high level of formal support by both groups also may be a function of similar attitudes about willingness to receive such help. For example, both HOPE IV participants and

comparison group members were similarly receptive when asked a series of questions about their attitudes toward receipt of services from different sources, and preferences for getting help from family and friends or government and community agencies. These questions were asked to determine if there might be differences between the two groups on variables related to the propensity to participate in programs that would otherwise have no direct bearing on premature institutionalization or other major outcomes of interest to the study. The similarity of the participant and comparison group responses regarding the willingness to accept services further confirms the viability of the comparison group design.

One issue is whether the comparison group will continue to receive the type and level of support received by the otherwise very similar HOPE IV participants. In light of this, one important finding from the follow-up interviews will be the relative ability of HOPE IV participants and comparison group respondents to sustain this support over the two years. This will help to determine, first, if HOPE IV better guarantees the continuation of needed supportive services, and, second, if any such differences in continuity of services can help to explain ultimate differences between these two groups in rates of overall well-being, institutionalization, mortality, and other reasons for leaving Section 8. In addition, to get a better idea of how the type and intensity of formal and informal case management reported by comparison group members compares to that received by HOPE IV participants, the follow-up survey will include additional questions to comparison group members on the type and frequency of case management services received.

If it continues throughout the two-year period of analysis, the receipt of a considerable level of formal services by the comparison group is potentially problematic to the quasi-experimental design, in that it may limit discernible differences between the two groups in outcomes such as rates of nursing home placement and other measures of independence and life satisfaction. Should this occur, we are prepared to implement a two-pronged analytic strategy for handling the situation. The first part of the strategy, essentially what was proposed in the work plan, would involve making direct comparisons between HOPE IV participants and comparison group respondents to estimate the incremental effects of HOPE IV on outcomes, or those effects attributable to incremental differences in service and service coordination between HOPE IV participants and comparison group members. We plan to adjust these comparisons for differences between participants and comparison group respondents in personal characteristics (e.g., ADL limitations at baseline, age), but not for differences in services received. Since the results of such comparisons will estimate only the incremental impact of HOPE IV,

performing these direct comparisons may not allow us to discern positive program effects on outcomes because it does not account for the common impact of services received by both groups.

The second part of the strategy would be designed to estimate HOPE IV's total, rather than incremental, impact on the participants. By definition, HOPE IV's total impact equals the effect of all services and service coordination provided to HOPE IV participants by the Program, not only the effect of the additional services HOPE IV participants receive above and beyond what comparison respondents may be receiving from other sources. This second part of our strategy assumes that HOPE IV participation can affect outcome measures both directly, and indirectly, by modifying the amount and mixture of services received. The specifics of this approach will be developed once preliminary analyses of the complete dataset have been completed, so at this point this discussion is necessarily only suggestive.

This second part of our strategy would involve making comparisons between the participants and comparison group members by simultaneously modeling both 1) the effects of HOPE IV participation on receipt of services and, 2) the effects of receipt of services on outcomes, while controlling for potential confounders. We will use standard techniques to estimate these models under the assumption that service frequency may be related to outcome, but provider type (e.g., HOPE IV or other) is not. This simultaneous equation model will measure the total impact of HOPE IV on outcomes inclusive of the impact of services and service coordination that comparison group members are receiving from other sources. Thus, this strategy will provide a more comprehensive assessment of HOPE IV's total impact than would be obtained from direct comparisons of HOPE IV participants and comparison group members alone. This is consistent with our finding that HOPE IV benefits participants through both direct provision of services and by facilitating the delivery of services from other programs (e.g., Older Americans Act Services) to participants.

5.3 Social Support and Satisfaction with the HOPE IV Program

Apart from its implications for the quasi-experimental design, as discussed above, the striking similarity between the HOPE IV participants and comparison group in both the frequency and patterns of their informal social contacts with children, other relatives, and friends and neighbors is itself quite interesting. To reiterate, both groups have regular telephone and in-person contact with at least one other person outside their household, on average, nearly every day in the month. However, the

distribution of contact is such that between one-fifth and one-quarter of both HOPE IV participants and comparison group members neither see nor speak on the telephone with anyone in the course of a month, while over one-third of both groups enjoy both types of contact several times a week, even daily. Future analyses will allow us to determine if it is the same individuals who lack both in-person and telephone contact, which would point to the existence of a cluster of extremely isolated individuals. We will also try to determine whether similarly skewed patterns of sociability and informal social support have been found for other frail elderly populations who do not live in Section 8 housing.

Along similar lines, although most HOPE IV participants are relatively happy and satisfied with their lives, about the same percentage (roughly one-fifth) of HOPE IV participants who report no monthly social contact indicate feeling quite unhappy with their lives and social lives on a variety of measures of life satisfaction and mental health. Consequently, future analyses might also examine whether the most socially isolated participants are also those who tend to feel most disheartened about their lives in general.

Most HOPE IV participants report extremely high levels of satisfaction with their service coordinators, the services they get, and the HOPE IV program overall. Virtually all the participants view the Program as essential in enabling them to remain independent in their own homes. The relatively few expressing any dissatisfaction basically want additional housekeeping or transportation services, or more contact with their service coordinators. The extent of participant satisfaction with HOPE IV is all the more impressive in light of peculiar circumstances at one of the sixteen grantee sites, where participants had to wait for many months, even up to one year after moving into Section 8 housing, before actually beginning to receive their supportive service packages.

Without discounting the very high level of initial satisfaction of participants with the HOPE IV Program, it is nevertheless interesting that comparison group members are also highly satisfied with their housing and supportive services. This no doubt partly reflects that comparison group respondents also receive Section 8 rental assistance, while a reasonably large segment get many of the same supportive services as the HOPE IV participants. However, from a "consumer satisfaction" perspective, these findings may also suggest that low-income frail elderly persons are so extraordinarily grateful for any help that keeps them from having to enter nursing homes, they may not be the most critical or discerning consumers. Even if it were true, this would in no way minimize the very real importance of HOPE IV to its participants.

APPENDIX A

COMPARISON GROUP SCREENER

HOPE for Elderly Independence Demonstration Program Evaluation

RESPONDENT NAME: _____

WESTAT ID: _____

COMPARISON GROUP SCREENER

(AFTER READING THE FIRST PARAGRAPH OF QUESTION S1, ASK: May I please speak with Mr./Mrs. {FULL NAME OF PERSON ON RIS}?)

S1. Hello, my name is {INTERVIEWER NAME} and I'm calling from Westat, in Rockville, Maryland on behalf of the U.S. Department of Housing and Urban Development (HUD).

Westat is conducting a study of elderly persons and their ability to manage living in their homes or apartments (either by themselves or with their families).

Your name was provided to us by the {PHA NAME}. While your participation is voluntary, we would very much appreciate if you could answer a few questions. Your answers will be kept strictly confidential. With the exception of our own research staff, no one will be able to identify your individual answers to our questions. Your cooperation is very important to the outcome and usefulness of this study.

Are you currently receiving a voucher or certificate for Section 8 housing assistance (rental assistance)?

YES	1	(S2)
NO	2	(Thank you very much, we need to interview persons who receive Section 8 housing assistance. These are all the questions I have for now. **CODE AS INELIGIBLE "I"**)

S2. Are you 62 years of age or older?

YES	1	(S3)
NO	2	(S4 IF MORE THAN 1 PERSON IN HH. OTHERWISE: Thank you very much, we need to interview only individuals 62 or older. These are all the questions I have for now. **CODE AS INELIGIBLE "I"**)

S3. By yourself and without using special equipment, do you usually have difficulty performing any of the following activities? (DO NOT INCLUDE OCCASIONAL DIFFICULTIES WHICH ARE A RESULT OF A TEMPORARY CONDITION)

	YES	NO	IF YES →	RELATIVE SCORE
a. Feeding yourself	1	2	_____	60
b. Cooking, preparing or serving meals	1	2	_____	40
c. Washing your hair	1	2	_____	40
d. Washing yourself	1	2	_____	40
e. Getting in and out of the shower or tub	1	2	_____	40
f. Personal grooming (e.g., brushing teeth)	1	2	_____	40
g. Dressing yourself	1	2	_____	40
h. Doing light housework (laundry, dishes)	1	2	_____	40
i. Going shopping, to the doctor, etc	1	2	_____	40
j. Getting in and out of bed or chair	1	2	_____	60
k. Paying bills/handling personal finances	1	2	_____	40

TOTAL SCORE: _____

SELECTION RULES:

1. IF THE RESPONDENT ANSWERED YES TO 2 OR MORE ACTIVITIES, AND THE TOTAL SCORE IS AT LEAST 100, IMMEDIATELY (ONCE YOU HAVE REACHED A TOTAL SCORE OF AT LEAST 100, DO NOT ASK THE REMAINING ITEMS) CONTINUE WITH THE EXTENDED INTERVIEW AND READ THE INTRODUCTION S9.

2. IF THE RESPONDENT'S TOTAL SCORE IS LESS THAN 100 OR THE ANSWERS TO S3a-k ARE ALL NOs, AND THE NUMBER OF PEOPLE IN THE HOUSEHOLD IS MORE THAN ONE, ASK QUESTION S4.

3. IF THE RESPONDENT'S TOTAL SCORE IS LESS THAN 100 OR THE ANSWERS TO S3a-k ARE ALL NOs, AND THE RESPONDENT IS THE ONLY PERSON IN THE HOUSEHOLD, END THE INTERVIEW: **Thank you very much, we are trying to find people 62 or older who have more difficulty than you with these types of activities. These are all the questions we have for now. CODE AS INELIGIBLE "I"**

S4. Is there anyone else who is a member of your household, and is 62 years of age or older?

YES	1	(S5)
NO	2	(Thank you very much, we need to interview only persons 62 or older. These are all the questions I have for now. **CODE AS INELIGIBLE "I"**)

S5. Could I please have the name and age of the person?

NAME OF OTHER HOUSEHOLD MEMBER:

_____ _____

FIRST NAME LAST NAME

AGE ____ SEX ____

S6. Could I please speak with her/him?

YES	1	(S7)
NO	2	(MAKE CALLBACK APPOINTMENT. WHEN CALLING BACK START AT S7)

S7. Hello, my name is {INTERVIEWER NAME} and I'm calling from Westat, in Rockville, Maryland on behalf of the U.S. Department of Housing and Urban Development (HUD).

Westat is conducting a study of elderly persons and their ability to manage living in their homes or apartments (either by themselves or with their families).

Your name was provided to us by the {PHA NAME}. While your participation is voluntary, we would very much appreciate if you could answer a few questions. Your answers will be kept strictly confidential. With the exception of our own research staff, no one will be able to identify your individual answers to our questions. Your cooperation is very important to the outcome and usefulness of this study.

Are you a member of this household and 62 years of age or older?

YES	1	(S8)
NO	2	(Thank you very much, we need to interview only persons 62 or over. These are all the questions I have for now. **CODE AS INELIGIBLE "I"**)

S8. By yourself and without using special equipment, do you have difficulty performing any of the following activities? (DO NOT INCLUDE OCCASIONAL DIFFICULTIES WHICH ARE A RESULT OF A TEMPORARY CONDITION)

	YES	NO	IF YES →	RELATIVE SCORE
a. Feeding yourself	1	2	_____	60
b. Cooking, preparing or serving meals	1	2	_____	40
c. Washing your hair	1	2	_____	40
d. Washing yourself	1	2	_____	40
e. Getting in and out of the shower or tub	1	2	_____	40
f. Personal grooming (e.g., brushing teeth)	1	2	_____	40
g. Dressing yourself	1	2	_____	40
h. Doing light housework (laundry, dishes)	1	2	_____	40
i. Going shopping, to the doctor, etc	1	2	_____	40
j. Getting in and out of bed or chair	1	2	_____	60
k. Paying bills/handling personal finances	1	2	_____	40

TOTAL SCORE: _____

SELECTION RULES:

1. IF THE RESPONDENT ANSWERED YES TO 2 OR MORE ACTIVITIES, AND THE TOTAL SCORE IS AT LEAST 100, IMMEDIATELY (ONCE YOU HAVE REACHED A TOTAL SCORE OF AT LEAST 100, DO NOT ASK THE REMAINING ITEMS) CONTINUE WITH THE EXTENDED INTERVIEW. READ THE INTRODUCTION S9.

2. IF THE RESPONDENT'S TOTAL SCORE IS LESS THAN 100 OR THE ANSWERS TO S8a-k ARE ALL NOs, END THE INTERVIEW:

Thank you very much, we are trying to find people 62 or older who have more difficulty than you with these types of activities. These are all the questions we have for now. CODE AS INELIGIBLE "T"

S9. INTRODUCTION TO EXTENDED INTERVIEW:

Based on your answers, we would like to conduct the basic interview with you.

As I said earlier, my name is {INTERVIEWER NAME} and I'm calling from Westat in Rockville, Maryland. The U.S. Department of Housing and Urban Development is sponsoring our study to determine the needs of persons like yourself. We would like to know what kind of services persons like you would need that would help them to continue living in their own homes or apartments.

START THE COMPARISON GROUP QUESTIONNAIRE (*YELLOW*) AND MODIFY QUESTION A1: Let me just verify your name please.

VERIFY NAME AND THEN READ: I'd like to begin by asking a few questions about your background. CONTINUE WITH A2.

APPENDIX B

PARTICIPANT SURVEY

OMB No.: 2528-0159
Expires: 5/31/97

U.S. Department of Housing and Urban Development
Office of Public and Indian Housing

HOPE for Elderly Independence Demonstration Program Evaluation

Participant Survey (Telephone Version)

Westat ID: _____

Date of Interview: _____
Interviewer Initials: _____
Final Outcome: _____

Prepared by:

Westat, Inc.

1650 Research Boulevard

Rockville, Maryland 20850

June 21, 1994

TIME BEGAN: ___ ___ : ___ ___ AM/PM

SECTION A

DEMOGRAPHIC INFORMATION

THERE ARE SOME ITEMS THAT HAVE BEEN SHADED IN THIS INSTRUMENT. THESE ITEMS DO NOT APPLY TO THIS INSTRUMENT AND SHOULD THEREFORE NOT BE READ TO RESPONDENTS. THEY HAVE BEEN INCLUDED TO ENABLE AN EASY COMPARISON OF DATA COLLECTED ON THIS SURVEY WITH DATA COLLECTED ON THE COMPARISON GROUP SURVEY.

I'd like to begin by asking a few questions about your background.

A1. What is your full name?

_____ _____ _____
FIRST NAME MIDDLE INITIAL LAST NAME

A2. What is your date of birth?

|__|__| |__|__| |__|__|__|__|
MONTH DAY YEAR

DON'T KNOW 8

A3. How old were you at your last birthday?

_____ YEARS

A4. Were you born in a . . .

country outside U.S. 1

(SPECIFY) _____

city/state inside U.S. 2

(SPECIFY) _____

DON'T KNOW 8

A5. Which of the following best describes your race?

American Indian or Alaskan Native	1	
Asian or Pacific Islander	2	
White	3	
Black	4	
DON'T KNOW	8	

A6. Are you of Hispanic origin or descent (for example, Mexican, Mexican-American, Chicano, Latin American, Puerto Rican or Cuban)?

YES, HISPANIC ORIGIN	1	
NO, NOT OF HISPANIC ORIGIN	2	
DON'T KNOW	8	

A7. Do you speak any other language besides English with your family and friends?

YES	1	(A8)
NO	2	(A9)
DON'T KNOW	8	(A9)

A8. What is that language?

(SPECIFY)_____

DON'T KNOW 8

A9. What is the highest grade or year of school you ever completed?

NO FORMAL SCHOOLING	0
NOT A HIGH SCHOOL GRADUATE	1
A HIGH SCHOOL GRADUATE	2
SOME COLLEGE	3
COLLEGE GRADUATE	4
DON'T KNOW	8

A10. Are you married, widowed, divorced, separated or have you never been married?

MARRIED	1	(A12)
WIDOWED	2	(A11)
DIVORCED	3	(A12)
SEPARATED	4	(A12)
NEVER MARRIED	5	(A12)
DON'T KNOW	8	(A12)

A11. **For how long have you been widowed (the most recent time)?**

(SPECIFY)_____ YEARS

DON'T KNOW 8

A12. **How many persons usually live in your household?**

ONE (JUST SELF)	1	(A14)
TWO (SELF PLUS ONE)	2	(A13)
THREE	3	(A13)
FOUR	4	(A13)
FIVE OR MORE PERSONS	5	(A13)

A13. **Please name the other people who usually live with you and tell me if they are male or female, what the relationship to you is, and their age.**

a. FIRST AND LAST NAME	b. SEX (M/F)	c. RELATIONSHIP TO RESPONDENT	d. AGE (YEARS)
(i) _____	____	_____	_____
(ii) _____	____	_____	_____
(iii) _____	____	_____	_____
(iv) _____	____	_____	_____
(v) _____	____	_____	_____

A14. **Do you have any living children (include adopted and stepchildren) in addition to any you mentioned as living with you?**

YES	1	(A15)
NO	2	(A16)
DON'T KNOW	8	(A16)

A15. **How many . . .**

a. Sons _____

b. Daughters _____

DON'T KNOW 8

A16. **Do you have any pets?**

YES	1	(A17)
NO	2	(A18)
DON'T KNOW	8	(A17)

A17. **Do you have a . . .**

	YES	NO	DK
a. Dog	1	2	8
b. Cat	1	2	8
c. Bird	1	2	8
d. Other (SPECIFY)_____	1	2	8

A18. **Please tell me the name, address and telephone number of two people (children, husband or wife, close relative, close friend or neighbor) who know you very well and who we might contact in case we have trouble getting in touch with you in the future.**

a. _____ NAME _____ RELATIONSHIP

_____ STREET ADDRESS

_____ CITY |_|_| STATE _____ ZIPCODE

(_ _ _) _ _ _-_ _ _ _

TELEPHONE NUMBER

b. _____ NAME _____ RELATIONSHIP

_____ STREET ADDRESS

_____ CITY |_|_| STATE _____ ZIPCODE

(_ _ _) _ _ _-_ _ _ _

TELEPHONE NUMBER

CHECKPOINT:

INTERVIEWER, FOLLOW GUIDELINES IN MANUAL TO DETERMINE WHETHER TO PROCEED WITH THE INTERVIEW OR USE A PROXY. IF A PROXY IS NEEDED, COMPLETE THE FOLLOWING INFORMATION:

☐ CHECK HERE IF THE REMAINDER OF QUESTIONS WILL BE ANSWERED BY PROXY

_____ _____

FIRST NAME OF PROXY LAST NAME OF PROXY

_____

RELATIONSHIP TO HOPE PARTICIPANT

(_ _ _) _ _ _ - _ _ _ _

TELEPHONE NUMBER

DESCRIBE REASON FOR USING A PROXY:

_____

_____

_____

SECTION B

HOUSING CHARACTERISTICS

The next few questions ask about your home and neighborhood.

B1. Do you live in an apartment building with more than one story?

YES	1	(B2)
NO	2	(B4)
DON'T KNOW	8	(B4)

B2. Which floor do you live on? Do you live . . .

on the first floor	1
on the second floor	2
on the third floor or a higher floor	3
DON'T KNOW	8

B3. Is there a working elevator in your building?

YES	1
NO	2
DON'T KNOW	8

B4. How many stairs do you have to climb to enter your home? Do you have to climb . . .

no stairs	1	(B6)
one stair	2	(B5)
two stairs	3	(B5)
three or more stairs	4	(B5)
DON'T KNOW	8	(B5)

B5. Is there some other way besides the stair(s) for entering your building?

There is a ramp that can be used for entering the building	1
There is another way of entering the building besides the stairs or a ramp ..... (SPECIFY) _____	2
There is no other way of entering the building besides the stairs	3
DON'T KNOW	8

B6. **How easy is it <u>for you</u> to get into your home or apartment from the outside? Would you say that . . .**

It is easy	1	
It is neither easy nor difficult	2	
It is difficult	3	
DON'T KNOW	8	

B7. **Are all the rooms in your home/apartment on the same floor?**

YES	1	(B10)
NO	2	(B8)
DON'T KNOW	8	(B8)

B8. **Do you have to go up or down any stairs to get from your kitchen to your bedroom?**

YES	1
NO	2
DON'T KNOW	8

B9. **Is there a bathroom on the same floor as your bedroom?**

YES	1
NO	2
DON'T KNOW	8

B10. **Have any changes been made to the interior of your home/apartment to make it easier for you to get around?**

YES	1	(B11)
NO	2	(B12)
DON'T KNOW	8	(B11)

B11. **Have you . . .**

	YES	NO	DK
a. added a stair lift?	1	2	8
b. added hand rails?	1	2	8
c. added ramps?	1	2	8
d. widened doorways?	1	2	8
e. lowered counters?	1	2	8
f. added slip resistant floors?	1	2	8
g. Other (SPECIFY)	1	2	8

B12. **How easy is it for you to get around in your home/apartment? Would you say that . . .**

It is easy	1
It is neither easy nor difficult	2
It is difficult	3
DON'T KNOW	8

B13. **Are the following facilities available within walking distance in the neighborhood near your home/apartment . . .**

		a. Available within walking distance? YES	NO		b. Do you use it? YES	NO
(i)	grocery store	1	2	IF YES →	1	2
(ii)	dry cleaners/laundromat	1	2	IF YES →	1	2
(iii)	bank	1	2	IF YES →	1	2
(iv)	drug store/pharmacy	1	2	IF YES →	1	2
(v)	medical clinic or doctor's office	1	2	IF YES →	1	2
(vi)	church/synagogue	1	2	IF YES →	1	2
(vii)	beauty parlor/barber shop	1	2	IF YES →	1	2

B14. **Would you say you feel safe and secure in your neighborhood . . .**

Most of the time	1
Some of the time	2
Rarely	3
Never	4
DON'T KNOW	8

COMMENTS: _____

B15. **How long have you lived at your present home?**

Less than 6 months	1	(B16)
6-11 months	2	(B16)
1-4 years	3	(B20)
5-10 years	4	(B20)
more than 10 years	5	(B20)
DON'T KNOW	8	(B20)

B16. **What was your main reason for moving to your present home? Was it . . .**

To participate in the HOPE program (that provides services in addition to rental assistance)	1
To receive Section 8 rental assistance	2
Or any other reason (SPECIFY)_____	3
DON'T KNOW	8

B17. **Was there any other reason (in addition to B16) for moving to your present home?**

YES	1	(B18)
NO	2	(B19)
DON'T KNOW	8	(B19)

B18. **What was the additional reason?**

(SPECIFY)_____

B19. **How does your current neighborhood compare to your last neighborhood? Please tell me if you agree or disagree with the following statements.**

	AGREE	DISAGREE	NEITHER AGREE NOR DISAGREE
a. My old neighborhood was more convenient to transportation and services	1	2	3
b. I feel more safe and secure in my present neighborhood	1	2	3
c. My family and friends come to visit me more often here than they did in my old neighborhood	1	2	3
d. My current neighborhood is noisier	1	2	3
e. I knew more of my neighbors well in my old neighborhood	1	2	3

B20. **Overall, how satisfied are you with where you currently live? Would you say you are . . .**

Very satisfied	1
Somewhat satisfied	2
Neither satisfied nor dissatisfied	3
Somewhat dissatisfied	4
Very dissatisfied	5
DON'T KNOW	8

SECTION C

HEALTH

The next set of questions asks about your health and use of medical services.

C1. **In general, compared with other people your age, would you say your health is . . .**

Excellent	1
Very good	2
Good	3
Fair	4
Poor	5
DON'T KNOW	8

C2. **Compared to 12 months ago, would you say your health in general is . . .**

Better now than one year ago	1
About the same, or	2
Worse	3
DON'T KNOW	8

C3. Has a doctor told you that you had . . .

		a.		b. Were you above age 60 when you were first told you had . . .		c. Were you above age 50 when you were first told you had . . .	
		YES	NO	YES (IF YES →)	NO (IF NO →)	YES	NO
(i)	Osteoporosis, sometimes called fragile or soft bones?	1	2	1	2	1	2
(ii)	A broken hip?	1	2	1	2	1	2
(iii)	Parkinson's disease?	1	2	1	2	1	2
(iv)	Pneumonia or another lung condition, such as emphysema or chronic obstructive pulmonary disease (COPD)?	1	2	1	2	1	2
(v)	High blood pressure, sometimes called Hypertension?	1	2	1	2	1	2
(vi)	Angina or heart trouble?	1	2	1	2	1	2
(vii)	A stroke?	1	2	1	2	1	2
(viii)	Arteriosclerosis, sometimes known as hardening of the arteries?	1	2	1	2	1	2
(ix)	Diabetes?	1	2	1	2	1	2
(x)	Arthritis?	1	2	1	2	1	2
(xi)	Other (SPECIFY)_____	1	2	1	2	1	2

C4. Has any of these health conditions/illnesses become <u>much</u> worse within the past 12 months?

YES	1	(C5)
NO	2	(C6)
DON'T KNOW	8	(C6)

C5. Which conditions/illnesses became much worse?

a. _____

b. _____

c. _____

COMMENTS: _____

C6. During the past 12 months, have you fallen?

YES	1	(C7)
NO	2	(C9)

C7. How many times did you fall during the past 12 months?

_____ NUMBER OF FALLS

C8. Did this fall/did any of these falls . . .

	YES	NO	DK
a. cause a broken bone?	1	2	8
b. cause you to injure your head?	1	2	8
c. cause you to seek medical care?	1	2	8
d. lead to hospitalization for more than a day?	1	2	8

C9. In the past 12 months, have you either gained or lost a lot of weight <u>without trying to</u>?

YES	1
NO	2
DON'T KNOW	8

C10. During the past 7 days was there any time when you ate fewer than 2 meals in a day?

YES	1
NO	2
DON'T KNOW	8

C11. **Is there <u>one</u> place where you usually go for medical care, like a family doctor or a clinic?**

YES 1
NO 2
DOES NOT GO TO A DOCTOR 3
DON'T KNOW 8

C12. **In the past 12 months, were you a patient in a hospital emergency room?**

YES 1 (C13)
NO 2 (C14)
DON'T KNOW 8 (C14)

C13. **How many different times during the past 12 months were you a patient in a hospital emergency room?**

_____ NUMBER OF TIMES IN EMERGENCY ROOM

C14. **In the past 12 months, were you a patient in a hospital overnight?**

YES 1 (C15)
NO 2 (C19)

C15. **How many different times were you a patient in a hospital overnight during the past 12 months?**

_____ NUMBER OF TIMES IN HOSPITAL OVERNIGHT

(IF ZERO OR DON'T KNOW GO TO C19)

C16. **How many nights did you stay the last time you were in the hospital?**

_____ NIGHTS → **(IF C15 IS 1, GO TO C19)**

DON'T KNOW 8

C17. **How many nights did you stay the time before last?**

_____ NIGHTS → **(IF C15 IS 2, GO TO C19)**

DON'T KNOW 8

C18. **What about the time before that? How many nights did you stay in the hospital?**

_____ NIGHTS

DON'T KNOW 8

C19. **In the last 12 months, were you a patient in a nursing home, convalescent home, or similar place?**

YES	1	(C20)
NO	2	(C22)

C20. **In the last 12 months, how many nights did you stay in a nursing home, convalescent home, or similar place?**

_____ NUMBER OF

NIGHTS	1
WEEKS	2
MONTHS	3

(IF ZERO OR DON'T KNOW GO TO C22)

C21. **Was the reason for your nursing home stay . . .**

	YES	NO	DK
a. post-hospital recuperation?	1	2	8
b. flare up of an illness?	1	2	8
c. temporary inability of family member to provide care?	1	2	8
d. or was there another reason? (SPECIFY)_____	1	2	8

C22. **In the past 3 months, how many times have you been seen by a medical doctor? Include doctor's visits in an office, a clinic, at home, or a walk-in center but <u>not</u> at emergency rooms, hospitals or nursing homes.**

_____ NUMBER OF MEDICAL VISITS

C23. **During the past 30 days, how many days have you had to stay in bed or a chair at home all or most of the time because of a health or physical problem?**

_____ NUMBER OF DAYS IN BED OR CHAIR

SECTION D

PROBLEMS AND ACTIVITIES OF DAILY LIVING

The next few questions ask about some every day activities and how hard it is for you to do them by yourself and without using special equipment. I know some of these questions are personal but please try to answer them.

D1. Which of the following activities do you have any difficulty doing by yourself and without using special equipment?

	YES	NO	DK
a. Getting in or out of a car	1	2	8
b. Going in and out of your house/building	1	2	8
c. Walking from one room to another (on the same floor) in your home	1	2	8
d. Walking up or down stairs	1	2	8
e. Grasping faucets, doorknobs, or pots on the stove	1	2	8
f. Reaching and getting down a light object from just above your head	1	2	8
g. Bending down to pick up clothing from the floor	1	2	8

D2. Are you <u>now</u> confined to a wheelchair?

YES 1
NO 2
DON'T KNOW 8

D3. Do you have any difficulty seeing well enough to read ordinary newspaper print when wearing glasses or contact lenses if you usually wear them?

YES 1
NO 2
DON'T KNOW 8

D4. **Do you have any difficulty seeing well enough to read medicine labels when wearing glasses or contact lenses if you usually wear them?**

YES 1
NO 2
DON'T KNOW 8

D5. **Do you have any difficulty hearing what is said in a normal conversation with another person even if you normally use a hearing aid?**

YES 1
NO 2
DON'T KNOW 8

D6. **By yourself and without using special equipment, how much difficulty do you have getting in and out of bed or a chair? Would you say you . . .**

Are unable to get in or out of bed by yourself 1 (D7)

Have a lot of difficulty getting in or out of bed 2 (D7)

Have some difficulty getting in or out of bed 3 (D7)

Have no difficulty getting in or out of bed 4 (D9)

DON'T KNOW 8 (D9)

D7. **Do you receive help with getting in and out of bed or a chair . . .**

		a. YES	a. NO		b. From whom?	c. Relationship to you?
(i)	From a person	1	2	IF YES →	_____	_____
(ii)	From special equipment .... (SPECIFY) _____	1	2			

(IF NO TO BOTH (i) AND (ii) GO TO D9)

D8. **How often do you have help with getting in and out of bed or a chair? Do you receive help . . .**

Always or almost always 1
Sometimes 2
Occasionally or rarely 3
DON'T KNOW 8

D9. **By yourself and without using special equipment, do you have much difficulty dressing? Would you say you . . .**

Are unable to dress yourself.....	1	(D10)
Have a lot of difficulty dressing yourself .	2	(D10)
Have some difficulty dressing yourself ...	3	(D10)
Have no difficulty dressing yourself.....	4	(D12)
DON'T KNOW	8	(D12)

D10. **Do you get help with dressing . . .**

		a. YES	a. NO		b. From whom?	c. Relationship to you?
(i)	From a person.....	1	2	IF YES →	_____	_____
(ii)	From special equipment.... (SPECIFY) _____	1	2			

(IF NO TO BOTH (i) AND (ii) GO TO D12)

D11. **How often do you have help with getting dressed? Do you receive help . . .**

Always or almost always	1
Sometimes.....	2
Occasionally or rarely.....	3
DON'T KNOW	8

D12. **By yourself and without using special equipment, how much difficulty do you have washing your hair? Would you say you . . .**

Are unable to wash your hair by yourself	1	(D13)
Have a lot of difficulty washing your hair.	2	(D13)
Have some difficulty washing your hair ..	3	(D13)
Have no difficulty washing your hair	4	(D15)
DON'T KNOW	8	(D15)

D13. **Do you get help with washing you hair . . .**

		a. YES	a. NO		b. From whom?	c. Relationship to you?
(i)	From a person.....	1	2	IF YES →	_____	_____
(ii)	From special equipment.... (SPECIFY) _____	1	2			

(IF NO TO BOTH (i) AND (ii) GO TO D15)

D14. How often do you have help with washing your hair?

Always or almost always	1
Sometimes	2
Occasionally or rarely	3
DON'T KNOW	8

D15. By yourself and without using special equipment, how much difficulty do you have with personal grooming (such activities as combing your hair, shaving, brushing your teeth)? Would you say you . . .

Are unable to groom yourself	1	(D16)
Have a lot of difficulty grooming yourself	2	(D16)
Have some difficulty grooming yourself..	3	(D16)
Have no difficulty grooming yourself	4	(D18)
DON'T KNOW	8	(D18)

D16. Do you get help with personal grooming . . .

		a. YES	a. NO		b. From whom?	c. Relationship to you?
(i)	From a person	1	2	IF YES →	_____	_____
(ii)	From special equipment (SPECIFY) _____	1	2			

(IF NO TO BOTH (i) AND (ii) GO TO D18)

D17. How often do you have help with personal grooming? Do you receive help . . .

Always or almost always	1
Sometimes	2
Occasionally or rarely	3
DON'T KNOW	8

D18. **By yourself and without using special equipment, how much difficulty do you have getting in and out of the shower or tub? Would you say you . . .**

Are unable to get in and out of the shower or tub by yourself.....	1	(D19)
Have a lot of difficulty getting in and out of the shower or tub by yourself.....	2	(D19)
Have some difficulty getting in and out of the shower or tub by yourself.....	3	(D19)
Have no difficulty getting in and out of the shower or tub by yourself.....	4	(D21)
Never use the shower or tub ..... (SPECIFY)_____	5	(D23b)
DON'T KNOW.....	8	(D21)

D19. **Do you get help with getting in and out of the shower or tub . . .**

		a. YES	a. NO		b. From whom?	c. Relationship to you?
(i)	From a person.....	1	2	IF YES →	_____	_____
(ii)	From special equipment.... (SPECIFY) _____	1	2			

(IF NO TO BOTH (i) AND (ii) GO TO D21)

D20. **How often do you receive help with getting in and out of the shower or tub? Do you receive help . . .**

Always or almost always	1
Sometimes.....	2
Occasionally or rarely.....	3
DON'T KNOW.....	8

D21. **By yourself and without using special equipment, how much difficulty do you have washing yourself in the shower or tub? Would you say you . . .**

Are unable to wash yourself in the shower or tub	1	(D22)
Have a lot of difficulty washing yourself in the shower or tub	2	(D22)
Have some difficulty washing yourself in the shower or tub	3	(D22)
Have no difficulty washing yourself in the shower or tub	4	(D24)
DON'T KNOW	8	(D24)

D22. **Do you get help with washing yourself in the shower or tub . . .**

		a. YES	a. NO		b. From whom?	c. Relationship to you?
(i)	From a person	1	2	IF YES →	_____	_____
(ii)	From special equipment (SPECIFY) _____	1	2			

(IF NO TO BOTH (i) AND (ii) GO TO D24)

D23a. **How often do you receive help with washing yourself in the shower or tub?**

Always or almost always	1	(D24)
Sometimes	2	(D24)
Occasionally or rarely	3	(D24)
DON'T KNOW	8	(D24)

D23b. **If you do not use a shower or tub, do you have any help washing yourself?**

YES	1	(D23c)
NO	2	(D24)
DON'T KNOW	8	(D24)

D23c. Do you get help with washing yourself . . .

		a. YES	a. NO		b. From whom?	c. Relationship to you?
(i)	From a person.....	1	2	IF YES →	_____	_____
(ii)	From special equipment.... (SPECIFY) _____	1	2			

(IF NO TO BOTH (i) AND (ii) GO TO D24)

D23d. How often do you receive this help?

Always or almost always	1
Sometimes	2
Occasionally or rarely.....	3
DON'T KNOW	8

D24. By yourself and without using special equipment, how much difficulty do you have using the toilet? Would you say you . . .

Are unable to use the toilet yourself	1	(D25)
Have a lot of difficulty using the toilet yourself.....	2	(D25)
Have some difficulty using the toilet yourself.....	3	(D25)
Have no difficulty using the toilet yourself	4	(D29)
Never use the toilet	5	(D27)
DON'T KNOW	8	(D29)

D25. Do you get help with using the toilet . . .

		a. YES	a. NO		b. From whom?	c. Relationship to you?
(i)	From a person.....	1	2	IF YES →	_____	_____
(ii)	From special equipment.... (SPECIFY) _____	1	2			

(IF NO TO BOTH (i) AND (ii) GO TO D27)

D26. **How often do you receive help with using the toilet? Do you receive help . . .**

Always or almost always	1
Sometimes	2
Occasionally or rarely	3
DON'T KNOW	8

D27. **Do you <u>usually</u> use any of the following . . .**

	YES	NO
a. Diapers such as "Depend"	1	2
b. Bedpan	1	2
c. Bedside commode	1	2
d. Catheter	1	2
e. Colostomy bag	1	2
f. Other (SPECIFY)	1	2

(IF YES TO D27 d OR e ASK D28, OTHERWISE GO TO D29)

D28. **If you use a catheter or colostomy bag, do you change this by yourself?**

YES	1
NO	2
DON'T KNOW	8

D29. **By yourself and without using special equipment, how much difficulty do you have feeding yourself? Would you say you . . .**

Are unable to feed yourself	1	(D30)
Have a lot of difficulty feeding yourself	2	(D30)
Have some difficulty feeding yourself	3	(D30)
Have no difficulty feeding yourself	4	(D33)
DON'T KNOW	8	(D33)

D30. **Have you had difficulty feeding yourself for more than three months?**

YES	1
NO	2
DON'T KNOW	8

D31. Do you receive help with feeding yourself . . .

		a. YES	a. NO		b. From whom?	c. Relationship to you?
(i)	From a person.....	1	2	IF YES →	_____	_____
(ii)	From special equipment.... (SPECIFY) _____	1	2			

(IF NO TO BOTH (i) AND (ii) GO TO D33)

D32. How often do you receive help with feeding yourself? Would you say you receive help . . .

Always or almost always	1
Sometimes	2
Occasionally or rarely	3
DON'T KNOW	8

D33. By yourself and without using special equipment, do you have any difficulty preparing your meals (on a stove/oven/microwave)? Would you say you . . .

Are unable to prepare your meals by yourself	1	(INTERVIEWER, PROBE IF ACTIVITY HAS EVER BEEN PERFORMED, D34)
Have a lot of difficulty preparing your meals by yourself	2	(D34)
Have some difficulty preparing your meals by yourself	3	(D34)
Have no difficulty preparing your meals by yourself	4	(D35)
Have never performed activity	5	(D35)
DON'T KNOW	8	(D35)

D34. Have you had difficulty with preparing meals for more than three months?

YES	1
NO	2
DON'T KNOW	8

D35. **Are you able to prepare light meals, such as a sandwich, by yourself?**

YES	1	(D38)
NO	2	(D36)
DON'T KNOW	8	(D36)

D36. **Do you get help with preparing light meals . . .**

		a. YES	a. NO		b. From whom?	c. Relationship to you?
(i)	From a person	1	2	IF YES →	_____	_____
(ii)	From special equipment/ Has meals delivered (SPECIFY) _____	1	2			

(IF NO TO BOTH (i) AND (ii) GO TO D38)

D37. **How often do you usually receive help with preparing your meals? Do you receive help . . .**

Always or almost always	1
Sometimes	2
Occasionally or rarely	3
DON'T KNOW	8

D38. **By yourself and without using special equipment, how much difficulty do you have doing light housework (such as doing dishes, straightening up, or light cleaning)? Would you say you . . .**

Are unable to do light housework by yourself	1	(INTERVIEWER, PROBE IF ACTIVITY HAS EVER BEEN PERFORMED, D39)
Have a lot of difficulty doing light housework by yourself	2	(D39)
Have some difficulty doing light housework by yourself	3	(D39)
Have no difficulty doing light housework by yourself	4	(D42)
Have never done activity	5	(D42)
DON'T KNOW	8	(D42)

D39. **Have you had difficulty doing light housework for more than three months?**

YES	1
NO	2
DON'T KNOW	8

D40. **Do you get help with light housekeeping . . .**

		a. YES	a. NO		b. From whom?	c. Relationship to you?
(i)	From a person	1	2	IF YES →	_____	_____
(ii)	From special equipment or housekeeping service ... (SPECIFY) _____	1	2			

(IF NO TO BOTH (i) AND (ii) GO TO D42)

D41. **How often do you receive help with doing light housework? Do you receive help . . .**

Always or almost always	1
Sometimes	2
Occasionally or rarely	3
DON'T KNOW	8

D42. **By yourself, assuming you have transportation, how much difficulty do you have shopping for personal items such as groceries, toilet items or medicines? Would you say you . . .**

Are unable to shop for personal items by yourself	1	(INTERVIEWER, PROBE IF ACTIVITY HAS EVER BEEN PERFORMED, D43)
Have a lot of difficulty shopping for personal items by yourself	2	(D43)
Have some difficulty shopping for personal items by yourself	3	(D43)
Have no difficulty shopping for personal items by yourself	4	(D47)
Have never done activity	5	(D47)
DON'T KNOW	8	(D47)

D43. **Have you had difficulty shopping for more than three months?**

YES	1
NO	2
DON'T KNOW	8

D44. **Are you <u>able</u> to go shopping if someone goes with you to help you manage?**

YES	1
NO	2
DON'T KNOW	8

D45. **Do you get help with shopping . . .**

		a. YES	a. NO		b. From whom?	c. Relationship to you?
(i)	From a person	1	2	IF YES →	_____	_____
(ii)	From a shopping service... (SPECIFY) _____	1	2			

(IF NO TO <u>BOTH</u> (i) AND (ii) GO TO D47)

D46. **How often do you receive help with shopping for personal items?**

Always or almost always	1
Sometimes	2
Occasionally or rarely	3
DON'T KNOW	8

D47. **How much difficulty do you have managing your money, for example, to pay rent or pay for HOPE Program services or other bills (such as utilities) by yourself? Would you say you . . .**

Are unable to manage your own money.	1	(INTERVIEWER, PROBE IF ACTIVITY HAS EVER BEEN PERFORMED, D48)
Have a lot of difficulty managing your own money	2	(D48)
Have some difficulty managing your own money	3	(D48)
Have no difficulty managing your own money	4	(D51)
Have never performed activity.....	5	(D51)
DON'T KNOW	8	(D51)

D48. **Have you had difficulty with managing your money for more than three months?**

YES	1
NO	2
DON'T KNOW	8

D49. **Do you get help with managing your money . . .**

		a. YES	a. NO		b. From whom?	c. Relationship to you?
(i)	From a relative or friend	1	2	IF YES →	_____	_____
(ii)	From a money management service..... (SPECIFY) _____	1	2			

(IF NO TO BOTH (i) AND (ii) GO TO D51)

D50. **How often do you receive help with managing your money? Do you receive help . . .**

Always or almost always	1
Sometimes	2
Occasionally or rarely.....	3
DON'T KNOW	8

D51. **Are you able to take care of money for day-to-day purchases (such as newspapers, medicines, groceries) by yourself?**

YES	1
NO	2
DON'T KNOW	8

SECTION E

MENTAL HEALTH

Now I'm going to ask some questions that might describe your attitudes and feelings.

E1. **In general, how satisfied are you with the way your life is going these days? Would you say . . .**

Very satisfied	1
Somewhat satisfied	2
Not satisfied	3
DON'T KNOW	8

E2. **Day to day, how much choice do you have about what you do and when you do it? Would you say you have . . .**

A great deal of choice	1
Some choice	2
No choice	3
DON'T KNOW	8

E3. **How confident are you in your ability to deal with daily living? Would you say you feel . . .**

Very confident	1
Somewhat confident	2
Not confident	3
DON'T KNOW	8

E4. **How much do you worry about not knowing who to turn to for help? Would you say you worry . . .**

A lot	1
Some	2
Not at all	3
DON'T KNOW	8

E5. **During the last 12 months, would you say your appetite generally has been . . .**

Good	1
Fair	2
Poor	3
DON'T KNOW	8

E6. **The next few questions are about how you feel and how things have been with you during the past 30 days. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 30 days . . .**

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. Did you feel full of life?	1	2	3	4	5
b. Have you been a very nervous person?	1	2	3	4	5
c. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5
d. Have you felt calm and peaceful?	1	2	3	4	5
e. Did you have a lot of energy?	1	2	3	4	5
f. Have you felt downhearted and low?	1	2	3	4	5
g. Did you feel worn out?	1	2	3	4	5
h. Have you been a happy person?	1	2	3	4	5
i. Did you feel tired?	1	2	3	4	5

Now I am going to ask you some questions that test your memory. Most people can answer some of these questions, but not all of them.

E7. **Can you tell me what year it is?**

CORRECT YEAR 1
WRONG YEAR 2
DON'T KNOW 8

E8. **What is the season?**

CORRECT SEASON 1
WRONG SEASON 2
DON'T KNOW 8

E9. **What is today's date?**

CORRECT DATE 1
WRONG DATE 2
DON'T KNOW 8

E10. What day of the week is it?

CORRECT DAY	1
WRONG DAY	2
DON'T KNOW	8

E11. What State do you live in?

CORRECT STATE	1
WRONG STATE	2
DON'T KNOW	8

E12. What county do you live in?

CORRECT COUNTY	1
WRONG COUNTY	2
DON'T KNOW	8

SECTION F

INFORMAL ASSISTANCE AND SOCIAL SUPPORT

The next set of questions I am going to ask is about the assistance you receive from friends and relatives and your social activities.

F1. **Excluding individuals living in the same household with you, do you see any family, friends or neighbors on a regular basis (at least once a month)? (DO NOT INCLUDE SERVICE COORDINATORS, SOCIAL WORKERS, HOME HEALTH WORKERS, DELIVERY PERSONS ETC.)**

YES	1	(F2)
NO	2	(F3)
DON'T KNOW	8	(F3)

F2. Please name the individuals you see and tell me their relationship to you, how often you see them, and if you see them more or less now than before you started in the HOPE Program. Please start with the person you see the most. (ASK a THROUGH d FOR EACH PERSON)

a. Can you give me the full name?	b. What is the relationship of {NAME} to you? (RELATIONSHIP)			c. How often do you see {NAME}? Would you say .. (FREQUENCY OF VISITS)					d. Compared with the time before the HOPE Program, do you see {NAME}..		
FIRST AND LAST NAME	CHILD	OTHER RELATIVE	FRIEND/ NEIGHBOR	Every day?	Several times a week?	Once a week?	2 -3 times a month?	Once a month or less?	More often?	The same?	Or less often?
(i)	1	2	3	1	2	3	4	5	1	2	3
(ii)	1	2	3	1	2	3	4	5	1	2	3
(iii)	1	2	3	1	2	3	4	5	1	2	3
(iv)	1	2	3	1	2	3	4	5	1	2	3
(v)	1	2	3	1	2	3	4	5	1	2	3

F3. a) **What do you and {NAME OF FIRST PERSON FROM F2} usually do when s/he comes to visit or spend time with you?**

_____

_____

b) **Have the activities that {NAME OF FIRST PERSON FROM F2} does or that you do together changed since you entered the HOPE program?**

YES	1	→	(GO TO c)
NO	2	→	(GO TO F4 IF F2(a)(ii) IS FILLED, ELSE GO TO F6)
DON'T KNOW	8	→	(GO TO F4 IF F2(a)(ii) IS FILLED, ELSE GO TO F6)

c) **How have the activities changed?**

_____

_____

(IF MORE THAN ONE PERSON IS LISTED AT F2, ASK F4. OTHERWISE, GO TO F6)

F4. a) **What do you and {NAME OF SECOND PERSON FROM F2} usually do when s/he comes to visit or spend time with you?**

_____

_____

b) **Have the activities that {NAME OF SECOND PERSON FROM F2} does or that you do together changed since you entered the HOPE program?**

YES	1	→	(GO TO c)
NO	2	→	(GO TO F5 IF F2(a)(iii) IS FILLED, ELSE GO TO F6)
DON'T KNOW	8	→	(GO TO F5 IF F2(a)(iii) IS FILLED, ELSE GO TO F6)

c) **How have the activities changed?**

_____

_____

(IF MORE THAN TWO PERSONS ARE LISTED AT F2, ASK F5. OTHERWISE, GO TO F6)

F5. a) **What do you and {NAME OF THIRD PERSON FROM F2} usually do when s/he comes to visit or spend time with you?**

_____

_____

b) **Have the activities that {NAME OF THIRD PERSON FROM F2} does or that you do together changed since you entered the HOPE program?**

YES	1	(c)
NO	2	(F6)

c) **How have the activities changed?**

_____

_____

F6. **Do you talk on the phone with any family, friends or neighbors on a regular basis?**

YES	1	(F7)
NO	2	(F8)
DON'T KNOW	8	(F8)

F7. Please name the individuals you talk to on the phone and tell me their relationship to you, how often you talk to them, and if you talk to them more or less now than before you started in the HOPE Program. Please start with the person you talk to most. (ASK a THROUGH d FOR EACH PERSON)

a. Can you give me the full name?	b. What is the relationship of {NAME} to you? (RELATIONSHIP)			c. How often do you talk to {NAME} on the phone? Would you say ... (FREQUENCY OF PHONE CALLS)					d. Compared with the time before the HOPE Program, is that ..		
FIRST AND LAST NAME	CHILD	OTHER RELATIVE	FRIEND/ NEIGHBOR	Every day?	Several times a week?	Once a week?	2 -3 times a month?	Once a month or less?	More often?	The same?	Or less often?
(I)	1	2	3	1	2	3	4	5	1	2	3
(II)	1	2	3	1	2	3	4	5	1	2	3
(III)	1	2	3	1	2	3	4	5	1	2	3
(IV)	1	2	3	1	2	3	4	5	1	2	3
(V)	1	2	3	1	2	3	4	5	1	2	3

F8. **During the last 2 weeks, did you participate in any social activities outside of your home, such as church or synagogue services, club meetings, senior center activities or movies?**

YES	1
NO	2
DON'T KNOW	8

F9. **Regarding your present social activities, do you feel that you are doing . . .**

too much	1
about enough, or that you	2
would like to be doing more	3
DON'T KNOW	8

F10. **Do you have someone you can trust and confide in?**

YES	1
NO	2
DON'T KNOW	8

F11. **Regarding how lonely you feel, would you say you feel lonely . . .**

Quite often	1
Sometimes	2
Almost never	3
DON'T KNOW	8

F12. **Regarding how often you see you relatives and friends, would you say . . .**

You see them as often as you want,	1
You are somewhat unhappy about how little you see them,	2
You are very unhappy about how little you see them, or	3
Something else? (SPECIFY)_____	4
DON'T KNOW	8

F13a. **Who would be the first person you would call in case of an emergency? Would you call . . .**

Your doctor	1
A relative (SPECIFY)_____	2
A friend or neighbor	3
911	4
(Your HOPE Program service coordinator)_____	5
Your building manager/superintendent	6
Other (SPECIFY)_____	7
DON'T KNOW	8

F13b. **Who would be the second person you would call in case of an emergency? Would you call . . .**

Your doctor	1
A relative (SPECIFY)_____	2
A friend or neighbor	3
911	4
(Your HOPE Program service coordinator)_____	5
Your building manager/superintendent	6
Other (SPECIFY)_____	7
DON'T KNOW	8

F14. **How quickly can the first person you named above get to your home in an emergency?** (CIRCLE THE APPROPRIATE UNIT OF MEASURE)

_____ NUMBER OF

MINUTES	1
HOURS	2
DAYS	3

F15. **Is there someone who could take care of you or help you in your home if you were sick or needed assistance?**

YES	1	(F16)
NO	2	(G1)
DON'T KNOW	8	(G1)

F16. **How long could this person care for your? (IF MORE THAN ONE INDIVIDUAL, ASK RESPONDENT TO PICK THE ONE (S)HE WOULD CALL FIRST)**

AS LONG AS NEEDED	1
FOR SEVERAL WEEKS OR MONTHS	2
FOR A WEEK OR LESS	3
NOW AND THEN	4
OTHER (SPECIFY)_____	5

SECTION G

PROGRAM PARTICIPATION/SERVICE UTILIZATION

This last set of questions are about your participation in the HOPE Program and the types of services you are currently receiving through HOPE and from other sources.

G1. How did you find out about the HOPE Program? (IF MORE THAN ONE, ASK FOR THE SOURCE THEY HEARD FROM FIRST)

From your Area Agency on Aging or local community service agency	1
From a relative (SPECIFY)_____	2
From a friend or neighbor	3
From the housing authority	4
From your church/synagogue	5
From a newspaper article, or radio announcement	6
From a brochure or flier	7
Other (SPECIFY)_____	8
DON'T KNOW	98

G2. Do you agree or disagree with the following statements:

		AGREE	DISAGREE	NOT APPLICABLE
a.	It was easy to provide all the financial information needed to enter the HOPE Program.....	1	2	3
b.	The process used to determine your need for assistance with various activities was complicated.....	1	2	3
c.	You actively participated in deciding which services you would receive through the program	1	2	3
d.	The entire program was explained to you clearly.....	1	2	3

G3. About how often have you seen (your service coordinator), _____ since you began participating in the HOPE Program?
(CIRCLE THE APPROPRIATE UNIT OF MEASURE)

_____ TIMES PER

WEEK..... 1
MONTH..... 2
YEAR 3

G4. Does (your service coordinator) _____ generally initiate contact with you or do you contact him/her if you need something?

(S)HE USUALLY INITIATES CONTACT . 1
YOU USUALLY INITIATE CONTACT..... 2
OTHER (SPECIFY)_____ 3

G5. **What does (your service coordinator) _____ do for you?**

a. _____

b. _____

c. _____

d. _____

e. _____

(IF NO ACTIVITIES MENTIONED, GO TO G7)

G6. **Of all the things you named that (your service coordinator) _____ does for you, which is most beneficial to you?**

_____

G7. **Is there anything you would like (your service coordinator) _____ to do to help you get more out of the HOPE Program?**

YES	1	(G8)
NO	2	(G9)

G8. **What more would you like (your service coordinator) _____ to do?**

a. _____

b. _____

c. _____

G9. **Overall, how satisfied are you with (your service coordinator) _____ and what s/he does for you? Are you . . .**

Very satisfied	1
Somewhat satisfied	2
Neither satisfied nor dissatisfied	3
Somewhat dissatisfied	4
Very dissatisfied	5
DON'T KNOW	8

G10. I am going to read you a list of services that you may receive from the HOPE Program or other service providers. For each service please tell me if you receive the service, when you started receiving the service, how often you receive the service, and how satisfied you are with it.
(IF RESPONDENT ANSWERS yes TO QUESTION a FOR ANY SERVICE TYPE, ASK b THROUGH d IMMEDIATELY FOR THE SAME SERVICE TYPE)

	SERVICE TYPE	a. Do you receive {SERVICE}? YES	a. NO	b. When did you start receiving {SERVICE}.... Less than one month ago?	Less than six months ago?	Six months to one year ago?	More than one year ago?
(i)	Transportation services such as a car/van or escort service to take you to your appointments or shopping	1	2	1	2	3	4
(ii)	Home-delivered meals or meals prepared in your home	1	2	1	2	3	4
(iii)	Meals at a senior center or other site	1	2	1	2	3	4
(iv)	Personal care services such as help with grooming,dressing, eating, toileting, or getting around your home	1	2	1	2	3	4
(v)	In-home health services such as a nurse or health aide to check on your health, bathe or provide your medication	1	2	1	2	3	4
(vi)	Housekeeping services such as laundry, dishes, or running errands or house cleaning	1	2	1	2	3	4
(vii)	Counseling services from a professional for mental health or emotional help	1	2	1	2	3	4
(viii)	Recreational services such as participating in activities at a senior center, having someone visit with you, etc.	1	2	1	2	3	4
(ix)	Any other services? (SPECIFY)_____	1	2	1	2	3	4
(x)	OTHER (SPECIFY)_____	1	2	1	2	3	4

c. How often do you receive {SERVICE}					d. How satisfied are you with {SERVICE}? Are you				
5-7 days a week?	2-4 days a week?	Once a week?	2-3 days a month?	Once a month or less?	Very satisfied?	Somewhat satisfied?	Neither satisfied nor dissatisfied?	Somewhat dissatisfied?	Very dissatisfied?
1	2	3	4	5	1	2	3	4	5
1	2	3	4	5	1	2	3	4	5
1	2	3	4	5	1	2	3	4	5
1	2	3	4	5	1	2	3	4	5
1	2	3	4	5	1	2	3	4	5
1	2	3	4	5	1	2	3	4	5
1	2	3	4	5	1	2	3	4	5
1	2	3	4	5	1	2	3	4	5
1	2	3	4	5	1	2	3	4	5
1	2	3	4	5	1	2	3	4	5

G11. Does a person or an agency currently:

	YES	NO
(a) Help you arrange for and get the different services you need	1	2
(b) Provide information about services available to you and how to access them	1	2

G12. Do you feel you need more of any of the services you are now receiving?

YES 1 (G13)
NO 2 (G14)

G13. Which of the services you are now receiving do you feel you need more of?

a. _____

b. _____

c. _____

G14. Are there any services you are not now receiving that you feel you need?

YES 1 (G15)
NO 2 (G16)

G15. Which of the services you are not now receiving do you feel you need?

a. _____

b. _____

c. _____

G16. Which one service you now receive do you think helps you most to continue to live in your own home as you are?

_____

G17. Not including rent, do you currently pay a portion of the cost of HOPE Program services?

YES 1 (G18)
NO 2 (G19b)

G18. **Since beginning in the HOPE Program, have you had any problems paying for the services you receive?**

YES	1	
NO	2	

G19a. **Supposing the HOPE Program rules were to change in such a way to require participants to pay more for the services they receive through the program. If your financial situation were to remain pretty much as it is now, would you be willing to pay more for the same services?**

YES	1	(G20a)
NO	2	(G21)
Other (SPECIFY)_____	3	(G21)

G20a. **How much more would you be willing to pay a month?**

$1 TO $25	1	(G21)
$26 - $50	2	(G21)
OVER $50	3	(G21)

G19b. **Supposing the HOPE Program rules were to change in such a way to require participants to pay some amount for the services they receive through the program. If your financial situation were to remain pretty much as it is now, would you be willing to pay something for the same services?**

YES	1	(G20b)
NO	2	(G21)
Other (SPECIFY)_____	3	(G21)

G20b. **How much would you be willing to pay a month?**

$1 TO $25	1
$26 - $50	2
OVER $50	3

G21. **Excluding your rent, about how much do you <u>now</u> pay per month for <u>all</u> the services you currently receive from the HOPE program <u>and</u> all other sources?**

NOTHING	1
$1 - $25	2
$26 - $50	3
OVER $50	4
DOES NOT GET SERVICES	5

G22. **Is this more or less than you paid for these types of services before you began in the HOPE program? Would you say . . .**

It is much more than you used to pay	1	(G23)
It is a little more than you used to pay	2	(G23)
It is about the same as you used to pay.	3	(G23)
It is a little less than you used to pay	4	(G23)
It is a lot less than you used to pay	5	(G23)
DID NOT RECEIVE ANY SERVICES BEFORE ENTERING HOPE	6	(G24)

G23. **How many of the services you currently receive did you receive before you entered the HOPE program? Would you say you received . . .**

All the same services you currently receive	1
Most of the same services you currently receive.....	2
Some of the same services you currently receive.....	3
None of the same services you currently receive.....	4

G24. **Do you think it is a good idea that those that can afford it have to pay something for HOPE Program services?**

YES.....	1
NO	2
DON'T KNOW	8

G25. **Do you think that people in general have a different attitude toward services they help to pay for than those they do not pay for?**

YES.....	1
NO	2
DON'T KNOW	8

G26. **If you want to get work done around the house that you cannot do yourself, who would you call first?**

A relative	1
A friend or neighbor	2
Your church/synagogue	3
(Your HOPE Program service coordinator)_____	4
Your social service agency, or	5
Someone else? (SPECIFY)_____	6

G27. **In general, do you prefer receiving help from a government or community agency or from family and friends? Would you say you . . .**

Prefer receiving help from family and friends	1
Have no strong preference either way	2
Prefer receiving help from a government or community agency, or	3
Something else? (SPECIFY)_____	4

G28. **When do you think a person should turn to a government agency or community organization for assistance? Do you think s/he should turn to a government agency or community organization . . .**

Whenever s/he needs help	1
When family members, friends and neighbors cannot provide help	2
Only as a last resort, or	3
For another reason? (SPECIFY)_____	4

G29. **Overall, how satisfied are you with the HOPE Program? Would you say you are . . .**

Very satisfied	1
Somewhat satisfied	2
Neither satisfied nor dissatisfied	3
Somewhat dissatisfied	4
Very dissatisfied	5
DON'T KNOW	8

G30. What is the one thing you like the most about the HOPE Program?

_____

_____

G31. What is the one thing you would like changed about the HOPE Program?

_____

_____

G32. How important do you think the HOPE Program has been in allowing you to live in your own home as you are? Would you say participating in the Program has . . .

Been very important in allowing you to continue to live in your own home as you are	1
Been somewhat important in allowing you to continue to live in your own home as you are	2
Made no difference one way or the other	3
Hurt your ability to continue to live in your own home as you are, or.....	4
Something else? (SPECIFY) _____	5

Thank you very much, that was our last question. I would like to thank you for your time and cooperation. You have been very helpful to us.

RESPONDENT COMMENTS: _____

_____

_____

_____

_____

_____

INTERVIEWER COMMENTS: _____

_____

_____

_____

_____

_____

TIME ENDED: ___ ___ : ___ ___ AM/PM