U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy

Issues in Developing the Client Assessment Instrument for the National Long-Term Care Demonstration

January 1981

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ISSUES IN DEVELOPING THE CLIENT ASSESSMENT INSTRUMENT FOR THE NATIONAL LONG-TERM CARE DEMONSTRATION

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I. INTRODUCTION

A. Background

The United States Department of Health and Human Services has initiated the National Long Term Care Demonstration to improve care for functionally impaired adults, particularly the elderly. The demonstration will emphasize community-based services, and a concept called "channeling," which relies on client assessment and case management to organize care that meets individual needs and controls long-term care expenditures. The purpose of the demonstration is to improve long-term care delivery systems at the state and the community level, and to evaluate the impact of channeling on costs, service utilization, providers, and client well-being. The project will require the development of an instrument capable of evaluating client functioning and service needs. Case managers will use this instrument to assess clients, and researchers will use its data to evaluate the effectiveness of the demonstration. Practitioners will administer the assessment questionnaire to clients receiving services at the sites, and trained interviewers will administer it to the research control group.

This draft report is the product of the first steps needed to develop a client assessment instrument for the National Long Term Care Demonstration: an extensive literature review, evaluation of existing instruments, and an appraisal of the previous experiences of others who have designed and used similar instruments (both practitioners and researchers). Before making recommendations, the report discusses conceptual and operational issues, representative instruments, and the advantages and liabilities of different approaches. It should provide a solid basis for review by the Department of Health and Human Services, experts in the field, states, demonstration sites, and other participants in the National Long Term Care Demonstration.

This draft report is not an exhaustive analysis of assessment of the aged and functionally impaired. It is a summary of major issues, available choices, and proposed ways to address the central issues in client assessment as they pertain to this project.

B. Context: The Channeling Demonstration and Evaluation

The objectives of the National Long Term Care Demonstration, as identified by the Department of Health and Human Services, are:

- to direct long-term care community resources in ways that minimize overall costs;
- to increase access to existing services;
- to match services to the identified needs of clients;
- to concentrate public resources on those persons with the greatest need for subsidized long-term care;

- to develop needed in-home and community services and increase those in short supply;
- to reduce unnecessary use of publicly-subsidized long-term care services, including costly medical and institutional services;
- to promote a reasonable division of labor between informal support systems (families, neighbors, friends), privately-financed services, and publicly-financed care; and
- to maintain or enhance client outcomes, including physical and mental functioning and quality of life.

To achieve these objectives, twelve sites have been selected across the nation to demonstrate application of the channeling concepts on the local level. Up to nine additional sites will be selected in FY 1981. In each, a community agency, whose auspices and structure will vary by state, will provide a set of core channeling functions--primarily centralized client assessment and case management. These functions, intended to decrease the fragmentation of services in the existing system, are directed at the problems faced by both the individual client and the service delivery system.

At the individual level, the idea of channeling is to ensure that functionally impaired persons with multiple needs have access to and receive the most appropriate services. It is proposed that this be accomplished through a central intake for needy individuals; systematic identification and assessment of their needs; and case management to arrange, monitor and adjust the appropriate set of services to changing client needs.

At the system level, channeling is intended to ensure that a wide range of services is available, accessible, responsive to the needs of the target population, and delivered in the most efficient and cost-effective manner. Channeling should help target government-financed services to the most needy clients in such a way that the service system and budget will not be overwhelmed by exploding demands.

The main purpose of the demonstration is to provide information the government can use to determine future national policy toward long-term care. To accomplish this, the research evaluation will attempt to answer the following basic questions:

- What are the barriers to effective implementation of channeling? How can they best be overcome? What are the best ways to organize and administer the channeling process?

- How does channeling affect client service use?

- What are the cost impacts of channeling to the government, to clients and their families, and to society?

- What impact does channeling have on the quality of life of clients and their families?

- What is the response of providers and the service delivery system to channeling?
- Is channeling cost-effective?
- Which channeling model is the most effective?

To answer these questions, the evaluation of the demonstration will use an experimental methodology to compare what happens under channeling, with what would have happened in its absence. By randomly assigning potential participants to a treatment or control group within the sites, observed differences in outcomes can be attributed to program impacts with a known degree of statistical confidence. This approach will be applicable to all questions that rely on data about individuals: the analyses of service utilization, individual well-being, costs and cost-effectiveness. The other research issues--implementation/process, and provider response/supply--are best evaluated by observing differences between demonstration sites and comparable comparison (non-demonstration) sites, and by examining differences among the demonstration sites.

Evaluating the multiple aspects of the channeling demonstration and answering the questions raised above clearly requires an extensive data collection effort. many sources will be used: individual participant interviews, project narratives, screening data, a mail survey of providers, extracts from provider records, special cost case studies, channeling agency expenditure reports, and data from an automated client tracking system. However, because so much of the evaluation is contingent on observation of and documentation about individuals, the most important data source will be the individual interviews, i.e., the client assessments and reassessments.

C. Client Assessment for Care Planning and Research

Client assessment is obviously central to evaluating the impact of channeling interventions on client populations, service systems, and public expenditures for long term care. But beyond its importance as a data source, client assessment is essential to adequate care planning, to procurement of appropriate services, efficient resource use, and for monitoring and modifying service delivery to individuals. Although research and practice may require different levels of specificity and content in the client assessment, both purposes must guide instrument development. The instrument must be relevant to the needs of caregivers if it is to be useful for research purposes. The factors that must be assessed are actually common to both groups: physical health and mental health, ability to perform activities of daily living, social support and participation, financial and related resources, physical environment and living arrangements, and services (as described in the RIP).

Among these components of general well-being, there exists considerable interaction, frequent overlap, and different theoretical bases. Consequently, existing

assessment instruments vary significantly in emphasis, structure, method of administration, and grouping and weighting of components and items. It is clear that one multidimensional instrument encompassing all these areas is needed for both operational and research purposes.

Given the nature of the service delivery process and of the research needs, it is appropriate to emphasize functional measures. For purposes of care planning, a client assessment should identify: major areas of impaired performance or ability; compensating or aggravating factors in an individual's behavior, skills, environment, social support systems or resources; and services an individual is already receiving. These need to be identified well enough to (a) provide a full baseline picture of an individual and (b) suggest appropriate referrals for delivery of services. Such referrals may include more detailed assessment (physical examination, medical history, psychological testing) in a particular functional domain by specialists. Assessment by a case manager (primary service contact) need not, and in some cases should not, encompass all the detail of specialized diagnostic evaluations. For purposes of evaluating the national demonstration, it will generally be more useful to know the domain, nature and impact on normal living of an asset or liability, than to know its etiology. Care planners will also be concerned with this, because decisions about what type of service provider a client should be directed to, the environment in which that care will be provided, and the degree to which a person will be removed from his (her) natural setting to receive care, all tend to be influenced greatly by the person's functional abilities.

D. Criteria for Selection of Instruments

This draft takes an "inclusive" rather than "exclusive" approach to areas of personal well-being and service use that may be measured in the assessment instrument. At this early stage, it is appropriate to consider all significant variables that may be pertinent to the demonstration. However, the length of the instrument and the duration of the assessment interview must be tightly controlled. After the research hypotheses, data collection strategies, and analytic design are final, and the operational needs of practitioners and the demonstration sites more clearly defined, the many variables considered in this draft can be reviewed and the final instrument limited to those items that are clearly essential.

Only a limited number of the myriad instruments in use or in the literature tap information on all the functional areas (plus services and resources) described above. Nor does any single multidimensional and functionally-oriented instrument meet both the operational and research needs of the demonstration. In addition, more limited instruments are available for in-depth assessment of dimensions not well covered in the multidimensional tools. The state of the art and the nature of this demonstration clearly point to a hybrid assessment instrument that draws on the strengths of established multidimensional instruments and on more specialized ones, when appropriate.

In order to develop a multidimensional, functionally-oriented client assessment instrument that also includes services data, the following criteria must be met. The instrument should:

- assess the basic areas of functioning and well being;
- include information on service utilization;
- satisfy the needs of case managers;
- provide research data.

Two additional criteria must be considered--strength of the instrument and operational constraints.

For research purposes, we must be certain the components of the instrument have a well-developed theoretical foundation and clearly define the variables being measured. It is particularly important that the various domains (such as social functioning and service utilization) be kept separate and distinct, because they often interact. The instrument should distinguish different levels of functioning, yield a good range of responses, and be sensitive to change over time. There should be clear, consistent procedures for administering the instrument and recording information. It is important that the components of the instrument be applicable to a wide range of disability types and levels, and to institutionalized persons and those in the community. The "burden" of the instrument, in terms of length and design, should be minimized to avoid attrition and subject fatigue, and to facilitate assessor use. We believe the assessment should be limited to approximately one hour. (Periodic reassessment will be somewhat briefer because certain baseline questions on demographics and other fixed items need not be asked again.)

Because of the complexity of this demonstration, meeting all the criteria for instrument selection and development is difficult, and establishing the reliability and validity of the instrument components is similarly difficult. Some well-tested instruments with established psychometric properties are not self-report tools; much of the psychometric evidence for existing instruments considers only summary scores or ratings for an entire instrument or its major domains; there is little published documentation of the strength of some other potential tools; and in other cases (such as the financial information needed understand demand for services), greater detail is required in this evaluation than in most previous studies. Such problems complicate the task of selection from existing instruments, and in some instances require reformatting or developing new questions.

The particular operational constraints imposed by the national demonstration make additional demands. The dual function of the instruments--data collection for research, and client assessment for care planning--create certain needs. Data must be specific and pertinent for the needs of case managers, yet capable of aggregation for statistical analysis by researchers without losing important distinctions about client well-being in different spheres. Components should be sensitive to change over time; for

program purposes it may be desirable that they be sensitive to small increments of change at the lower functioning end of the spectrum.

Another point to consider is that the instrument will be administered by channeling agency staff to clients and by trained interviewers to those persons assigned to the control group. To ensure comparability of data, the assessment instrument must rely on self-reported information from respondents rather than on observations and clinical or other subjective ratings and judgments. This somewhat limits a practitioner's assessment (which would normally integrate observation, interview, and the assessor's experience and intuition), and decreases the number of applicable existing instruments. Because the assessment will be administered by persons from various professional disciplines, paraprofessionals, and non-professionals (to the control group), it is critical that the language and procedures for assessment and scoring be simple and direct. Training procedures for both site workers and nonprofessional interviewers should be brief. Training and administration costs must be minimized. As noted earlier, assessments will be administered to a range of disability groups in a variety of settings. Depending on the eventual casemix of sites, it will be helpful to choose assessments that have already been used for both aged and non-aged populations. Special procedures for use with persons suffering major impairments to communication--sight, speech, hearing, disorientation should be contemplated; and because some impaired persons may be unable to respond to an interview-based assessment instrument, it should be designed so that essential information may be obtained from a knowledgeable informant (or "proxy") when necessary.

Despite substantial overlap between practitioner and research needs for client assessment data, there may be demand for "clinical" information not essential to the research design (detailed medical history, for example) and for "research" detail not necessarily important to case managers (specific individual expenditure data, for instance). To reduce burden and to encourage conscientious use of the assessment tool, all such items must be absolutely essential to either research or care planning, and not feasible or appropriate to collect in other ways.

The necessity of using a standardized approach across all sites may be perceived as limiting flexibility in the assessment process. Case managers and other practitioners may favor a less structured approach that would permit probing beyond, branching out from, or supplementing the questions asked in the standard instrument to complete the assessment of a particular individual. A channeling agency might wish to add certain questions to be asked of all its clients. The standard instrument must address those areas of concern common across sites and users. But attempting to integrate into the basic instrument site-specific or case-specific interests would raise other problems. It would result in a burdensome tool, detract from the consistency of the data across sites, raise obstacles to OMB clearance, and pose problems for implementation of the automated client tracking system. Our objective is to provide the standard core instrument. Individual sites and practitioners might add some items at the end of the assessment to suit special local concerns, subject to DHHS approval.

E. Sources on Which This Draft Report is Based

This preliminary report is the product of several months work by the evaluators and their consultants. An extensive literature review on client assessment and the aged was conducted, relying on major anthologies and primary studies of major instruments and issues. Instrument review was done of those multidimensional tools that approximated the general criteria described here, as well as scores of more limited scales that tapped a specific dimension particularly well. Background reports on the assessment of each of the principal domains were prepared by consultants, comparing available tools against our general criteria. Experts in the field--both authors and users--were contacted and they suggested conceptual issues and operational solutions concerning widely-used scales and approaches. Representatives of some existing channeling-type agencies and service providers were also interviewed regarding these issues; and copies of assessment tools designed for similar program purposes were collected and reviewed. Over the past 25 years, a formidable number of relevant assessment tools have been developed. Through continuous refinement of the concepts, approaches, and basic scales, a rich data base has been created, on which we can draw.

Based on these sources, a rough draft report was prepared, and distributed for review to a broad cross-section of researchers, HHS staff, the national technical assistance and survey contractors, and a panel of practitioners experienced in assessment of the aged and functionally impaired. The results are summarized in this draft.

The chapters that follow reflect tentative findings and recommended directions resulting from out initial investigation. This draft report:

- states the purposes of the client assessment instrument;
- identifies conceptual approaches and dimensions of functioning;
- recommends criteria for selection of instrument components;
- delineates methodological and operational constraints;
- considers pros and cons of available representative approaches; and
- proposes the directions to be taken.

It is intended to provide the states and demonstration sites, the government, the technical assistance contractor, the national survey contractor, consultants, and other interested parties with an opportunity for early review and comment. These comments will help guide further analysis, the process of instrument development, and the content of the final report.

II. PHYSICAL HEALTH

A. Rationale

It is obvious that assessment of well-being should include measurement of physical health. The issue is not whether to consider physical health but rather which aspects of physical health status should be included. There are a number of ways to categorize physical health status. A recent annotated bibliography of health status assessments (Freeburg, Lave, Lave and Leinhardt, 1979) groups them into eight categories:

- Self-perceived health status
- Physician-rated health status
- Symptoms, conditions, or illnesses
- Disability incapacitation, restriction
- Chronic illness and disability
- Acute illness and disability
- Composite measures
- Specific symptoms or diseases.

Because diagnosis may provide little information about capacity (Jones et al. 1974; Lawton, Ward and Yaffe, 1968), the emphasis in long term care is properly on functional ability or impairment. This emphasis is reflected in the National Minimum Data Set for Long Term Care (U.S. National Committee on Vital and Health Statistics, 1979) which recommends that information be collected on vision, hearing and communication impairment, ability to perform physical activities of daily living and instrumental activities of daily living, and diagnoses. With the exception of diagnoses, all these reflect concern with the impact of illness, rather than illness per se. In the next chapter we consider ability to perform activities of daily living. It is appropriate to consider this separately because impairments of such ability may reflect mental as well as physical health conditions. In this chapter, we consider other aspects of physical health--impairment of vision, hearing and communication, diagnoses, other physical conditions, treatments; and self-perceived health status. We recommend inclusion of physical conditions generally, and treatments rather than diagnoses only (as in the National Minimum Data Set), because care planning requires consideration of conditions whether or not they have been diagnosed or treated. Practitioners need to understand the medical conditions that people face. They need to determine whether there are any conditions that are not being treated, what conditions are responsible for an individual's impairment, and whether a medical condition makes certain services inappropriate.

Turning to research data needs, information on medical condition is an important control variable. Holding functional status constant, treatment and control group members could differ with respect to medical conditions in important ways, either as a

result of sampling error or of randomization failure. Moreover, by providing clients with needed services, channeling may improve their physical condition and medical conditions may be alleviated.

We recommend including a measure of self-perceived health status because subjective measures of health status may be important intervening factors in the utilization of health care services. Moreover, perceived health status is an aspect of overall life satisfaction (Campbell, Converse, and Rogers, 1976; Andrews and Withey, 1976), and it is reasonable to hypothesize that by supplying needed services channeling may affect self-perceived health status. Consequently, self-perceived health status provides an outcome variable for the analysis.

Another set of health status measures involves days of restricted activity (i.e., days in the hospital, days in various institutions, and days at home in bed). These are critical outcome variables for the evaluation of the channeling project. However, because major measures of activity restriction (those involving hospitalization and institutionalization) involve the use of health services, we consider them in Chapter VII, "Service Utilization."[1] Self-report data on service utilization will be supplemented by data from provider records. The procedures for extracting data from provider records are discussed in Chapter VII.

It is also noteworthy that although measures of restricted activity are considered with other services in this report, such need not be the case in the instrument. From the perspective of question logic and flow, it may be desirable to include questions on hospitalization and institutionalization in the physical health module.

B. Measures of Physical Health

1. Medical Conditions

The major self-report multidimensional assessment instruments use similar procedures to assess medical conditions or diagnoses. All utilize an inventory or checklist format; they differ in the conditions that are specifically listed, and in the language used to describe the conditions. There is considerable variation in the lengths of the lists and, consequently, in the conditions that are specified. The OARS[2] checklist, for example, contains 26 specific conditions, while the Havens and Thompson (1971) checklist contains 14. Checklists do not necessarily have to be lengthy to meet the, needs of practitioners in care planning. The SAAF, an instrument specifically designed for care planning, includes eleven (11) specific items in the medical conditions checklist. All self-report instruments use lay language rather than medical terms to describe medical conditions. For instance, the term "cancer" would be used rather than

[1] Days at home in bed may or may not involve service utilization and thus does not clearly come under the discussion in Chapter VII. However, we do recommend that an item on this type of activity restriction be included.

[2] Because most instruments are commonly known by their acronyms rather than their full titles, we use the acronyms in the text. A glossary at the end of this report (Appendix A) provides full titles and references.

"neoplasm." However, even in lay language there are differences in the level of detail across instruments. For instance, the SAAF checklist includes "skin problems," while the OARS checklist includes "skin disorders such as pressure sores, leg ulcers or severe burns."

The National Minimum Data Set for Long Term Care recommends that information on diagnoses be collected in terms of the major International Classification of Diseases (ICD) categories. One advantage of using the ICD categories is that it ensures that all diagnoses are covered. However, although some assessment instruments (e.g., PACE II) use IQ categories to record information on diagnoses, no existing self-report instrument does.[3]

Exhibit II.1 presents the medical conditions checklists from OARS and SAAF and the ICD codes from the National Minimum Data Set. Together these illustrate the issues involved in the development of a checklist. The OARS checklist also includes information on the level of disability associated with each condition.[4]

We suggest that a checklist of medical conditions be developed which uses lay language and which can be coded using ICD categories as recommended by the National Minimum Data Set on Long Term Care.

2. Treatment

The approach to dealing with treatment varies across self-report instruments. Information on type of medication is very often included, although there are some instruments (e.g., PGC-MAI) that do not consider medication.[5] Some instruments (e.g., OARS) use checklists of medications and ask specifically about the use of each medication listed. Other instruments (e.g., COMPASS, SAAF) rely on open-ended questions. Dosage and frequency may or may not be obtained.

Detailed knowledge about medications including type, dosage and frequency are quite important in care planning. There is much a practioner can learn from medications. For example, the client's diagnosed illnesses and complaints can be compared to his (her) list of medications to evaluate whether any medical problems are not being treated, the mix or medicines can suggest that the medication regime should be reviewed by a physician, and possible side effects (such as disorientation) of specific medications can be evaluated. A limited amount of information on medications is also useful for the research purposes of this project. The number of medications provides a good indicator of poor physical health and consequently, a good control variable.

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[3] The instrument developed for the California Multipurpose Senior Services Project uses ICD codes; however; it is not clear that this portion of the instrument is intended to be used for self-report data because the items are not phrased in lay language.

[4] The measures developed by the Rand Corporation for their Health Insurance Study (Stewart et al., 1978; Ware et al., 1978) also associate medical conditions with resulting disability. The procedure used is to present a list of conditions and ask which one is the main cause of the individual's disability.

[5] The PGC-MAI includes a question on whether any medicines are taken.

Given the substantial differences in the level of detail required by practitioners and researchers, we, recommend that the item on medications be an open-ended question such as, "Do you regularly take any medicines? What do you take?" The responses would be checked off on a pre-coded list and optional space would be provided for practitioners to add information on dosage and frequency for channeling clients. The latter information would not be collected for control group members and would not be entered in the client tracking system.

Other treatments besides medications can be quite important in care planning. For example, practitioners need to know about intravenous and tube feedings, irrigations and dressings, supportive devices and prostheses and special diets. We recommend that a checklist on prostheses be added to the instrument. The checklist need not be lengthy but should specifically cover the most widely used aids. Optional space would be provided for practitioners to note further information about prostheses such as the circumstances of use and the brand. We also recommend items on whether the respondent is on a special diet and whether s/he is receiving any other treatment. Space would be provided for practitioners to note the type of diet or treatment if they wish to do so for care planning purposes.

3. Self-Perceived Health Status

Existing multidimensional assessment instruments differ in their consideration of subjective health status. Many include a single item on overall perception of current health. If another item is included, it is likely to be a question comparing current health status to past health status, although the time frame varies across instruments (one year, three years, five years). The OARS and PGC-MAI devote three and four items, respectively, to self-perceived health status. These are very similar except for the addition in the PGC-MAI of an item comparing one's health status to that of others of the same age. (Exhibit II.2 represents the module from PGC-MAX.)

Single-item indicators of self-perceived health status would allow case managers to identify people with health problems that have not been identified by inventorying diagnosis and other medical conditions. However, for research purposes a single-item indicator will be less reliable than a scale. Given the use of self-perceived health-status as an outcome measure, we recommend the use of a scale of several items. The PGC-MAI item comparing one's health to that of others makes it an attractive choice. As discussed above, physical health status is an important control variable in the research. In this regard we are especially concerned with the severity of illness. Self-perceived health status, in general, and especially health status compared with others of the same age may be a useful indicator of the severity of illness.[6]

[6] The utility of self-perceived health as a control variable is unclear because evidence on the relationship of self-perceived health to "objective" health status is conclusive. The association between self-perceived health and external judgments has been found to be strong (Maddox and Douglass, 1973) and weak (Suchman, Phillips and Strieb, 1958).

4. Other Issues in Physical Health

In addition to the inventory of diagnoses and medical conditions, we recommend that separate questions be asked on impairment of vision and hearing, and problems with nutrition, teeth or dentures, feet and skin cars. We also recommend that data on difficulty in communication be collected, using assessor observation.

The purpose of these questions is to help practitioners identify individuals with health problems that might not be captured in the other questions on physical health. Some individuals may view problems in these areas as the result of aging and not associate them with a need for medical care. We have selected problem areas that are common to the elderly. A further comment about nutrition is in order. We believe it is important to assess nutrition because better nutrition may be an important mechanism through which channeling affects the physical health of its clients.

Because the chief purpose of these questions is to identify problem areas for further follow-up as practitioners judge necessary, we propose to limit the number of questions to one or two for each problem area. Poor example, we might ask whether the person had problems with his (her) teeth or dentures and when s/he last visited a dentist.

C. Summary of Recommendations

We recommend an inventory of diagnoses and medical conditions that is phrased in lay language but that can be coded using the major International Classification of Disease categories. A checklist format would be used. Turning to treatment, we recommend the questions on medications be open-ended, with pre-coded responses and an optional space for practitioners to enter information on dosage and frequency. In addition, we recommend a short checklist of prostheses and supportive devices and individual items on special diets and other treatments. Self-perceived health status is important for research purposes because it may affect utilization of services and may be affected by participation in channeling. We recommend that it be measured using the PGC-MAI battery of four items.

Finally, we recommend the inclusion of one or two questions on several health problems common in the elderly, but that may not be identified in the inventory of diagnoses and medical conditions. These include questions on impairment of vision, hearing and communciation (collected by observation), problems with nutrition, teeth or dentures, feet and skin care.

EXHIBIT II.1.
OARS Medical Condition Checklist

44. Do you have any of the following illnesses at the present time?

[CHECK "YES" or "NO" FOR EACH OF THE FOLLOWING. IF "YES", ASK: "How much does it interfere with your activities, not at all, a little (some), or a great deal?" AND CHECK THE APPROPRIATE BOX.]

[IF "YES", ASK:] How much does it interfere with your activities?

YES	NO 0	NOT AT ALL 1	A LITTLE 2	A GREAT DEAL 3		CODE (0,1,2,3, or 4 for Yes but Not How Much)
					Arthritis or rheumatism	38
					Glaucoma	39
					Asthma	40
					Emphysema or chronic bronchitis	41
					Tuberculosis	42
					High blood pressure	43
					Heart trouble	44
					Circulation trouble in arms or legs	45
					Diabetes	46
					Ulcers (of the digestive system)	47
					Other stomach or intestinal disorders or gall bladder problems	48
					Liver disease	49
					Kidney disease	50
					Other urinary tract disorders (including prostate trouble)	51
					Cancer or Leukemia	52
					Anemia	53
					Effects of stroke	54
					Parkinson's Disease	55
					Epilepsy	56
					Cerebral Palsy	57
					Multiple Sclerosis	58
					Muscular Dystrophy	59
					Effects of Polio	60
					Thyroid or other glandular disorders	61
					Skin disorders such as pressure sores, ulcers or severe burns	62
					Speech impediment or impairment	63

EXHIBIT II.1. (*continued*)
SAAF Medical Condition Checklist

Do you have any of these conditions now?

CODES:
(1) Yes
(2) No
(9) Not asked/ not answered/ don't know

Heart trouble	
Arthritis	
Nervous Trouble	
Stomach or bowel problems	
Diabetes	
Skin problems	
Epilepsy [frequency of seizures _____]	
Multiple Sclerosis or Parkinson's	
Lung or breathing problems (emphysema, black lung)	
Bladder or kidney problems	
High blood pressure	
Any other illness or health problems	

EXHIBIT II.1. (*continued*)
National Minimum Data Set for Long Term Care Diagnoses

Definition: Primary diagnosis is the disease associated with the chronic condition, disability, handicap, or impairment for which the client is currently receiving long-term care. Other significant diagnoses are coexisting diseases that affect the treatment received and/or the length of stay. (Code numbers are those of the U.S. Clinical Modification of the 9th Edition of the International Classification of Diseases (ICD).)

Primary Diagnosis (check only one category)	Other Significant Diagnoses (check all categories that apply)	
		Neoplasms (ICD-9-CM 140-239) (e.g., cancer, malignancy, benign tumors, leukemia, Hodgkins disease, carcinoma)
		Endocrine, nutritional, and metabolic diseases and immunity disorders (ICD-9-CM 240-279) (e.g., gout, obesity, phenylketonuria acidosis, cystic fibrosis, diabetes, malnutrition, vitamin deficiency)
		Blood and blood forming organs (ICD-9-CM 280-289) (e.g., anemia, polycythemia, purpura)
		Organic psychotic conditions (ICD-9-CM 290-294) (e.g., senile dementia, psychotic organic brain syndrome, drug and alcohol-related organic psychoses)
		Other psychoses (ICD-9-CM 295-299) (e.g., schizophrenia, manic and depressive disorders, autism)
		Neurotic and personality disorders (ICD-9-CM 300-316) (e.g., anxiety state, hysteria, depression, chronic alcoholism, drug dependencies)
		Mental retardation - Mild (ICD-9-CM 317 - IQ 50-70)
		Mental retardation - Moderate (ICD-9-CM 318.0 - IQ 35-49)
		Mental retardation - Severe (ICD-9-CM 318.1 - IQ 20-34)
		Mental retardation - Profound (ICD-9-CM 318.2 - IQ under 20)
		Mental retardation - Level Unspecified (ICF-9-CM 319)
		Nervous system and sense organs (ICD-9-CM 320-389) (e.g., brain abscess, Parkinson's disease, multiple sclerosis, cerebral palsy, epilepsy, muscular dystrophy, glaucoma, cataract, blindness, deafness)
		Stroke including late effects (ICD-9-CM 431, 432, 434, 436, and 438)
		Atherosclerosis (ICD-9-CM 440)
		Circulatory system other than stroke or atherosclerosis (ICD-9-CM 390-459, excluding ICD-9-CM 431, 432, 434, 436, 438 and 440) (e.g., rheumatic fever, hypertensive disease, heart failure, cerebrovascular disease)
		Respiratory system (ICD-9-CM 460-519) (e.g., asthma, bronchitis, pneumonia, influenza, emphysema, chronic obstructive lung disease, pleurisy)
		Digestive system (ICD-9-CM 520-579) (e.g., gastric, duodenal, peptic ulcer; gastritis, hernia, intestinal obstruction; irritable colon, peritonitis, chronic liver disease and cirrhosis, gallbladder disease, pancreatitis, diseases of the oral cavity)
		Genitourinary system (ICD-9-CM 580-629) (e.g., nephritis, renal failure, infections of urinary tract, hyperplasia of prostate, disorders of breast, vaginal bleeding)
		Skin and subcutaneous tissue (ICD-9-CM 680-709) (e.g., arthritis, rheumatoid arthritis, osteoarthrosis, osteoporosis, intervertebral disc disorder, sciatica-lumbago, tendonitis, bursitis, myositis)
		Congenital anomalies (ICD-9-CM 740-759)
		Injury and poisoning (ICD-9-CM 800-999) (e.g., fractures, dislocations, sprains and strains, lacerations and open wounds, contusions, crushing injury, burns, poisonings, toxic effects, complications of surgery and medical care)
		Symptoms, signs, and ill-defined conditions (ICD-9-CM 780-799.8) (e.g., coma, unconsciousness, convulsions, chills, fever, old age, senility without mention of psychosis, spasms not otherwise specified, tremor not otherwise specified, anorexia, headache, cough, chest pain, nausea, vomiting)

National Minimum Data Set for Long Term Care Diagnoses (*continued*)		
Primary Diagnosis (check only one category)	**Other Significant Diagnoses (check all categories that apply)**	
		Other diagnosis (e.g., infectious and parasitic diseases (ICD-9-CM 001-139); complications of pregnancy, childbirth, and puerperium (ICD-9-CM 630-676); certain conditions originating in the perinatal period (ICD-9-CM 760-779)
		Unknown diagnosis (ICD-9-CM 799.9)
		No disease

EXHIBIT II.2. **PGC-MAI Self-Perceived Health Status Battery**					
How would you rate your overall health at the present time - excellent, good, fair, or poor?	Excellent 1	Good 2	Fair 3	Poor 4	NA, DK
Is your health <u>now</u> better, about the same, or not as good as it was three years ago?	Better 1	Same 2	Not as good 3		NA, DK
Do your health problems stand in the way of your doing the things you want to do - not at all, a little, or a great deal?	Not at all 1	Little 2	Great deal 3		NA, DK
Would you say that your health is better, about the same, or not as good as most people your age?	Better 1	Same 2	Not as good 3		NA, DK

III. ACTIVITIES OF DAILY LIVING

A. Rationale

Among all the aspects of well-being to be considered in the assessment instrument, the ability to perform activities of daily living is, perhaps, the most crucial. These abilities reflect both physical and mental health status (Katz, Downs, Cash and Gratz, 1970; Fillenbaum, 1975; Kuriansky and Gurland, 1976).[7] Further, because they focus on what a person can and cannot do, measures of activities of daily living (ADL) are critical to care planning. As major outcome variables for the analysis of the impact of the demonstration on individuals, they are also central to the research.

The majority of ADL scales are intended for use in institutional settings and, in particular, in rehabilitation settings. Consequently, they tend to focus on the minutiae of behavior and on distinguishing among relatively severe levels of impairment. Examples of these scales are the Barthel (Mahoney and Barthel, 1965) and that used by Moskowitz and McCann (1957). Although such scales are appropriate in institutional settings, where impairment may be severe, they are insufficient for community settings because many of the disabled living in a community are less impaired. A scale for community use mast discriminate among less severe levels of impairment.[8] In addition, most ADL scales consider only the ability to perform personal self-maintenance tasks, such as bathing and eating. However, the disabled living in a community may be able to perform personal self-maintenance tasks, but unable to function independently without assistance in household management tasks. Thus, while ability to perform these personal self-maintenance tasks is crucial, for community-resident elderly it is also necessary to consider other tasks, such as meal preparation and housekeeping, which bear on the ability to live independently. Lawton and Brody (1969) labeled these tasks instrumental activities of daily living (IADL) and developed separate scales for ADL and IADL.

[7] The relationship between measures of physical health and mental health and ADL can be substantial. On a precursor of the current) OARS questionnaire, ADL functioning was found to have a correlation of .65 with Physical Health and .55 with Mental Health (Fillenbaum, 1975).

[8] A random sample of community resident elderly in Cleveland indicates that the vast majority are able to perform personal self-maintenance tasks unaided. The proportions able to perform six common ADL tasks without assistance were as follows:

bathe	90 percent
remain continent	94 percent
transfer to bed	96 percent
groom self	97 percent
dress self	97 percent
feed self	99 percent

B. Activities of Daily Living

The most widely used self-report measures of physical ADL are modifications of the scales of Katz et al. (1963) and of Lawton and Brody (1969) and Lawton (1971). The Katz scale is based on the empirical observation that elderly patients pass through three stages of recovery of independence: first in feeding and continence, second in transferring and toileting and third in dressing and bathing. Lawton and Brody added walking, wheeling, and grooming to the Katz tasks and eliminated transferring. Other modifications have added going outside and climbing stairs.[9] Table III.1 indicates the tasks considered in selected physical ADL scales and in the National Minimum Data Set for Long Term Care (U.S. National Committee on Vital and Health Statistics, 1979). Because the scales have borrowed heavily from each other, it is not surprising that there is considerable overlap among the tasks they consider. Some of the differences may be attributed to differences in the populations for which they were designed. For example, PACE II, which includes wheeling, is intended for the institutionalized.

Gurland (1980) argues that the six Katz activities are sufficient to measure ADL because other tasks were tested, and eliminated, in the development of the Katz scale. However, the National Minimum Data Set for Long Term Care recommends the inclusion of walking and ambulation out of doors in addition to the six Katz tasks. Except for the Katz scale, all the instruments in Table III.1 consider walking and some aspect of mobility. However, several (PGC-MAI, OARS, SAAF, Manitoba) do not include toileting, which is included in the Katz scale. The physical demands involved in toileting (transferring to toilet, adjusting clothes, cleaning oneself) seem to be largely covered in other activities (for example, in transferring, dressing and grooming). This approach has the advantage of eliminating a potentially embarrassing question.

Physical ADL scales also differ in their treatment of various forms of assistance. Some differentiate mechanical aid and human assistance, others group the need for assistance from a device and human assistance, and still others treat performance with a mechanical device as unaided performance. We recommend that the two forms of assistance be distinguished. The distinction between mechanical assistance and human assistance is important from the clinical perspective of care planning. Moreover, the National Minimum Data Set an Long Term Care recommends treating performance with mechanical devices as unaided performance. If the two types of assistance are differentiated, it will be possible to collapse the unaided and mechanical assistance categories.[10]

Most of the existing ADL scales that differentiate between human and mechanical assistance are not self-report scales. The ADL scale of SAAF is an

[9] The Lawton and Brody ADL scale drew on the earlier work of Lowenthal (1964).

[10] Questions could be worded to group unaided and mechanical assistance, but the phrasing would be awkward and less information would be available for care planning.

Although we will also be collecting information on what aids are used, this alone will not permit us to distinguish between the need for human and mechanical assistance. Some individuals may require both types of assistance.

exception; it distinguishes between the need for a helper and other limitations such as using mechanical aids and the inability to perform a task in a reasonable amount of time. The ADL scale of the instrument used in the South Carolina Community Long Term Care project also distinguishes between mechanical and human assistance. However, it is a lengthy battery and is not entirely self-report. Table III.2 indicates the treatment of mechanical and human assistance in selected self-report ADL scales.

Another difference among the physical ADL scales involves the distinction between current performance and potential performance of tasks. Two types of potential performance can be distinguished--prognosis, that is, likely performance given change in capacity over time and current capacity, that is, performance that would currently be possible, given opportunity and desire. Institutional rules often proscribe activities for which an individual has the capacity. Rules in nursing homes against unsupervised bathing are the classic example. (The institutional setting also limits the opportunity to perform many instrumental activities of daily living. This is considered in the next section.)

Professional judgment is required to assess prognosis and such judgments are difficult to make at best. Because the control group will not be assessed by practitioners, we cannot collect information in the standardized core assessment instrument on potential capacity given change over time. (We could provide practitioners with the option to record treatment group members' potential capacity.) However, we will ask about current capacity, that is, ask clients what personal self-maintenance tasks they can do without assistance or if institutional rules permitted.

Existing self-report ADL scales differ in their treatment of current performance and capacity. As Table III.2 indicates, some clearly distinguish between current performance and capacity. Others ask only about current performance, that is, about the tasks one does perform. Still others mix current performance and capacity by asking about the tasks one can perform.

Exhibit III.1 presents the Katz, OARS, and SAAF scales as examples of various approaches to measuring activities of daily living.

Turning now to the psychometric properties of ADL scales, the fact that the Katz scale was patterned on the empirical process of rehabilitation in elderly patients is evidence for its construct validity. Moreover, the Katz Index of ADL forms a Guttman scale that has been shown to be highly reproducible (Katz et al., 1963; Sherwood et al., 1977). The Lawton scale was found to form a Guttman scale when administered to an institutional sample (Lawton and Brady [1969]); however, this was not the case for a large sample of community residents (Fillenbaum, 1975). Among the self-report instruments, high criterion validity has also been demonstrated for an assessor rating of ADL and IADL based on the OARS' scales; self-care capacity as rated by physical therapists correlated 0.83 with the OARS rating scale (Fillenbaum and Symer, forthcoming). Scores on a similar PGC-MAI rating scale have been shown to be significantly higher for persons living in the community than for persons receiving in-

home services or on the waiting lists for institutions, indicating that it has predictive validity. (Moss, Fulcomer and Kleban, 1978). Because the items for the principal ADL scales overlap so extensively, this body of evidence indicates that the ADL tasks do provide valid measures of functional capacity.

Again considering the self-report scales, levels of reliability that are adequate or better are reported for both the PGC-MAI and OARS rating scales. (Fillenbaum, 1975; Lawton et al., no date). We find no information on the reliability of the ADL measures used in the SAAF, the self-report form of the Katz scale used in COMPASS, or the California or South Carolina instruments. All of these have been used with community-resident elderly.

C. Instrumental Activities of Daily Living

As Table III.3 indicates, a common core of seven IADL tasks are included in most instruments used in community settings. These tasks include the abilities to:

- use the telephone
- travel out of walking distance shop
- prepare meals do housework
- take medications
- manage personal finances.

In addition, many instruments distinguish between laundry and other housework. A few include other tasks; in particular, handyman and work and carrying out the rubbish or getting the mail.

The National Minimum Data Set on Long Term Care lists the following as adaptive tasks: taking care of personal possessions, securing personal items; handling money; and using the telephone. Securing personal items would be covered by the core IADL item on shopping, and taking care of personal possessions, by the housework item. The other two National Minimum Data Set adaptive tasks are directly addressed by core IADL items.

The tasks involved in instrumental activities of daily living are more complex than those involved in physical activities of daily living. They are likely to be more sensitive than ADL items to variations in mental health and in motivation and opportunity. As a result, the problem of differences between actual and potential performance discussed above for AOL are pervasive for IADL. In the first place, measuring ability to perform household activities is problematic in institutional settings because residents have only very limited opportunities to perform such tasks.[11] Second, in community settings, current performance and capacity to perform may vary because of motivation or, for

[11] Unfortunately, actual capacity may deteriorate rapidly when there is no opportunity to perform a task.

household tasks, differentiation of roles by sex.[12] Given lack of opportunity or desire, the method of choice would be to design empirical tests of ability to perform various household tasks. This is the approach taken in the Performance Activities of Daily Living Scale (PADL) by Kuriansky and Gurland (1976). However, for the National Long Term Care Demonstration Evaluation we must rely almost entirely on self-report data and such empirical tests are not feasible. If an individual does not currently perform a task, for whatever reason, the only means we have of collecting information about potential capacity is to ask about his (her) perception of that capacity.

Instruments in use in community settings vary in their treatment of current performance and capacity for IADL. As Table III.4 indicates, some consider current performance only and others, current capacity only. The latter procedure is used in the OARS IADL battery and in the most recent version of the PGC-MAI (Lawton et al., no date). The original version of the PGC-MAI distinguished between actual performance and current capacity. If individuals did not perform an activity, they were asked whether they could do so. For some tasks, a question was also included on the reasons a client did not perform that task. A somewhat different technique is used in COMPASS. A person is asked whether s/he can perform a task and then whether s/he receives any help, thus collecting information on both current capacity and performance.[13]

Exhibit III.2 presents the IADL scales from OARS and the original PGC-MAI. They are presented as examples of different treatments of current performance and capacity.

The core IADL items clearly have high face validity as measures of ability to function independently in the community. Moreover, Lawton and Brody (1969) report evidence of validity for their original IADL scale, which contained seven "core" items listed above plus laundry, but which was not self-report. They found that IADL scale scores were moderately related to other measures of functional capacity. Beyond this initial work, there is evidence for the validity of the OARS and PGC-MAI assessor ratings based on combined ADL and IADL scales. (See the discussion in the previous section of this chapter.) Little evidence has been reported on the psychometric properties of the variant IADL scales used in other instruments. In some cases, evidence has been reported for entire instruments but not for individual scales.

[12] Most IADL items are biased toward household activities traditionally performed by women. (Handyman chores and shoveling snow are two exceptions; they are biased toward traditionally male roles.) In the original PGC-MAI, the scoring procedures for the IADL battery varied by sex of the respondent.

[13] The OARS services modules asks about help in the last six months on IADL tasks. However, whether help is currently received is not asked.

D. Recommendations

1. Physical Activities of Daily Living

We recommend that the six tasks of the Katz scale--bathing, dressing, toileting, transfer, continence and feeding--and walking be included in the ADL battery in the client assessment instrument. We recommend these items because they are included in the National Minimum Data Set for Long Term Care and because the validity of the Katz scale is well established. In addition to these items we would add an item on grooming. With the addition of grooming a subset of the ADL tasks in the client assessment instrument would be identical to the tasks considered in scales known to be reliable in self-report instruments with community-resident elderly.

We recommend that the client assessment instrument differentiate between mechanical and human assistance for physical ADL. This distinction is fundamental to care planning in the demonstration because individuals who need only mechanical assistance may bb better able to function independently. Moreover, the ability to perform activities of daily living is one of the most important outcome measures for the research. It is extremely important that this scale be sensitive to changes in functional ability. Existing self-report scales for which reliability and validity data are available do not differentiate between mechanical and human assistance: therefore, it will be necessary to revise the answer coding categories. Because the administration of these scales involves assessor coding of a client's answers,[14] revising the precoded answer categories should have little or no effect upon validity or reliability.

As we cannot collect valid self-report data on prognosis, we recommend that the instrument focus on the ADL tasks the client actually performs and those for which s/he currently has the capacity. Both are necessary for care planning and for research involving comparisons across setting.[15] However, because practitioners will also need to form judgments about an individual's prognosis with respect to ADL tasks, we can provide a place for these judgments to be recorded on the clinical assessment tool.

No existing self-report ADL meets the four criteria of task coverage, distinction between mechanical and human assistance, consideration of current performance and capacity, and known reliability and validity. Perhaps SAAF comes the closest. However, although its ADL tasks overlap with those of other scales known to be valid, no evidence is yet available on the psychometric properties of the SAAF scale per se.

2. Instrumental Activities of Daily Living

Because almost all IADL scales consider the same basic set of tasks and because this basic set encompasses the recommendation on adaptive tasks of the National Minimum Data. Set on Long Term Care, the major issue in the choice of scales

[14] Coding is required to differentiate levels of assistance.

[15] For a discussion of the importance of comparable data across setting, see Chapter VI.

is the treatment of actual performance and current capacity. We recommend that current performance and capacity be distinguished. The rationale for this recommendation is twofold. First, a clear distinction between actual performance and current capacity is important to care planning. Practitioners need to understand what clients are currently doing as well as what they perceive themselves able to do. Second, to evaluate the impact of the demonstration, we must compare the capacity of treatment and control group members. Because community services will not be available to control group members through the demonstration, they are more likely to be institutionalized than treatment group members. Because of the limited opportunities within an institution, a measure of performance alone is inadequate for comparison of functional capacity across setting.

Several existing self-report IADL scales consider both current performance and current capacity and include the basic core of IADL tasks. The approach that we recommend is to ask current capacity and then ask whether someone also is currently performing the task, for the client or whether s/he does it her/himself. One advantage of this approach is that it combines in a single section the information needed for care planning for household maintenance tasks.[16]

A research advantage of this approach is that an identical set of questions on current capacity is asked of all clients regardless of their sex or the setting in which they reside.

TABLE III.1. Physical ADL Tasks Considered in Selected Instruments

	NMDSLTC[a]	PACEII[b]	PGC-MAI	COMPASS	OARS	SAAF	Manitoba[e]	ACCESS[f]	TRIAGE
Bathe/ shower	+	+	+	+	+	+	+	+	+
Dress	+	+	+	+	+	+	+	+	+
Use Toilet	+	+		+				+	+
Transfer	+	+	+	+	+	+	+	+	+
Continence	+	[c]	+	+	+	+	+	+	+
Feed self	+	+	+	+	+	+	+	+	+
Walking	+	+	+	+	+	+	+	+	+
Groom		+	+		+	+			
Go outside	+	+	[c]	[d]					+
Climb stairs		+		+		+	[d]		+
Wheel		+		+		+	[d]	+	+

a. National Minimum Data Set for Long Term Care.
b. Includes rehabilitation potential.
c. Item not part of ADL battery, but included in instrument.
d. Included in another item in ADL battery.
e. Also includes responsibility for own treatment and own medication.
f. Also includes endurance.

[16] Other information on services related to household management might also be collected in the same module.

TABLE III.2. Treatment of Type of Assistance and Current Performance and Capacity in Selected Self-report ADL Scales

Instrument	Type of Assistance			Current Performance vs. Current Capacity		
	Mechanical and Human Assistance Differentiated	Mechanical Grouped with Unaided	Mechanical and Human Assistance Grouped	Performance and Capacity Differentiated	Performance Only	Current Performance and Capacity Combined
California		x[a]			x	
COMPASS			x			x
OARS			x			x
PGC-MAI			x		x[b]	
SAAF	x			x		
South Carolina[c]	x				x	

a. For continence, use of a catheter is grouped with human assistance. Human and mechanical assistance are differentiated for walking, however this is not included in the ADL scale in this instrument.
b. Current performance and capacity are differentiated for IADL but not for ADL.
c. Some ADL items involve assessor observation.

TABLE III.3. Tasks Considered in IADL Batteries in Selected Instruments for Use with Community-Resident Elderly

	ACCESS	California	COMPASS	Havens and Thompson[e]	Manitoba	OARS	PGC-MAI	SAAF	South Carolina	TRIAGE
Use the telephone	+	+	+	d	+	+	+	+	+	+
Travel out of walking distance	+	+	+		+	+	+	+	a	+
Shopping	+	+	+	+	+	+	+	+	+	+
Meal preparation	+	+	+	+	+	+	+	+	+	+
Housework	+	+	+	+	+	+	+	+	+	+
Laundry	+	+	+	+			+	+	b	+
Take medications	+	+	c	d	d	+	+	+	+	+
Manage finances	+	+	+	+	+	+	+	+	+	+
Handyman, yard work				+			+			
Rubbish/ mall			+							

a. Travel to doctor.
b. Specifically included in housework.
c. Also includes management of other treatments such as dressing changes.
d. Included in personal care battery.
e. Also includes making a cup of tea or coffee.

TABLE III.4. Current Performance and Capacity in Selected IADL Batteries Used in Community Settings			
Instrument	**Current Performance Only**	**Current Capacity Only**	**Current Performance and Capacity[a]**
ACCESS	x		
California	x		
COMPASS			x
Havens and Thompson	x		
Manitoba	x		
OARS		x	
PGC-MAI (original version)			x
PGC-MAI (original version)		x	
SAAF			x[b]
South Carolina	x		
TRIAGE	x		

a. Includes asking capacity if not now performing an activity.
b. Interviewers are instructed to ask whether a client could do an activity if he (she) is not now performing it. However, the questions on current performance are phrased as can you, not do you?

EXHIBIT III.1.
Katz Index of ADL
Index of Independence in Activities of Daily Living

The Index of Independence in Activities of Daily Living is based on an evaluation of the functional independence or dependence of patients in bathing, dressing, going to the toilet, transferring, continence, and feeding. Specific definitions of functional independence and dependence appear below the index.

A. Independent in feeding, continence, transferring, going to the toilet, dressing, and bathing.
B. Independent in all but one of these functions.
C. Independent in all but bathing and one additional function.
D. Independent in all but bathing, dressing, and one additional function.
E. Independent in all but bathing, dressing, going to the toilet, and one additional function.
F. Independent in all but bathing, dressing, going to the toilet, transferring, and one additional function.
G. Dependent in all six functions.

Other Dependent in at least two functions, but not classifiable as C, D, E, or F.

Independence means without supervision, direction, or active personal assistance, except as specifically noted below. This is based on actual status and not on ability. A patient who refuses to perform a function is considered as not performing the function, even though he is deemed able.

BATHING (Sponge, shower or tub) Independent: assistance only in bathing a single part (as back or disabled extremity) or bathes self completely. Dependent: assistance in bathing more than one part of the body; assistance in getting in or out of tub or does not bathe self.	**TRANSFER** Independent: moves in and out of bed independently and moves in and out of chair independently (may or may not be using mechanical supports). Dependent: assistance in moving in or out of bed and/or chair; does not perform one or more transfers.
DRESSING Independent: gets clothes from closets and drawers, puts on clothes, outer garments, braces; manages fasteners; act of tying shoes is excluded. Dependent: does not dress self or remains partly undressed.	**CONTINENCE** Independent: urination and defecation entirely self-controlled. Dependent: partial or total maintenance in urination or defecation; partial or total control by enemas, catheters, or regulated use of urinals and/or bedpans.
GOING TO TOILET Independent: gets to toilets, gets on and off toilets, arranges clothes, cleans organs of excretion, (may manage own bedpan used at night only and may or may not be using mechanical supports). Dependent: uses bedpan or commode or receives assistance in getting to and using toilet.	**FEEDING** Independent: gets food from plate or its equivalent into mouth; (precutting of meat and preparation of food, as buttering bread are excluded from evaluation). Dependent: assistance in act of feeding (see above); does not eat at all or parenteral feeding.

EXHIBIT III.1. (*continued*)
SAAF ADL Battery

DIRECTIONS

Ask each "Do you?" question.

If the applicant is "Intact," skip questions as indicated.

If the applicant answers "Helper" or "Does not do," then ask the "could you...if you had to now?" Use the "could you" codes to code the applicant's response.

For all mentally retarded applicants, ask all questions (do not skip) in order to identify any specific problems or needs for help.

16. Do you walk up and down a flight of stairs? (1) Intact -- Able to go up and down at least one flight of stairs safely without using any type of support. (2) Limited -- Able to go up and down at least one flight of stairs with the use of side support or handrail or by using a cane or portable supports which must be managed without assistance. (3) Helper -- Able to go up and down at least one flight of stairs but needs assistance or supervision for safety. (4) Does not do. (9) Not asked / not answered / don't know IF "INTACT" SKIP TO QUESTION 19	Do you? _____ Could you? _____ (1) Yes (2) No (0) Inappropriate (9) Not asked / Not answered / Don't know
17. Do you walk a distance of 50 yards on level ground without help of any kind? (1) Intact -- Able to walk at least 50 yards without use of aids. (2) Limited -- Able to walk 50 yards by uses a brace or prosthesis on leg; or uses a cane, crutches, walkerette, or special shoes; no assistance, supervision for safety or guarding is needed. (3) Helper -- Able to walk at least 50 yards with a person to assist or supervise for safety. (4) Does not do. (9) Not asked / not answered / don't know (0) Inappropriate, coded intact on Q. 16.	Do you? _____ Could you? _____ (1) Yes (2) No (0) Inappropriate (9) Not asked / Not answered / Don't know
OF WHEELCHAIR PEOPLE ONLY	
18. Do you travel a distance of 50 yards, go around corners in your wheelchair without someone pushing you? (1) Intact -- Able to propel wheelchair independently for at least 50 yards; able to go around corners, turn around, maneuver the chair to a table, bed, toilet, etc.; able to negotiate up to a 3° grade, maneuver on rugs; over doorsills, etc. (2) Limited -- As above but requires a powered wheelchair or takes more than a reasonable time. (3) Helper -- Needs assistance of a person in propelling or maneuvering wheelchair. (4) Does not do. (9) Not asked / not answered / don't know (0) Inappropriate, applicant not in wheelchair.	Do you? _____ Could you? _____ (1) Yes (2) No (0) Inappropriate (9) Not asked / Not answered / Don't know

SAAF ADL Battery (*continued*)	
19. Do you get in and out of the bath or shower without assistance? (1) Intact -- Able to enter and leave a tub or shower safely. (2) Limited -- As above but requires adaptive or assistive devices such as grab bars or special seat or a lift, or takes more than a reasonable amount of time but not assistance. (3) Helper (4) Does not do. (9) Not asked / not answered / don't know IF "INTACT" SKIP TO QUESTION 21	Do you? _____ Could you? _____ (1) Yes (2) No (0) Inappropriate (9) Not asked / Not answered / Don't know
20. Do you sit down in a chair and get up from a chair without assistance? (1) Intact -- Able to approach, sit down or get up from a regular chair safely; if in wheelchair, able to approach and safely perform either a standing pivot or sliding transfer; able to return safely. (2) Limited -- As above but requires adaptive or assistive devices like sliding board or lift, or takes more than a reasonable time. (3) Helper -- Minimal assistance or lifting is required. (4) Does not do. (9) Not asked / not answered / don't know	Do you? _____ Could you? _____ (1) Yes (2) No (0) Inappropriate (9) Not asked / Not answered / Don't know
21. Do you ever have any accidents with your bladder or bowels? 21A. BLADDER FUNCTIONING (1) Intact -- Complete voluntary and elective control of the bladder (never incontinent). (2) Limited -- May have bladder urgency; or urinary diversion; able to irrigate catheter without assistance; able to clean, sterilize and apply condom drainage or able to empty, put on, remove and clean any equipment or appliance used. (3) Helper -- Needs assistance with external device, or has occasional accidents, or cannot wait to get bed pan or to the toilet in time. (4) Null -- Incontinent despite aids or assistance (9) Not asked / not answered / don't know 21B. BOWEL FUNCTIONING (1) Intact -- Complete voluntary and elective control of the bowles (never incontinent). (2) Limited -- Regularly requires stool softeners, digital stimulation, suppository, laxative or enema but does not require assistance; has colostomy but does not require assistance; no accidents. (3) Helper -- Needs assistance (e.g., using suppository or taking an enema) or has occasional accidents (4) Null -- Incontinent despite aids or assistance (9) Not asked / not answered / don't know	Do you? _____ Could you? _____ (1) Yes (2) No (0) Inappropriate (9) Not asked / Not answered / Don't know Do you? _____ Could you? _____ (1) Yes (2) No (0) Inappropriate (9) Not asked / Not answered / Don't know

SAAF ADL Battery (*continued*)	
22. Do you dress and undress yourself without any help? (1) Intact -- Able to dress and undress including obtaining clothes from drawers and closets; able to handle underpants, bras, slacks, skirt, shirt, belt, stockings and shoes with laces; able to manage zippers, buttons, snaps and garters. (2) Limited -- Requires prior retrieval or arrangement of clothing, or use of special closures, or loafer shoes; or takes more than a reasonable time. (3) Helper -- Patient performs at least half the effort himself. (4) Does not do. (9) Not asked / not answered / don't know	Do you? _____ Could you? _____ (1) Yes (2) No (0) Inappropriate (9) Not asked / Not answered / Don't know
23. Do you prepare your bath and wash and dry yourself on your own? (Does not mean transfer) (1) Intact -- Able to wash and dry face and entire body (except shampoo hair) including all preparations such as obtaining water if bath is taken away from the sink or tub, or takes sponge bath. (2) Limited -- As above, but requires an adaptive or assistive device or takes more than a reasonable time. (3) Helper -- Requires physical assistance. (4) Does not do. (9) Not asked / not answered / don't know IF "INTACT" SKIP TO NEXT SECTION	Do you? _____ Could you? _____ (1) Yes (2) No (0) Inappropriate (9) Not asked / Not answered / Don't know
24. Do you clean your teeth, comb your hair and (shave) (apply makeup) by yourself? (1) Intact -- Able to clean teeth or dentures, comb and brush hair, shave, apply makeup including all preparation. (2) Limited -- As above but requires adaptive or assistive device or takes more than a reasonable time. (3) Helper (4) Does not do (9) Not asked / not answered / don't know	Do you? _____ Could you? _____ (1) Yes (2) No (0) Inappropriate (9) Not asked / Not answered / Don't know
25. When you eat, do you use utensils and feed yourself without help? (1) Intact -- Able to eat from a dish or tray or table as customarily prepared; able to cut meat and butter bread. (2) Limited -- Requires prior preparation such as meat being cut or bread buttered, or an adaptive or assistive device such as a special spoon, rocking knife, etc., or takes more than a reasonable time. (3) Helper -- Must be fed (4) Does not do -- stomach feeding, I.V. (9) Not asked / not answered / don't know	Do you? _____ Could you? _____ (1) Yes (2) No (0) Inappropriate (9) Not asked / Not answered / Don't know

EXHIBIT III.1. (*continued*) OARS Physical ADL Battery	
63.	Can you eat... 2 without help (able to feed yourself completely), 1 with some help (need help with cutting, etc.), 0 or are you completely unable to feed yourself? - Not answered
64.	Can you dress and undress yourself... 2 without help (able to pick out clothes, dress and undress yourself), 1 with some help, 0 or are you completely unable to dress and undress yourself? - Not answered
65.	Can you take care of your own appearance, for example combing your hair and (for men) shaving... 2 without help, 1 with some help, 0 or are you completely unable to maintain your appearance yourself? - Not answered
66.	Can you walk... 2 without help (except from a cane), 1 with some help from a person or with the use of a walker, or crutches, etc., 0 or are you completely unable to walk? - Not answered
67.	Can you get in or out of bed... 2 without any help or aids, 1 with some help (either from a person or with the aid of some device), 0 or are you totally dependent on someone else to lift you? - Not answered
68.	Can you take a bath or shower... 2 without help, 1 with some help (need help getting in and out of the tub, or need special attachments on the tub), 0 or are you completely unable to bathe yourself? - Not answered
69.	Do you ever have trouble getting to the bathroom on time? 2 No 0 Yes 1 Have a catheter or colostomy - Not answered
[IF "YES" ASK a.]	
a.	How often do you wet or soil yourself (either day or night)? 1 Once or twice a week 0 Three times a week or more - Not answered

OARS Physical ADL Battery (*continued*)	
70.	Is there someone who helps you with such things as shopping, housework, bathing, dressing, and getting around? 1 Yes 0 No - Not answered
[IF "YES" ASK a. AND b.]	
a.	Who is your major helper? Name _____ Relationship _____
b.	Who else helps you? Name _____ Relationship _____

EXHIBIT III.2.
OARS Instrumental ADL Battery

ACTIVITIES OF DAILY LIVING

Now I'd like to ask you about some of the activities of daily living, things that we all need to do as a part of our daily lives. I would like to know if you can do these activities without any help at all, or if you need some help to do them, or if you can't do them at all.

[BE SURE TO READ ALL ANSWER CHOICES IF APPLICABLE IN QUESTIONS 56. THROUGH 69. TO RESPONDENT.]

Instrumental ADL

56. Can you use the telephone...

2 without help, including looking up numbers and dialing
1 with some help (can answer phone or dial operator in an emergency, but need a special phone or help in getting the number or dialing),
0 or are you completely unable to use the telephone?
- Not answered

57. Can you get to places out of walking distance...

2 without help (can travel alone on buses, taxis, or drive your own car),
1 with some help (need someone to help you or go with you when traveling) or
0 are you unable to travel unless emergency arrangements are made for a specialized vehicle like an ambulance?
- Not answered

58. Can you go shopping for groceries or clothes [ASSUMING S HAS TRANSPORTATION]

2 without help (taking care of all shopping needs yourself, assuming you had transportation),
1 with some help (need someone to go with you on all shopping trips),
0 or are you completely unable to do any shopping?
- Not answered

59. Can you prepare your own meals...

2 without help (plan and cook full meals yourself),
1 with some help (can prepare some things but unable to cook full meals yourself),
0 or are you completely unable to prepare any meals?
- Not answered

60. Can you do your housework...

2 without help (can scrub floors, etc.),
1 with some help (can do light housework but need help with heavy work),
0 or are you completely unable to do any housework?
- Not answered

61. Can you take your own medicine...

2 without help (in the right doses at the right time),
1 with some help (able to take medicine if someone prepares it for you and/or reminds you to take it),
0 or are you completely unable to take your medicines?
- Not answered

OARS Instrumental ADL Battery (*continued*)	
62.	Can you handle your own money... 2 without help (write checks, pay bills, etc.), 1 with some help (manage day-to-day buying but need help with managing your checkbook and paying your bills), 0 or are you completely unable to handle money? - Not answered

EXHIBIT III.2. (*continued*) PGC-MAI Instrumental ADL Battery	
44.	Do you use the telephone: 3 without help (including looking up numbers and dialing (SKIP TO Q47) 2 with some help (answer phone, dial operator in an emergency, but have a special phone or help in getting a number or dialing), or 1 don't you use the telephone at all?
45.	Why is it that you (have some help/don't use the telephone)?
46.	Can you use the telephone: 3 without help 2 with some help, or 1 are you completely unable to use the telephone?
47.	Do you get to places out of walking distance: 3 without help (travel alone on buses, taxis, or drive your own car), (SKIP TO Q50) 2 with some help (have someone to help or accompany) 1 don't you go at all (unless arrangements are made for a specialized vehicle like an ambulance)?
48.	Why is it that you (have some help/don't go at all)?
49.	Can you get to places out of walking distance: 3 without help 2 with some help, or 1 are you completely unable to travel unless special arrangements are made?
50.	Do you need (more) help with transportation to places out of walking distance? 3 Yes 1 No 2 DK
51.	Do you (or your husband/wife) own and drive a car now? 2 Yes 1 No
52.	Do you go shopping for groceries: 3 without help (take care of all shopping needs yourself), (SKIP TO Q55) 2 with some help (have someone to go with you on all shopping trips), or 1 don't you shop for groceries at all?
53.	Why is it that you (have some help/don't shop at all)?
54.	Can you go shopping for groceries: 3 without help 2 with some help, or 1 are you completely unable to do any shopping
55.	Do you need (more) help with shopping? 3 Yes 1 No 2 DK
56.	Do you prepare your own meals: 3 without help (plan and cook full meals) (SKIP TO Q59) 2 with some help (prepare some things but don't cook full meals yourself), or 1 don't you fix any meals at all?
57.	Why is it that you (have some help/don't fix any meals at all)?
58.	Can you prepare your own meals: 3 without help 2 with some help, or 1 are you completely unable to prepare any meals?

PGC-MAI Instrumental ADL Battery (*continued*)	
59.	Do you need (more) help with meal preparation? 3 Yes 1 No 2 DK
60.	Do you do your own housework: 3 without help (do heavy housework, scrub floors, etc.) (SKIP TO Q63) 2 with some help (do light housework but have help with heavy work), or 1 don't you do housework at all?
61.	Why is it that you (have some help/don't do housework at all)?
62.	Can you do your housework: 3 without help 2 with some help, or 1 are you completely unable to do any housework?
63.	Do you need (more) help with housework: 3 Yes 1 No 2 DK
64.	Do you do your own handyman work: 3 without help, (SKIP TO Q67) 2 with some help (do some things, not others), or 1 don't you do handyman work at all?
65.	Why is it that you (have some help/don't do handyman work at all)?
66.	Can you do your own handyman work: 3 without help 2 with some help, or 1 are you completely unable to do any handyman work?
67.	Do you need (more) handyman help? 3 Yes 1 No 2 DK
68.	Do you do your own laundry: 3 without help (take care of all laundry or all except sheets and towels), (SKIP TO Q71) 2 with some help (does small items only), or 1 don't you do any laundry at all?
69.	Why is it that you (have some help/don't do laundry at all)?
70.	Can you do your own laundry: 3 without help, 2 with some help, or 1 are you completely unable to do any laundry at all?
71.	Do you need (more) help with laundry? 3 Yes 1 No 2 DK
72.	Do you take any medicines or use any medications? 2 Yes (ASK Q73) 1 No (ASK Q74)
73.	Do you take your own medicine: (CHECK BELOW)
74.	If you had to take medicine, could you do it: (CHECK BELOW) 3 without help (in the right doses at the right time), (SKIP TO Q76) 2 with some help (take medicine if someone prepares it for you and/or reminds you to take it), or 1 (are you/would you be) completely unable to take your own medicines?
75.	Why is it that you (have some help/need medicine given)?

PGC-MAI Instrumental ADL Battery (*continued*)	
76.	Do you need (more) help with taking your medication? 3 Yes 1 No 2 DK
77.	Do you manage your own money: 3 without help (writes checks, pays bills, etc.), (SKIP TO Q80) 2 with some help (manages day-to-day buying but has help with managing your checkbook and paying your bills), or 1 don't you handle money at all (no day-to-day buying)?
78.	Why is it that you (have some help/don't handle money)?
79.	Could you handle your own money: 3 without help, 2 with some help, or 1 are you completely unable to handle money?
80.	Do you need (more) help with handling your money? 3 Yes 1 No 2 DK

IV. MENTAL FUNCTIONING

A. Rationale

Mental health is an important component of overall well-being and functional status. Mental functioning is included in the 1948 World Health Organization definition of health, is a component of most existing multidimensional functional assessment instruments and is included in the National Minimum Data Set for Long Term Care (U.S. Committee On Vital and Health Statistics, 1979). Although nearly everyone would agree that mental functioning is significant, there are many different perspectives on how mental functioning is best conceptualized and, hence, measured.

B. The Concept of Mental Health

One issue in conceptualizing mental health is the distinction between assessment of mental functioning (i.e., the extent to which cognitive or affective impairments impede role performance and subjective life quality) and psychiatric diagnosis. While diagnosis may reflect etiology better than assessment of functioning, there is considerable evidence that functional status is more predictive of role performance, subjective life quality, social relationships, and service utilization. Also relevant for the purposes at hand, short batteries of questions administered by trained, but nonprofessional interviewers are better able to tap mental functioning than to meet complex diagnostic criteria for the identification of specific psychiatric disorders. The appropriate emphasis for the National Long Term Care Demonstration Evaluation, therefore, is assessment of mental functioning rather than psychiatric diagnosis.

Given that mental functioning is the appropriate focus, it is still necessary to define its conceptual boundaries. One relevant issue is scope: may mental illness/mental health be viewed as a continuum ranging from impairment to superior or optimal functioning? Most available empirical evidence suggests this is not the case. Bradburn (1969), for example, has demonstrated that negative and positive affect may be distinct and independent dimensions rather than opposite ends of a single continuum. Similarly, cognitive and affective aspects of mental functioning are not on a single dimension.

Mental functioning must be clearly distinguished from other functional dimensions, in particular from social functioning and physical health. Mental functioning and social functioning can be conceptually and empirically distinguished so long as affective evaluations of social functioning are clearly and exclusively phrased in terms of social relationships. The potential overlap between mental functioning and physical health reflects the fact that psychological problems often are manifested and experienced as somatic complaints (see, for example, Langner and Michael, 1963). The same symptoms (for instance, headaches, weight loss, nausea) may represent either

physical or mental problems or an intertwining of the two. Although a substantial research tradition suggests that these psychosomatic symptoms can be effectively distinguished from physical problems, there is also considerable evidence that physical problems are frequently misdiagnosed as psychological disorders. Special care must be taken when using symptom scales; but if appropriately used, mental functioning can be conceptually and empirically distinguished, with some confidence, from physical functioning.

C. Aspects of Mental Health

Four specific aspects of mental functioning appear most frequently in the literature, and are candidates for inclusion in the assessment instrument.

(1) cognitive or organic function
(2) disturbance of mood or affect
(3) psychological well-being
(4) behavior problems.

All are recommended in the National Minimum Data Set for Long Term Care.

Cognitive function is particularly important in evaluating the mental functioning of older people, for whom rates of organic impairment are the highest in the population. It typically is manifested by disorientation, short- or long-term memory loss, and reduced or lost ability to perform cognitive tasks (for example, simple arithmetic). Disturbance of mood involves such common affective disorders or dysfunction as depression and anxiety, which are typically measured by multi-item symptom checklists. Psychological well-being refers to reports of positive mental functioning and is typically manifested in terms of morale, life satisfaction, or similar constructs. Behavior problems refer to behaviors judged to be unsuitable or disruptive to normal patterns of action and assumed to reflect psychological problems, for example disrobing, exposing oneself, screaming, physical abuse, hoarding and stealing, wandering off, hallucinating, hostility, expressions of paranoia, among others.

For the purposes of the National Long Term Care Demonstration Evaluation, we recommend that three aspects of mental functioning be assessed directly: cognitive function, disturbance of mood, and psychological well-being. Assessment of behavior problems is much more problematic for our purposes. First, because such behaviors are distinct, it is necessary to ask specific questions about each. Yet because each is relatively infrequent, items related to any one behavior would apply to only a very small fraction of the population being assessed. Second, we must rely on self-report data but the quality of self-report data on many of these behaviors is open to serious question.

D. Measuring Cognitive Functioning

The available brief screening instruments to measure basic cognitive abilities contain very similar items, their differences generally reflect the expected level of impairment in the individual being assessed.[17] Some are self-report and some rely on ratings by those in contact with the subject. Among the self-report instruments the Mental Status Questionnaire (MSQ), developed by Kahn, Goldfarb et al. (1960) and the Short Portable Mental Status Questionnaire (SPMSQ) are by far the most widely used. Exhibit IV.1 presents these scales.

The MSQ consists of ten objective items for which there are clearly correct and incorrect answers. These items tap fundamental aspects of short- and long-term memory and orientation. Scoring is straightforward in that the number of incorrect answers is simply summed to yield a total score. The MSQ has been used in hundreds of studies, ranging from clinical diagnostic trials to surveys of entire populations. The reliability and validity of the MSQ are well documented (see Gurland, 1980).[18] The MSQ includes items on the names of the current and past U.S. presidents to tap awareness of current events and memory for more distant events. Although the latter questions occur in a number of mental status tests, some suggest that these items are irrelevant to many elderly individuals, especially to those residing in institutions.

The SPMSQ, developed by Pfeiffer (1975; Duke-OARS, 1978) is a modification of the MSQ. It, too, contains ten objective items that are simply summed. Four items are exactly the same in the two instruments, three items are essentially the same, and three items differ. Scoring procedures for the SPMSQ differ depending on the race and educational level of the respondent. In addition to items on orientation and memory from the MSQ, the SPMSQ considers remote memory (mother's maiden name) and mathematical ability. The SPMSQ is somewhat more difficult than the MSQ; for example, the subject must know day, month, and year to score any points on date or birthdate. Despite its greater difficulty, the SPMSQ generates a full range of scores even among the institutionalized.

Both the MSQ and the SPMSQ appear to be adequate measures of organic functioning--both are brief, easily administered and scored, and psychometrically adequate. Two recent studies--a comprehensive review of assessment measures by Gurland (1980) and an empirical study comparing the MSQ and SPMSQ (particularly the discriminability of the two measures) reported by Tillenbaum (1980)--conclude that the two instruments are equally sound. However, for use in the National Long Term Care Demonstration Evaluation, we recommend the MSQ. The chief disadvantage of the SPMSQ is that mother's maiden name would not normally be available to assessors, preventing them from readily validating responses to this item and deriving a

[17] For example, the Philadelphia Geriatric Center (PGC) Mental Status Questionnaire (Fishback, 1977) is capable of producing a range of scores among those who would receive a score of zero on other tests.

[18] Test-retest reliability is better than 0.8 (Kahn et al., 1960a, 1960b) and internal consistency reliability is 0.84 (Sherwood et al. 1977).

score for the scale.[19] Use of the MSQ does require that assessors know the respondent's birthdate. To ensure that it is available for all respondents, we recommend that this information be included in the screening instrument and supplied to the assessor.

In some instruments (e.g., PGC-MAI, Havens and Thompson, 1971) the items of the MSQ are dispersed to a greater or lesser degree. The avowed purpose of this is to make the scale seem less test-like and intrusive. We recommend that the MSQ not be dispersed. While there is anecdotal evidence that interviewers (who are not practitioners) prefer to administer a dispersed version,[20] practitioners with whom we discussed this issue agreed that from the standpoint of establishing trust in a relationship with a client, it was far better to identify the scale as a test that provides important information, and ask the respondent's cooperation in completing it.

We also recommend that the MSQ be placed well into the body of the instrument and administered after rapport has been established between the respondent and the assessor. We do not recommend its use as a screen because a poor score on the MSQ does not necessarily imply that an individual is unable to answer most or all of the questions. For example, someone who suffers from disorientation with respect to time or place, may still be able to answer questions about his/her attitudes and feelings. When a respondent seems confused, we prefer to have assessors attempt the interview, concentrating on the questions that cannot be appropriately addressed to a proxy respondent. This approach is respectful of the individual and has the advantage of limiting missing data to the maximum possible extent. The fact that an interviewer viewed certain responses as unreliable could be indicated in the instrument.

E. Measuring Psychological Well-Being

Various terms are used to describe a positive constellation of attitudes toward oneself and one's relationship with the external world. These include happiness, morale, life satisfaction, contentment, personal adjustment, and subjective well-being. Although these terms have slightly different connotations, there have been few attempts to specify the theoretical domains of the concepts involved. Neugarten, Havighurst, and Tobin (1961) is an exception; these authors attempted to specify the theoretical domains of life satisfaction. They hypothesized that the essential aspects of a positive mental state were mood, tone, zest, congruence, resolution, and self-concept.[21] Lawton (1977) differentiated twelve domains within well-being. These are:

[19] Even if a special effort were made, it would sometimes be difficult to obtain accurate information because of lost records, name changes with immigration, marriage and remarriage, and so on.

[20] Charles Fogelman of ACTION (personal communication, 1980) reports that interviewers who have administered both the OARS SPMSQ and the PGC-MAI version of the MSQ, prefer the latter because it is less likely to "put off" a respondent.

[21] It should be noted, however, that empirical attempts to verify the theoretical components hypothesized by Neugarten, Havighurst, and Tobin found that it was not possible to do so. See, for example, Adams (1969).

(1) life satisfaction
(2) happiness
(3) mood
(4) age-related morale
(5) continuity of self
(6) positive self-concept
(7) intrapsychic symptoms
(8) psychophysiological and somatic symptoms
(9) self-rated health
(10) satisfaction with the status quo
(11) attitudes
(12) loneliness.

As these lists of hypothesized domains within well-being suggest that measures of psychological well-being can be criticized as diffuse amalgamations of several concepts.

Serious attention has been paid to the psychometric properties of two measures of psychological well-being widely used with the elderly. These are the Life Satisfaction Index A (LSIA) (Neugarten, Havighurst, and Tobin, 1961) and the Philadelphia Geriatric Center (PGC) Morale Scale (Lawton, 1972).[22] The Life Satisfaction Index was designed to be "relatively independent of level of social activity and participation." (Neugarten, Havighurst, and Tobin, 1961). This is advantageous because social functioning is also to be measured in the National Long Term Care Demonstration Evaluation and non-overlapping measures of these two domains are desirable. However, two recent reviewers of measures of subjective well-being (Sauer and Warland, in press; and Kane and Kane, in press), question whether reliability or validity has been adequately established for the LSIA.

The PGC Morale Scale has been subjected to factor analysis using a number of samples. The original scale (Lawton 1972) contained 22 items and six factors. overall test-retest reliabilities for two samples were 0.75 and 0.80, although the reliabilities for some of the factors were considerably lower. Further factor analysis using three independent samples by Morris and Sherwood (1975) and Lawton (1975) identified three scales (measuring agitation, attitude toward own aging, and lonely dissatisfaction) in shorter 15- and 17-item scales. However, Gilford (1980) was unable to replicate these three factors with a sample of elderly more frail than the earlier samples.

Both the LSIA and the PGC Morale scale contain items which refer specifically to the age of the respondent. For example, the PGC Morale Scale includes the items "I am as happy now as when I was younger" and "As you get older, you are less useful," and the LSIA includes "I feel old and tired," and "I feel my age, but it doesn't bother me." Because impaired individuals under 65 are eligible for the National Long Term Care

[22] Another potential measure of positive affect are the positive items from the Bradburn Affect Balance Scale. One advantage of this scale is that the items include no reference to the age of the respondent. However, Lawton and Kleban (1979) conclude that it has not had enough predictive testing to determine its utility in care planning.

Demonstration, the appropriateness of such age-related items may be questioned. However, both scales have been successfully administered to younger age groups. In fact, a shortened form of the Life Satisfaction Index (LSIZ), which included age-related items, was administered to a national sample of persons 18 years of age and older (Harris, 1975).

Upon reviewing all this evidence, there is little reason to favor either the LSIA or the PGC-Morale Scale over the other as the best measure of overall life satisfaction. Two factors lead us to recommend the LSIA. First, we are seeking an overall measure of psychological well-being. Lawton (1977) has argued that the LSIA is preferred when interest is in a single general measure, and the PGC Morale Scale preferred when interest centers on separate dimensions of morale. Second, the 17-item version of the PGC-Morale scale and the morale scale used in the PGC-MAI contain items that involve loneliness, that is, a subjective evaluation of social functioning.[23] For purposes of the research, we would prefer that the measures of mental and social functioning be as distinct as possible.

F. Measuring Disturbance of Mood

Lawton (1977) has defined mood as "time-limited happiness or unhappiness." Mood represents a somewhat longer time period than an emotion, but a shorter period than "temperament" or "personality." Nor does mood have the implication of generality of the latter two terms. This is related to the distinction between a "trait" and a "state." A trait measure is concerned with a condition that is stable for a considerable period of time, whereas a state measure is concerned with an immediate emotion (Levitt and Lubin, 1975). For the research purpose of measuring the impact of channeling, it is not appropriate to measure personality traits. These are unlikely to be affected by the experiment.[24] Nor is it appropriate to consider fleeting emotions because these do not provide information about the life quality of an individual. Our measures of mood should address an intermediate time period.

As Salzman et al., (1972) point out, because mood is a private experience, it can be reported accurately only by a cooperative subject. Among the elderly, cooperation is more likely if the scale is brief, clearly stated, and relevant to the respondent's circumstances.

Although there are a number of inventories to measure mood states, depression, and anxiety, many are lengthy or difficult to administer and not appropriate for studies of elderly patients (Salzman et al., 1972). The self-report mood scales most widely used with the elderly are the Zung Self-Rating Depression Scale, the Beck Depression

[23] It should be noted that these items are not contained in the Morris and Sherwood (1975) revision of the PGC Morale Scale.

[24] The evidence indicates basic stability and continuity in personality functioning in the latter part of life. (See Dye, in press.)

Inventory and the depression items from the Hopkins Symptom Checklist. Exhibit IV.3 presents these scales.

As originally proposed, the Zung and Beck scales are keyed quite closely to the somatic symptoms of depression, while the Hopkins places minimal emphasis on clinical symptoms. Because we wish, for research purposes, to distinguish between physical and mental health, the inclusion of somatic items is a disadvantage of the Zung scale and the Beck scale as originally proposed. However, the shortened form of the Beck, developed by Sherwood and her collegues (Sherwood et al., 1977) does not contain somatic items.[25]

A difficulty with the Hopkins scale is that it includes an item on loss of sexual energy. There is little information on whether loss of sexual libido is associated with depression among the elderly (Kane and Kane, in press). Moreover, this item may be problematic for the institutionalized elderly, who often have restricted opportunity for sexual experience. There seems to be no information on the properties of the Hopkins scale when this item is excluded. In addition, the Hopkins includes a measure on loneliness, so that it would overlap with affective assessment of social functioning as we define it in Chapter V.

As originally suggested, the Beck scale was difficult to administer and likely to be fatiguing for the elderly. However, Sherwood and her colleagues have suggested seven-item and three-item short forms (Sherwood et al., 1977), and Gallagher (1979) has suggested simplified wording for oral administration.

Given the criteria of lack of overlap with other domains, appropriateness to an elderly population, and ease of administration and brevity, we conclude that the three-item form of the Beck scale using simplified wording is most appropriate for the purposes of the National Long Term Care Demonstration Evaluation.

Up to this point, we have been considering measures of depression. We also recommend that a measure of anxiety be included in the client assessment instrument. A major goal of the demonstration is to meet individuals' needs for services; it seems reasonable that they will be less anxious as a result of having those needs met. There are several anxiety scales to chose from, or one might select the anxiety items from a more general measure such as the Hopkins Symptom Checklist or the Langner 22-item scale (1962). One attractive alternative is the anxiety scale developed by the Rand Corporation for the Health Insurance Study (HIS). To illustrate the types of items in an anxiety scale, we present the Rand HIS anxiety scale in Exhibit IV.4. There are two major advantages of this scale. First, its psychometric properties have been studied and it has adequate reliability and validity. Second it was developed in conjunction with a depression scale and the items in the two scales are empirically distinct (Brook et al., 1979; Ware, 1979). A disadvantage of the Rand anxiety scale is that it has been used with the adult population including some elderly, but not with the very old or frail. In

[25] Morris, Sherwood, and their colleagues have suggested and developed subscales of the Zung scale (Morris, Wolf, and Klerman, 1975; Sherwood at al., 1977). The negative affect subscale (Agitation) contains several somatic items.

addition, the Rand scale was designed as a self-administered battery. Because the answer categories are lengthy, altering it for oral administration would be difficult.

A specific recommendation on an anxiety measure must await further review of existing measures. Among the criteria to be used in the selection of a scale would be ease of administration and brevity.

G. Measuring Problems Manifested in Interpersonal Relationships

Most scales to measure behavior problems (disrobing/exposing oneself, screaming, and so forth) require the ratings of observers who are familiar with the individuals' typical behaviors. While practitioners in the National Long Term Care Demonstration Evaluation will often be able to question a client's caregiver, this will not be the case for the interviewers of the control group members. Consequently, rating scales on behavior problems are inappropriate for the standardized client assessment instrument.

As Lawton and Kleban (1979) point out, there is no good self-report instrument that efficiently detects serious behavior problems. They suggest that it may be necessary to leave determination of behavior problems to clinical procedures. Because of the number of separate problems involved, many questions would be needed to tap them in a self-report instrument. Moreover, it is likely that some respondents would be alienated by the content of these questions.

Although we do not recommend an attempt to capture serious behavior problems within the client assessment instrument, it would be possible to ask assessors to note, on the basis of their observation during the interview, whether the respondent was dirty, odorous, poorly groomed or untidily dressed. Because these observations do not involve clinical judgment, it is appropriate for these data to be recorded for the control group. Problems such as those with cleanliness and grooming may strain interpersonal relationships and be important factors in the decisions of families to seek institutionalization. We recommend that such data be collected.

H. Stressful Life Events

Stressful life events are often associated with declines in emotional, social, or physical functioning. In some instances they may trigger such declines, in others the events reflect a combination of deteriorating health or circumstances or aggravate pre-existing conditions. Whatever the causal relationships, such events clearly represent an important risk factor that should be identified both for research and care planning purposes. At the extreme, stressful events such as the death of a spouse can trigger a chain of circumstances that leads to institutionalization or death. The association of such events with changes in service needs also makes them of interest from a research perspective.

We recommend that an inventory of recent stressful life events be included in the client assessment instrument. Respondents would be asked whether any of to events listed had happened to them in the past year. In the interest of brevity, we recommend that the checklist focus on events that can be particularly stressful including:

- death of spouse
- major injury or illness
- death of close family member or friend
- divorce or separation
- relocation or retirement.

I. Recommendations

We recommend that the client assessment instrument include measures of three aspects of mental functioning: cognitive functioning, psychological well-being, and disturbance of mood. The latter would involve measures of depression and anxiety. We do not recommend the inclusion of measures of serious behavior problems--the other aspect of mental functioning frequently considered in the literature. The quality of self-reported information on these behaviors is open to serious question and numerous items are required to address the variety of possible problems. Nevertheless, assessors can observe a limited number of less serious behavior problems which may strain interpersonal relations and be a factor in decisions to seek institutionalization.

As a measure of cognitive functioning, we recommend the MSQ. It is reliable and valid, brief, and easily administered. We do not recommend that it be dispersed, but rather placed well into the body of the instrument so that it is administered after rapport has been established between the respondent and the assessor.

There is little reason to favor either the LSIA or the PGC Morale Scale as a measure of psychological well-being. We recommend the LSIA because we are seeking a global measure of psychological well-being, and it is the more general of the too. Moreover, in the forms used by Lawton, the PGC Morale Scale contains items on loneliness that overlap with subjective assessment of social functioning, a separate domain of well-being that we prefer to distinguish.

We recommend the three-item form of the Beck Depression Inventory as a measure of depression. It does not contain any items on somatic complaints that could result in confounding of the domains for physical and mental health. Although the original version of the Beck was difficult to administer, it has been simplified for oral administration. We recommend that a measure of anxiety be included in the client assessment instrument; however, further review is required before a specific recommendation can be made. The criteria to be used in selecting an anxiety scale include brevity and ease of administration.

Although this may not necessarily be the case, recent stressful life events are frequently associated with emotional problems. In any event, knowledge of such events are critical to care planning and should be quite useful in the research. We propose that major stressful life events be inventoried, using a checklist format.

Finally, although not discussed in this report, we are considering recommending that the instrument include measures of coping and sense of security about the future. We are interested in coping styles because they may be important in decisions about service utilization. We are interested in sense of security about the future because it seems reasonable to hypothesize that by supplying needed service, channeling will relieve concern about future welfare. However, from the perspectives of both theory and measurement, the state of the art is much less well advanced for these variables than for the other aspects of mental health considered in this chapter. Consequently, without further review we cannot recommend the inclusion of measures of coping and security about the future.

EXHIBIT IV.1.
MSQ, Mental Status Questionnaire

1. What is this place?
2. Where is this place located?
3. What day in the month is it today?
4. What day of the week is it?
5. What year is it?
6. How old are you?
7. When is your birthday?
8. In what year were you born?
9. What is the name of the President?
10. Who was President before this one?

Score shows severity of brain syndrome

0-2 errors = none or minimal
3-8 errors = moderate
9-10 errors = severe

EXHIBIT IV.1. (*continued*)
SPMSQ, Short Portable Mental Status Questionnaire

1. What is the data today? (Month/Day/Year)
2. What day of the week is it?
3. What is the name of this place?
4. What is your telephone number? (If no telephone, what is your street address?)
5. How old are you?
6. When were you born? (Month/Day/Year)
7. Who is the current President of The United States?
8. Who was the President just before him?
9. What was your mother's maiden name?
10. Subtract 3 from 20 and keep subtracting each new number you get, all the way down.

0-2 errors = intact
3-4 errors = mild intellectual impairment
5-7 errors = moderate intellectual impairment
8-10 errors = severe intellectual impairment

Allow one more error if subject had only grade school education.
Allow one less error if subject has had education beyond high school.
Allow one more error for blacks, regardless of education criteria.

EXHIBIT IV.2.
LS/A, Life Satisfaction Index, A[a]

1. As I grow older, things seem better than I thought they would be. (Agree)
2. I have gotten more of the breaks in life than most of the people I know. (Agree)
3. This is the dreariest time of my life. (Disagree)
4. I am just as happy as when I was younger. (Agree)
5. My life could be happier than it is now. (Disagree)
6. These are the best years of my life. (Agree)
7. Most of the things I do are boring or monotonous. (Disagree)
8. I expect some interesting and pleasant things to happen to me in the future. (Agree)
9. The things I do are as interesting to me as they ever were. (Agree)
10. I feel old and tired. (Disagree)
11. I feel my age, but it doesn't bother me. (Agree)
12. As I look back on my life, I am fairly well satisfied. (Agree)
13. I would not change my past life, even if I could. (Agree)
14. Compared to other people my age, I've made a lot of foolish decisions in my life. (Disagree)
15. Compared to other people my age, I make a good appearance. (Agree)
16. I have made plans for things I'll be doing a month or a year from now. (Agree)
17. When I think back over my life, I didn't get most of the important things I wanted. (Disagree)
18. Compared to other people, I get down in the dumps too often. (Disagree)
19. I've gotten pretty much what I expected out of life. (Agree)
20. In spite of what people say, the lot of the average man is getting worse, not better. (Disagree)

SOURCE: Havighurst, Neugarten, and Tobin, 1961.

a. The correct answer, shown in parentheses, is scored one point.

EXHIBIT IV.2. (*continued*)
Philadelphia Geriatric Center Morale Scale[a]

1. Things keep getting worse as I get older. (No)
2. I have as much pep as I did last year. (Yes)
3. How much do you feel lonely? (Not much)[b]
4. Little things bother me more this year. (No)
5. I see enough of my friends and relatives. (Yes)[b]
6. As you get older, you are less useful. (No)
7. If you could live where you wanted, where would you live? (Here)[b,c]
8. I sometimes worry so much I can't sleep. (No)
9. As I get older, things are (better,worse, the same) than/as I thought they'd be. (Better)
10. I sometimes feel that life isn't worth living. (No)
11. I am as happy now as I was when I was younger. (Yes)
12. Most days I have plenty to do. (No)[b,c]
13. I have a lot to be sad about. (No)
14. People had it better in the old days. (No)[b,c]
15. I am afraid of a lot of things. (No)
16. My health is (good, not so good). (Good)[b]
17. I get mad more often than I used to. (No)
18. Life is hard for me most of the time. (No)
19. How satisfied are you with your life today? (Satisfied)
20. I take things hard. (No)
21. A person has to live for today and not worry about tomorrow. (Yes)[b,c]
22. I get upset easily. (No)

SOURCE: Lawton, 1972.

a. The correct answer, shown in parentheses, is scored one point.
b. Items dropped from scale in Morris and Sherwood's revision (1975).
c. Items dropped from scale in Lawton's revision (1975).

EXHIBIT IV.3.
Zung Self-Rating Depression Scale

Because of Copywrite issues, we are unable to show this Exhibit at this time. Please see the Source for further information.

SOURCE: Zung. 1965.

EXHIBIT IV.3. (*continued*)
Hopkins Symptom Check List - Depression Items

Because of Copywrite issues, we are unable to show this Exhibit at this time. Please see the Source for further information.

SOURCE: Derogatis, et al., 1974.

EXHIBIT IV.3. (*continued*)
Modified Beck Depression Inventory

Because of Copywrite issues, we are unable to show this Exhibit at this time. Please see the Source for further information.

SOURCE: Beck, et al., 1961, as modified by Gallagher, 1979.

EXHIBIT IV.4. **Rand HIS Anxiety Scale**
During the past month, have you been anxious, worried, or upset? 1. Not at all 2. A little bit 3. Some--enough to bother me 4. Quite a bit 5. Very much so 6. Extremely so--to the point of being sick or almost sick
During the past month, have you been bothered by nervousness of your "nerves"? 1. Not at all 2. A little bit 3. Some--enough to bother me 4. Quite a bit 5. Very much so 6. Extremely so--to the point of being sick or almost sick
Have you been under or felt you were under any strain, stress, or pressure during the past month? 1. Not at all 2. Yes--a little 3. Yes-some but about normal 4. Yes-more than usual 5. Yes--quite a bit of pressure 6. Yes--almost more than I could stand or bear
During the past month, did you feel relaxed, at ease **or** high strung, tight, or keyed up? 1. Felt relaxed and at ease the whole month 2. Felt relaxed and at ease most of the time--seldom or never felt high strung 3. Generally felt relaxed but at times felt fairly high strung 4. Generally felt high strung but at times felt fairly relaxed 5. Felt high strung most of the time--seldom or never felt relaxed
During the past month, were you generally tense or did you feel any tension? 1. I never felt tense or any tension at all 2. My general tension level was quite low 3. I felt a little tense a few times 4. Not generally tense, but did feel fairly tense several times 5. Yes--very tense most of the time 6. Yes--extremely tense, most or all of the time
Scoring: Sum metric values of respondents' answers.

V. SOCIAL FUNCTONING

A. The Importance of Social Health

There is no consensus regarding the importance of including a social functioning dimension on multidimensional functional assessment instruments--let alone consensus about the form such a module might take. Although the majority of multidimensional assessment instruments currently available do include such questions (e.g., OARS, PGC-MAI, COMPASS), some do not include social functioning items (e.g., Reynolds et al., 1974) or include only one or two relevant items, with those items being insufficient for consideration as a separate dimension (e.g., PACE II). Most notably, perhaps, the task force that developed the National Minimum Data Set for Long-Term Care failed to recommend inclusion of social functioning items (U.S. National Committee on Vital and Health Statistics, 1979).

Given this lack of consensus, it is prudent to consider briefly the rationale for including a social functioning dimension in assessment instruments. There are several reasons. First, it is by now clear that meaningful and satisfying social interaction is a major component of the quality of life for most older people (see, Lemon et al., 1972). Second, social support networks contribute many tangible services to impaired older persons. They provide a high proportion of all care (Comptroller General, 1977), often serving as the critical factor permitting an impaired older person to remain in the community (Lowenthal, 1964, Lowenthal and Robinson, 1976), and, in general, reduce the burden upon publicly provided services. Third, there is considerable evidence that social functioning, especially social support, is related to the utilization of service programs by older adults (see, for example, Sussman, 1976). In the language of health service researchers, social support is an "enabling factor" that contributes to service utilization patterns, independent of service need. Fourth, existing studies suggest that social functioning is significantly related to (but conceptually and empirically distinct from) other dimensions of functional status (see, for example, Brook at al., 1979; Duke-OARS, 1978; Moss et al., 1978). However, measures of mental health do not capture social health intentionally or directly. Finally, service programs often influence dimensions of functioning other than those which they are specifically designed to affect. Some health services, for example, undoubtedly facilitate social functioning; others may unwittingly hinder it. If we are to identify and evaluate the total impact of service programs, multidimensional assessment, including assessment of social functioning, is merited.

B. Aspects of Social Functioning

Social functioning is a multidimensional concept and traditionally has been conceptualized and measured in a multidimensional manner. As Donald at al. (1978) note, most measures of social functioning emerge from one of two research traditions.

The first tradition focuses specifically upon social functioning, excluding notions of functional status in a broader sense. The second tradition focuses upon social functioning as one component of functional status more broadly defined. For our purposes, the second tradition is more relevant.

Because research investigators in the first tradition are not concerned with other areas of functioning, they need not and typically have not worried about maintaining conceptual and empirical distinctions between social functioning and other functional dimensions. For example, many of these instruments have measured social functioning in terms of the capacity to meet role obligations and engage in preferred activities. This emphasis on capacity is difficult to separate from the content of many instruments that measure ability to perform activities of daily living. Thus, different dimensions of well-being may be confounded. In addition, investigators developing and using measures exclusively focused on social functioning often have had the luxury of measuring social functioning in considerable depth, with the need to collect few additional data. Consequently, the specific measures of social functioning tend to be long and conceptually complex. Blazer (1980), for example, has recently conceptualized social support as including nine dimensions and developed an eighty-item questionnaire to measure them.

For the purposes of this project, it is important that the measure of social functioning be conceptually and empirically distinct from other functional domains and that the battery of questions be brief. For these reasons, previous research in which social functioning is measured in the context of a multidimensional functional asessment instrument is more useful.

Three aspects of social functioning frequently appear in the relevant literature. Although these three aspects are conceptually distinct, they often are not measured as separate dimensions. The first, and most commonly used aspect of social functioning is social interaction or social participation. This concept is typically viewed as an objective indicator of social functioning and measured in terms of the frequency of interpersonal contacts and participation in social groups. It is generally assumed that more social interaction is better than less. Nonetheless, we are aware of no empirical demonstration that shows the relationship between social interaction and an outcome measure to be essentially linear, with increased interaction consistently related to a more positive outcome. Nor is there empirical evidence of a threshold or cut-point that discriminates "impaired" from "unimpaired" social interaction levels. Because social functioning is heavily value laden, it is essential to discriminate socially valued behavior patterns from factors empirically related to functional status.

Although there are a number of conceptual problems with measures of the frequency of interaction, it is important to note that this measure does identify those who are socially isolated. Isolation is a major risk factor related to institutionalization and a critical factor in care planning.

The second aspect of social interaction receiving widespread attention is social support which typically is defined as the availability of significant others who provide both tangible services and emotional sustenance--or would do so in times of need. Again, the literature is contradictory on the issue of how much social support is enough. Some authors argue that the greater the density and extensivity of the social support network, the better (e.g., Blazer, 1980). Other investigators claim that "one versus none" is the critical issue.[26]

A third, and less common, aspect of social functioning is the individual's affective or qualitative assessment of his/her social functioning. The importance of this aspect of social functioning is clear when one considers that the quantity of social interaction is not the same as its quality. Most instruments considering affective assessment measure such perceptions as satisfaction with amount of social interaction, satisfaction with quality of interaction, and feelings of loneliness. Items related to qualitative assessment of social functioning, especially with respect to loneliness, are sometimes included in measures of affective mental health, although it is possible to distinguish affective assessment of social health from mental health by ensuring that item content focuses on social relationships. It is important to note in this regard that being alone does not imply that one is lonely and that loneliness is not necessarily emotionally debilitating.

We recommend that these three aspects of social functioning--social interaction, social support, and affective assessment of social functioning--be included in the client assessment instrument.

In addition to the three aspects of social functioning discussed above, some measures of social health also include measures of activities, typically involving checklists of leisure time activities. From a theoretical standpoint, such measures are problematic for several reasons. First, although some of the activities involved are social activities, others are not, and the rationale for considering them in the context of social behavior is suspect. In fact, Lawton separates activities (which he terms effectance) from social behavior (Lawton, 1972; Lawton and Kleban, 1979). Second, measurement in this area is almost totally undeveloped.

One obvious problem is that the number of possible activities is very large and only a small proportion can be included in a list. Finally, there has been little or no theoretical progress made toward understanding the values and sources of satisfaction associated with different activities.[27] Such understanding would inform the development of a list of basic activities. Because of these conceptual and measurement problems, we do not plan to include an objective level measure as an outcome variable for the research.[28] On the other band, clinicians may often find it useful to have information on dissatisfaction with current activity level and we recommend that an item be included to identify those individuals.

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[26] For example, Lowenthal (1964) claims that a single confidante is the critical cut-point.

[27] There is some work in this area. See Havighurst, (1961), Neulinger (1974), Pierce (in press) and Gordon, Gaitz and Scott (1973).

[28] Limited information on some activities will be collected in conjunction with the modules on service utilization.

C. Social Functioning and the Purposes of the Project

For the purposes of the National Long Term Care Demonstration Evaluation, social support is far more significant than the other two aspects of social support that we recommend be included. One of the major issues in the research is the effect of channeling on the informal provision of services. With publicly provided services available, a family might tend to reduce the level of assistance it provides in favor of public services. On the other hand, public services might provide the support a family needs to maintain an elderly member in the community; without such services the burden upon the family might be so great that it would be forced to choose institutionalization.

In Chapter VII we consider the services that family and friends are currently providing. The quantity of assistance and the relationship of the caregiver to the elderly individual will be collected on a service-specific basis for a large number of services. In addition to this service-specific data, we recommend in Chapter VII that some information be collected from the elderly respondent on the characteristics of the three persons currently providing the most informal care. We recommend that this caregiver-specific information include the geographical proximity, sex, family structure, and employment status of the caregiver. This information will help us to characterize the other responsibilities of the caregiver and evaluate--the burden associated with providing informal services.

In Chapter VII we consider services currently provided by family and friends; in the present chapter, we consider potential assistance from these sources, including both tangible service and emotional support.

Beyond social support, measures of the other-aspects of social functioning are important to the demonstration as well. Affective perception of one's social functioning is an important measure of quality of life and an outcome measure for the research. Both Campbell, Converse, and Rogers (1976) and Andrews and Withey (1976) find that there is a substantial relationship between overall life satisfaction and satisfaction with relationships with family and friends. Moreover, practitioners will want to identify those individuals with little social interaction and those who are dissatisfied with their level of social interaction so that increased social interaction can be provided as part of the care plan if that seems appropriate.

D. Measuring Social Functioning

The choice of a scale or set of subscales to measure social functioning depends to a large extent on the time within the interview to be devoted to social health. Quite detailed and specific measures of social interaction and affective assessment of that interaction are available in instruments which use a social network approach. For

example, the Hebrew Rehabilitation Center for the Aged (HRCA) Social Interaction Inventory (Sherwood et al., 1977) considers social interaction with friends, children, siblings, grandchildren and other relatives, and affective assessment of that interaction. A short form of the HRCA inventory (sea Exhibit V.1) has been developed which collapses some of the questions and does not consider siblings and grandchildren separately. The Adult Isolation Index (Tee and Granick [Bennett], 1960; Weinstock and Bennett, 1971; Bennett, 1973a, 1973b) uses a similar general approach. Patterns of isolation (past and present) are tapped in terms of different types of social contact (for example, children, siblings, organizations). One variation of this scale has been incorporated into CARE (Garland et al., 1977). In some instruments differential weights are arbitrarily assigned to various types of social contact. This is the procedure for the Cummings and Henry (1961) Lifespace measure, and it is followed by Ravens and Thompson (1976). The latter instrument is presented in Exhibit V.1.

The PGC-MAI takes a somewhat different approach. Respondents are asked to name relatives (besides those living with them) with whom they feel close. Questions on frequency of interaction are asked for each of those named. In addition, two general questions on affective assessment of social functioning are included in a morale scale.

Yet another approach to assessing functional health is exemplified by OARS (see Exhibit V.1) and Health Care Needs of the Elderly and Chronically Disabled by Branch and Fowler (1975). This approach uses general questions on social interaction and affective assessment of interaction rather than repeating similar questions for different groups or named individuals.

Despite the similarity in the approaches used in some instruments, there is much diversity within the instruments themselves. Lawton and Kleban (1979) suggest that researchers have tended to create new instruments in this area because of dissatisfaction with existing ones, but their efforts have not resulted in much improvement. Typically, they resort to analysis of single-item indicators. What is more, Lawton and Kleban (1979) argue that the current state of the art in the measurement of social functioning is "totally chaotic".

Given the many demands on the client assessment instrument, and the limited time available for its administration, these difficulties in measurement suggest that the scale chosen to access social participation and affective assessment of social functioning should be brief. Because the issue of social support is so important in the demonstration, we do not recommend that the number of items tapping this aspect of social functioning also be minimized.

Among the brief scales on social participation and affective assessment of social functioning, those of the OARS are by far the most widely used. Data are available on the reliability and validity of the OARS social battery items. The validity data consist of comparisons of social battery scores with the independent evaluations of seven clinicians (psychiatrists and social workers). There are no significant differences between the questionnaire scores and clinicians' rating (Fillenbaum and Symer, in

press). However, internal consistency reliability for the social participation and affective assessment scales was only marginally adequate, 0.66 and 0.70, respectively (Comptroller General, 1977). In these circumstances it would be desirable, for research purposes, to add a limited number of items to these subscales to increase their reliability.[29] One attractive potential addition to the affective assessment subscale is the item in Branch and Fowler (1975) on satisfaction with frequency of contact with a confidante.

Turning to the measurement of potential social support, three types of information are important.

First, whether the respondent is married and with whom s/he lives. There is no need to collect fine detail on the exact relationship of other individuals in the household. Rather, we recommend coding usual living arrangements in the manner recommended in the National Minimum Data Set for Long Term Care, with the exception that the codes pertaining to other relatives be expanded to consider whether an individual lives with his (her) spouse, children, or parents. Thus, we recommend the following codes for usual living arrangements:

- living alone
- living in a household with spouse only
- living in a household with spouse and children
- living in a household with spouse and other relatives
- living in a household with children
- living in a household with other relatives
- living in a household with spouse and parents
- living in a household with parents
- living in a household with non-relatives
- living in group quarters other than a health-related facility.

Second, because children are likely to be a primary source of potential support, the number of children, if any, should be ascertained as well as the number living close enough to the respondent to provide assistance.

Third, friends, neighbors and other relatives may also be a source of assistance.

We recommend that respondents be asked whether there is anyone other than their children who could be called on for assistance and, if so, the relationship of these individuals to the respondent. We are aware that this approach may result in defensive responses. However, this information should be a useful addition to that on children.

[29] It should be noted in this regard that depending on the choice of scale, the measure of psychological well-being may contain items on affective assessment of social functioning.

E. Recommendations

We recommend that three aspects of social functioning be measured in the client assessment instruments social participation, social support, and affective assessment of social functioning. Of these, social support is the most important because a major issue in the National Long-Term Care Demonstration Evaluation is the impact of channeling on the provision of assistance by family and friends. Furthermore, information on social support networks is quite important in care planning. Affective assessment of social functioning is important because it is associated with life quality and is an outcome measure the research. Practitioners will also be interested in identifying individuals who have little social participation or who are dissatisfied with their social functioning, so that these needs can be taken into account in care planning.

We recommend that the three basic types of information related to social support be collected: first, information on marital status and household structures second, information on total number of children and number of children in close geographical proximity; third, information on the relationship of other individuals the respondent indicates would be willing to provide assistance, if necessary.

We recommend that very brief scales be used to assess social participation and affective assessment of social functioning. Detailed information about these areas is unnecessary for purposes of this project. Recommendations on specific scales for this aspect of social functioning must await further review.

EXHIBIT V.1.
OARS Social Resources Battery

Now I'd like to ask you some questions about your family and friends.

6. Are you single, married, widowed, divorced or separated?

1 Single
2 Married
3 Widowed
4 Divorced
5 Separated
- Not answered

(Inst.)
[IF "2" ASK a.]

a. Does your spouse live here also?

1 Yes
2 No
- Not Answered

Inst.: Do not ask 7. Ask 7. (Inst.) Instead.

7. Who lives with you?
[CHECK "YES" OR "NO" FOR EACH OF THE FOLLOWING.]

1 YES	0 NO	
		No one
		Husband or wife
		Children
		Grandchildren
		Parents
		Grandparents
		Brothers and sisters
		Other Relatives [Does not include in-laws covered in the above categories.]
		Friends
		Non-related paid* helper [* Includes free room]
		Others [SPECIFY.]

7. (Inst.) In the past year about how often did you leave here to visit your family and/or friends for weekends, or holidays, or to go on shopping trips or outings?

1 Once a week or more
2 1-3 times a month
3 Less than once a month or only on holidays
4 Never
- Not answered

8. How many people do you know well enough to visit with in their homes?

3 Five or more
2 Three to four
1 One to two
0 None
- Not answered

OARS Social Resources Battery (*continued*)
9. About how many times did you talk to someone--friends, relatives, or others on the telephone in the past week (either you called them or they called you)? [IF SUBJECT HAS NO PHONE, QUESTION STILL APPLIES.] 3 Once a day or more 2 2-6 times 1 Once 0 Not at all - Not answered
10. (Inst.) Substitute italized paragraph.
10. How many times during the past week did you spend some time with someone who does not live with you, that is you went to see them or they came to visit you, or you went out to do things together? *How many times in the past week did you visit with someone, either with people who live here or people who visited you here?* 3 Once a day or more 2 2-6 times 1 Once 0 Not at all - Not answered
11. Do you have someone you can trust and confide in? 2 Yes 0 No - Not answered
12. Do you find yourself feeling lonely quite often, sometimes, or almost never? 0 Quite often 1 Sometimes 2 Almost never - Not answered
13. Do you see your relatives and friends as often as you want to or are you somewhat unhappy about how little you see them? 1 As often as wants to 2 Somewhat unhappy about how little - Not answered
14. Is there someone *(Inst.: outside this place)* who would give you any help at all if you were sick or disabled, for example your husband/wife, a member of your family, or a friend? 1 Yes 0 No one willing and able to help - Not answered IF "YES" ASK a. AND b.

OARS Social Resources Battery (*continued*)

a. Is there someone *(Inst.: outside this place)* who would take of you as long as needed, or only for a short time, or only someone who would help you now and then (for example, taking you to the doctor, or fixing lunch occasionally, etc.)?

1 Someone who would take care of Subject indefinitely (as long as needed)
2 Someone who would take care of Subject for a short time (a few weeks to six months)
3 Someone who would help the Subject now and then (taking him to the doctor or fixing lunch, etc.)
- Not answered

b. Who is this person?

Name _____
Relationship _____

EXHIBIT V.1. (*continued*) Havens and Thompson (1976) Social Functioning Items	
P	How many persons in household in addition to Respondent? No. _____ X 30 = _____ (CODE PRODUCT AS BELOW) HOUSEHOLD 000-029 = 5 030-059 = 4 060-149 = 3 150-209 = 2 210 plus = 1 Do you have any relatives? (IF NO, CODE 5, AND GO TO 37; IF YES, ASK:)
P	Where do your nearest relatives live? 1. In same household 2. In same building 3. In same neighbourhood/community 4. Less than one day's journey (BY LAND TRAVEL) 5. More distant in Canada than one day's journey or in another country (ALSO NO RELATIVES)
P	Of the relatives (INCLUDING ANY IN HOUSEHOLD) you feel closest to, how many do you see and how often? (IF NO RELATIVES USE 5) 1. Everyday _____ no. x 30 = _____ 2. Once a week _____ no. x 4 = _____ 3. A few times a month _____ no. x 3 = _____ 4. Once a month _____ no. x 2 = _____ 5. Less often than once a month _____ no. x 0 = _____ _____ TOTAL = _____ (CODE PRODUCE AS BELOW) RELATIVES 000-011 = 5 012-041 = 4 042-131 = 3 132-191 = 2 192 plus = 1
P	Is there any person(s) (IN ADDITION TO SPOUSE WHERE APPLICABLE) who is totally dependent upon you (AND/OR SPOUSE) for their full living maintenance? If so, how many? 1. None 2. Yes, one 3. Yes, two 4. Yes, three 5. Yes, four or more

Havens and Thompson (1976) Social Functioning Items (*continued*)	
P	How often do you get together with the neighbour which you see most frequently? (IF RESPONDENT SEES NO NEIGHBOURS, CODE 5) 1. Everyday 2. At least once a week 3. A few times a month 4. About once a month 5. Anything less than once a month
P	How many people that you know do you consider close friends - that is people you can confide in and talk over personal matters with? (GET RESPONDENT TO GIVE YOU A SPECIFIC NUMBER. IF NO FRIENDS, THEN ENTER CODE 0, BELOW AND CODE 5 IN ITEM 40) Number _____
P	Now take the friends you're closest to - about how often do you get togehter with any of them? 1. Every day _____ no. x 30 = _____ 2. Once a week _____ no. x 4 = _____ 3. A few times a month _____ no. x 3 = _____ 4. About once a month _____ no. x 2 = _____ 5. Anything less than once a month _____ no. x 0 = _____ _____ TOTAL = _____ (CODE PRODUCT AS BELOW) <u>FRIENDS</u> 00-07 = 5 08-20 = 4 30-41 = 3 42-59 = 2 60 plus = 1

EXHIBIT V.1. (*continued*)
Short HRCA Social Contact Inventory

Ask for A and B for each category of person:

A How often do you see your .....?
(Code each category or persons separately.)

(0) Inapp.; R has no children, etc.
(1) Never, almost never
(2) Once a year or less
(3) Several times a year
(4) Monthly
(5) Several times a month
(6) Weekly
(7) Several times a week
(8) Daily
(9) DK/NA

B. Would you like to see .... more often than you do?

(1) More often
(2) Same
(3) Less often
(0) Inapp.; R has no child, siblings, etc.

	A	B
Children		
Other relatives		
Friends		
Other residents of this facility		

VI. PHYSICAL ENVIRONMENT AND LIVING ARRANGEMENTS

A. Rationale

It is important to consider the physical environment in an assessment of functioning because, as Lawton (1970) pointed out, different environments make different demands upon the competencies of individuals. For example, the fact that the living and sleeping areas of a home are on different floors would pose no problem for most people, but would be a serious impediment for someone who had difficulty walking or climbing stairs. Practitioners must consider environmental demands in assessing community-based care and to determine the need for modifying the environment to overcome architectural barriers to independent functioning.

The interaction of a person with his (her) environment extends beyond physical competency to include the congruence of an individual's preferences and expectations with the demands of the environment. This concept of person-environment fit (to use the phrase of Kahana (1974),[30] is important to practitioners concerned with care planning that involves a move to a different setting or efforts to help individuals overcome problems with their environments. Measures of the physical environment are important to researchers in the National Long Term Care Demonstration Evaluation because, as Lawton and Nahemov (1973) and Carp (1977) argue, the physical environment is an important aspect of quality of life. This is confirmed by the empirical work of Campbell, Converse and Rogers (1976) and Andrews and Withey (1976) who found moderate correlations between measures of several aspects of the physical environment (housing, community, security from crime) and a global measure of life satisfaction. Given that individual expectations and preferences about physical environments can differ greatly, subjective measures of the environment (that is, self-perceptions) are at least as relevant, if not more relevant than objective measures. The social aspects of living arrangements (marital status, people in household) were considered in Chapter V. The physical aspects of living arrangements are considered in this chapter.

B. Measuring the Physical Environment

1. Issues in Measuring the Physical Environment

There are two major issues that bear on the selection or design of a measure of the physical environment for the National Long Term Care Demonstration Evaluation: the state of the art in theory and measurement, and the lack of measures applicable to more than one setting.

[30] The phrase person-environment fit is associated with the work of Kahana, but concern with the same issues is reflected in earlier work; in particular, that of Bennett and Nahemov (1965) and Lawton (1970).

The state of the art in the theory and measurement of the physical environment is not far advanced. After reviewing instrumentation on the adjustment of the elderly to their environments, Windley (in press) concludes that most of the methodologies are too narrowly focused and bound to a single discipline and that no consensus has developed on a theoretical framework for inquiry. There is substantial question about which aspects of the physical environment are important and the validity of measures to capture them.

The vast majority of the instruments concerned with the physical environments of the elderly are setting-specific. It is very difficult to make measures relevant to more than one setting. Yet, as Anderson and Patten (in press) point out, optimal measures for evaluating alternate approaches to long term care would be applicable in multiple settings, so that the same measures could be used without bias. This issue is important in the National Long Term Care Demonstration Evaluation because the analysis of the impact of channeling fundamentally involves comparison of treatment and control group members. Because channeling services will not be available to control group members, it is hypothesized that they are more likely to be institutionalized than are treatment group members. To the extent that measures of the physical environment are not setting-free, differences that are artifacts of measurement may be confounded with differences between treatment and control group members that reflect the impact of channeling.

C. Measures of the Physical Environment

1. Existing Instruments

Most measures of the physical environments of the elderly are setting-specific and are concerned with the psychosocial and/or physical environments of institutional and group living settings. These range from measures of adaptation to nursing homes (e.g., McCaffree and Harkins, 1976) to checklists of architectural features (e.g., Moos, 1979).

A few instruments focus upon the physical environments of the elderly living in the community. Much of this work has been done by Lawton and his colleagues at the Philadephia Geriatric Center. The PGC-MAI considers architectural barriers (stairs), sense of personal security, convenience, the structural quality of the living unit, satisfaction with various aspects of the living unit, and satisfaction with neighbors and the neighborhood. A subset of these items forms three subscales: a subjective housing index, a subjective neighborhood index, and a personal security index (Moss, Fulcomer, and Kelban, 1978). In addition, the PGC-MAI contains a short inventory; which may be completed by observation, on the facilities and amenities of the environment. (Exhibit VI.1 presents the PGC-MAI battery on the physical environment). CARE uses an approach to the physical environment in community settings similar to the PGC-MAI. It contains indices on dissatisfaction with the neighborhood, fear of crime and housing

problems. Havens and Thompson (1971) take a somewhat different approach. They focus upon the adequacy of physical facilities, and satisfaction with specific aspects of the dwelling. There are also some interesting items on privacy (availability of a room to oneself, a place to store belongings, secure places to keep valuables), and an overall question on convenience.

There has been a limited amount of work on setting-free measures of the physical environment. A few instruments provide alternate wording for institutional and community-settings. For example, SAAF provides alternate wordings in a question to identify problems in the physical environment. It asks whether any of the following present a problem:

- a having to climb stairs;
- bad neighbors (bad roommate in an institution);
- upkeep of the building (room or ward in an institution);
- getting to shopping;
- getting to a doctor or clinic;
- feeling safe in the neighborhood.

Whether these alternate wordings measure comparable concepts is not clear. No evidence on the psychometric properties of the SAAF has yet been reported. Nevertheless, the SAAF does suggest aspects of the physical environment for which setting-free measures may be feasible.

Coulton (1979) has recently began to develop a setting-free instrument concerned with person-environment fit. While some of the subscales in Coulton's work are inappropriate in a consideration of the physical environment, other items deal with privacy and peace and quiet. This work is in its early stages and as yet no information is available on the reliability and validity of the scale or subscales.

2. The Physical Environment and Quality of Life

Some of the items included in all the instruments discussed above have consensual validity. Surely an adequate environment meets some minimal levels of safety (both structurally and with respect to crime) and of comfort. But it is difficult to validate which aspects of the environment are important to the quality of life of the elderly. We know little about the relative values that the elderly place on dimensions of their environments (Windley, in press). For example, Lawton (1980) asked a panel of elderly in a community setting to rank various aspects of the environment that they might look for in choosing a new home. For data collected after a one-year interval, the rankings were quite different from that of the previous year. Because CARE contains items similar to the MAI, these results on rankings cast doubt on the validity of both the MAI and CARE indices on the physical environment and on the Manitoba items on satisfaction with aspects of the environment. Other evidence also suggests difficulties with the validity of scales on the physical environment. Lawton et al., (no date) report that compared to other indices in the PGC-MAI, agreement was poor between

interviewer ratings of the physical environment and the environmental indices from the MAI. In addition, the internal consistency reliability (alpha) of the MAI 3-item sense of personal security scale was not high (0.57).

Lawton and his colleagues have recently developed shorter forms of the PGC-MAI using multiple regression analysis to select those items from each domain sub scale of the full PGC-MAI that were important in predicting the full length summary score (Lawton et al., no date). Excluding sense of personal security, this analysis indicates that five items contain almost as much information on perceived quality of the environment as 24 items in the full-length PGC-MAI. The five items concern overall satisfaction with the living unit and its state of repair, noise, privacy, satisfaction with the neighborhood and neighbors, and convenience of the housing unit for visiting friends.

Despite high overlap of the information (in short and full length forms) on overall quality of the physical environment, for purposes of the research we must be concerned with the psychometric properties of the subscales as well. Satisfaction with the physical environment (satisfaction with housing, satisfaction with neighborhood, sense of security) may be affected differently by channeling. For example, short of relocation it might be very difficult to alter clients' perceptions of their neighborhoods, but relatively easier to improve the state of repair of their homes. Given variation across subscales in the potential impact of channeling, it is important to include enough items from each sub scale to ensure a reliable measure. A limited number of items may need to be added to the PGC-MAI short form to produce reliable subscales. One alternative is to use the scales of the mid-length PGC-MAI, which contains a total of thirteen items across the three subscales. We plan to pursue further the issue of the reliability of the subscales of PGC-MAI before making a final recommendation.

Some items in the short and mid-length forms of the PGC-MAI seem to be setting-free. For example the items on noise and privacy should be applicable across setting. Other items may be apparently made setting-free with relatively minor changes, following the approach used in SAAF. For example, instead of house/apartment one may ask about room or ward. Although it seems reasonable that minor wording changes for institutions will yield generally comparable data, we have no evidence that this is, in fact, the case. Somewhat more problematic are the items on satisfaction with the neighborhood. Depending on the type of institution, some individuals may have little or no contact with the neighborhood in which the institution is located. The questions about the neighborhood may take on a different meaning under these circumstances.

3. Architectural Barriers and Objective Characteristics of the Environment

From the perspective of care planning, it is important to identify architectural barriers to functioning. We recommend that these include stairs inside the dwelling, stairs outside the dwelling, and whether the sleeping areas and bathrooms are on different floors from the living areas. Most of the time it will be possible to code this information by observation. Respondents need be asked about these items only when it is not obvious.

We also recommend that an item on proximity to public transportation be included. Access to public transportation may be related to service utilization. Consequently, it is important from both care planning and research perspectives.

As a supplement to the information on the individuals' perception of the physical environment, it may also be useful to ask the assessor to categorize the state of repair of the dwelling and furnishings. If these are so dilapidated that they represent a hazard, practitioners will want to take this into account.

We have not recommended a checklist of facilities (toilet, telephone, refrigerator, stove) and amenities (television, radio) in the home. Such a list was included in the PGC-MAI, but has been eliminated due to lack of variation in samples from Philadelphia. The Philadelphia experience suggests that there will be little variation in the urban sites. If rural sites feel this information is important, it could be added on a site-specific basis. In any event, these data could usually be obtained through interviewer observation.

We recommend that consideration of physical aspects of living arrangements include the type of architecture of the dwelling, whether the person lives in a private household, an institution or in another group living arrangement, and the type of institution or group living arrangement.[31] The architecture of the dwelling (single family home, walk-up apartment, high-rise apartment and so on) may be related to the presence of architectual barriers and to sense of security in one's[32] home and neighborhood. Type of institution or group living arrangement is an important outcome variable because we will want to analyze the impact of channeling by the level of care as well as on whether institutionalization occurs at all.

Assessor observation can be used to collect information on type of housing. Information on type of institution can be ascertained separately so that the interviewer need only record the name of the institution. The advantage of this procedure is that it eliminates the need to ask respondents to distinguish between various types of health-related facilities and other group quarters. This could sometimes present a problem. For example, it might be easy for respondents to confuse board and care homes with boarding homes that had no formal provisions for care. More importantly, respondents will sometimes be unable to distinguish levels of care within health-related facilitites. For example, some might not be able to differentiate skilled pursing facilities from intermediate care facilities, even if the question identified the distinguishing characteristics of the two.

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[31] For simplicity, we have differentiated here between private households, institutions, and group living arrangements. In terms of services provided, degree of control over residents, social psychological setting and other characteristics, institutions and group living arrangements can be viewed as falling along a continuum. The classic work of Bennett and Nahemon (1965) on "total institutions" is particularly appropriate in considering differences in living arrangements.

[32] Concerning the effect of architecture on fear among public housing residents, see Newman and Franck, 1980.

D. Recommendations

Because subjective perceptions of the physical environment are important to overall quality of life and because channeling may have a different impact on various aspects of satisfaction with the environment, we recommend that the instrument include measures of satisfaction with residence, satisfaction with neighborhood, and sense of security from crime. Short scales to measure these aspects of satisfaction are available in the PGC-MAI, and we recommend that they be included in the client assessment instrument.

Practitioners must evaluate the demands of the physical environment as they relate to the compentencies of the client. Therefore, we recommend that items be included on architectural barriers, specifically on stairs (inside and out) and whether living areas, sleeping areas and bathrooms are on different floors. These data could usually be obtained through observation. We also recommend an objective item on access to public transportation, and assessor evaluation of the state of repairs of the dwelling and furnishings.

In regard to the physical aspects of living arrangements, we recommend that questions be included on the physical characteristics of the dwelling, whether it is a private household, institution, or group living arrangement, and the type of institution or group living arrangement. It should be possible to obtain these data without questioning the client.

EXHIBIT VI.1.
PGC-MAI Physical Environment Battery

How satisfied are you with this (house/apt) as a place to live? Are you:

1 Not very satisfied	2 Fairly satisfied	3 Very satisfied?	

Would you like to move to another place?

3 Yes	2 Not certain, DK	1 No	

Do you feel that this (house/apartment) is:

3 Very well built	2 Fairly well built, or	1 Not very well built?	

Overall, how attractive do you consider the inside of your (house/apt.)? Is it:

3 Very attractive	2 Fairly attractive, or	1 Not very attractive?	

How satisfied are you with the state of repairs or maintenance of your (house/apt)? Are you:

3 Very satisfied	2 Fairly satisfied, or	1 Not very satisfied?	

How comfortable is the temperature in your (house/apt) during the winter? Is it:

3 Always comfortable	2 Fairly comfortable, or	1 Often too cold?	

How about during the summer? Is it:

3 Always comfortable	2 Fairly comfortable, or	1 Often too hot?	

How much does any noise from the outside bother you in your (house/apt)? Does it bother you:

3 A lot	2 A little, or	1 Not much?	

Would you say you have all the space you need in this (house/apt), that it is a little small, or that it is much too small?

3 All you need	2 A little small, or	1 Much too small	

How satisfied are you with the amount of privacy you have here: that is, being able to do what you wish without other people seeing you or hearing you? Would you say that you are:

3 Very satisfied	2 Fairly satisfied, or	1 Not very satisfied?	

CHECK BY OBSERVATION	**Yes**	**No**	
CONDITION OF BUILDING AND DWELLING UNIT IS GENERALLY SOUND (NOT DILAPIDATED)	2	1	
FURNISHINGS ARE GENERALLY SOUND (NOT DILAPIDATED)	2	1	
CHECK BY OBSERVATION OR ASK IF NOT KNOWN			
Dwelling unit has:			
a. Flush toilet, tub or shower, piped hot water, central heat (all four)	2	1	
b. Telephone	2	1	
c. Refrigerator and stove (not hot plate)	2	1	
d. Television	2	1	
e. Radio	2	1	
Number of steps:	**No steps**	**1-3 steps**	**4 or more**
a. From street to dwelling unit	1	2	3
b. From first floor of unit to bedroom or bathroom	1	2	3

Would you say that you like this neighborhood:

4 Very much	3 Somewhat	2 Not much, or	1 Not at all?

PGC-MAI Physical Environment Battery (*continued*)			
How satisfied are you with the peace and quietness of the neighborhood? Are you:			
1 Not very satisfied	2 Fairly satisfied, or	3 Very satisfied?	
How convenient is this neighborhood for shopping and getting the things you need? Is it:			
3 Very convenient	2 Fairly convenient, or	1 Not very convenient?	
Is this (house/apt) within 4 blocks (or a ten minute slow walk) of a grocery store or supermarket?			
2 Yes		1 No	
How convenient is this place for visiting with friends? Is it:			
3 Very convenient	2 Fairly convenient, or	1 Not very convenient?	
How convenient is this place for getting medical care? Is it:			
3 Very convenient	2 Fairly convenient, or	1 Not very convenient?	
How satisfied do you feel with (Philadelphia/other town) as a place to live? Would you say that you are:			
3 Very satisfied	2 Fairly satisfied, or	1 Not very satisfied?	
How satisfied are you with the public transportation around here? Are you:			
3 Very satisfied	2 Fairly satisfied, or	1 Not very satisfied?	
Is this (house/apt) within four blocks (or a ten minute slow walk) of public transportation?			
2 Yes		1 No	
What about the conditions of the house in this neighborhood? Would you say that they are:			
3 Very well kept up	2 Fairly well kept up, or	1 Not very well kept up?	
What about the people who live around here? As neighbors, would you say that they are:			
3 Very good neighbors	2 Fairly good neighbors, or	1 Not very good neighbors?	

	Yes	No	
Do you feel safe in your (house/apt) at night?	2	1	
Do you feel safe in your neighborhood during the day?	2	1	
Do you feel safe in your neighborhood at night?	2	1	
Have you been robbed or attacked or the victim of any other crime? (IF YES): When? (Year) _____ Please describe what happened:	2	1	

VII. SERVICES

A. Rationale

The primary purpose of channeling is to provide appropriate services to the functionally impaired so that institutionalization can be avoided when possible, independent living in the community can be continued, the quality of clients' lives maintained or enhanced, and the cost of care controlled. Given this purpose, identifying individual service needs and maintaining an inventory of services provided are central to the channeling process and to research interests. With respect to the client assessment, the needs of researchers and practitioners. for data on services overlap, but differ in some respects.

The basic operational purpose of the assessment instrument is to facilitate the comprehensive assessment of clients as a foundation for service planning and monitoring. Part of the information required for the service planning process includes which services are being received, the quantity of and setting for these services, the identity of the service providers (both formal and informal), the perceived need for additional assistance and the potential sources of assistance. In Chapter IV, in the context of social functioning, we discussed the collection of information on potential social support from family or friends. Here we consider data collection on service use, including services received from family or friends.

The National Long Term Care Demonstration Evaluation is designed to analyze service utilization and the factors associated with it, trade-offs among alternative services, and the differential costs of the services received by treatment and control group members. The analyses of service utilization and of service costs involve data collection seldom required or made by practitioners, or at least that have a much lower priority from the perspective of service planners. Researchers especially need to know the costs of services but practitioners do not need cost data to develop a care plan. Research and practitioner data needs also differ with respect to time frame. In general, practitioners are less concerned with service use over time; their focus is appropriately on current use, although they may wish to compare current service use to what has been typical for the client over the last few years or months. This applies both to acute and to long term care services.

To summarize, operational and research needs require that data be collected on:

- the type, quantity and setting for services used over time
- the identity of service providers
- the costs of services
- the perceived need for additional services.

It is important to note that not all of these data need be collected in the client assessment instrument. We will return to this point after considering the development of a taxonomy of services.

B. A Conceptual Framework for Services

1. Issues in Developing a Conceptual Framework

The same service may be provided in private homes or in institutions and by individuals with very different credentials. Performance of a service may be an act of love or friendship or part of a provider's job. In the latter case, the provider may be the employee of an organization or someone in private practice. Services may be provided individually or as part of a "package." A charge may or may not be involved, and charges, when they occur, may be for an entire service package and may not be itemized. Furthermore, charges for some services, but not for others, are eligible for reimbursement under various public programs. Thus, in general, the concept of service is closely linked with the setting in which the service is received, the identity of the provider and the billing organization.

These linkages complicate the task of developing a uniform list of services for the National Long Term Care Demonstration Evaluation. In order to evaluate the success of the demonstration in providing alternatives to institutionalization and fostering care by family and friends, measures of service utilization must be free of setting and of provider credentials. In addition, because cost data are to be collected from providers, it must be possible to relate services to billing organizations. What is required, therefore, rather than a simple list of services, is the development of a conceptual framework that relates services, settings, providers, and billing organizations. From this conceptual framework one may develop various "lists" of services for different operational and research purposes.

Our development of a conceptual framework begins with generic definitions of services, that is, definitions that are comparable across settings and providers. Such generic definitions are essential for the comparison of formally and informally provided services and of services received by those in community and institutional settings. Unless the questions in the client assessment instrument about overall service are setting-free and provider-free, the amount of service provided informally by family and friends is quite likely to be inaccurately estimated. Nursing care is a good example of this. Some nursing tasks are often performed by family members. If nursing services were defined only by the credentials of the provider, this source of care would be overlooked entirely. Using generic definitions does not necessarily require asking people directly about individual services. Given a conceptual framework that relates typical service "packages" to institutional settings, in some cases me need only determine the type of institution. For example, skilled nursing care, personal care and meal services are presumed to be part of a skilled nursing home's basic package of services. Table VII.1, which is adapted from Scanlon, DiFederico, and Stassen (1979),

illustrates the types of generic services provided in several different types of institutions. It is important to note that the services within a typical service package will not be utilized to the same extent by all individuals in a given institution.

In addition to serving the research need for data on services that are comparable across setting and provider, generic service definitions may also be operationally useful. They may facilitate consideration of alternative approaches to the provision of a given service. In particular, they may encourage care planners to pay greater attention to informal sources of care.

Given a set of generic definitions within a conceptual framework one may then develop different groupings of services for different purposes. For example, for the collection of individual-specific service quantity and charge data from providers, one would group services that are billed together. Such a list might include medical services provided by hospital employees as one item and medical services provided in the hospital by a private practitioner (and billed separately) as another. A related issue for the collection of information on service cost is whether individuals are charged at all for a given type of service or whether the program is funded through public funds or contributions. As part of the research, a survey of community service providers is planned. This survey will include information on whether an agency charges individuals for its services.[33] When there are no charges, costs will be investigated through a limited number of case studies that use the accounting records of providers to arrive at estimates of the costs of services.

2. The Process of Developing a Conceptual Framework

The first step in developing a set of generic service definitions was to compile a comprehensive list of services. To do so, we drew upon two types of sources: (1) lists of services published for administrative purposes and (2) items on services covered in functional assessment instruments. In addition to reviewing administrative lists and existing instrumentation, we carefully reviewed the lists of services in the National Minimum Data Set for Long Term Care (U.S. National Committee on Vital and Health Statistics, 1979). Principal among the lists examined are those published by Commerce Clearinghouse, the National Association of Area Agencies on Aging, and the Health Care Financing Administration. We also examined the lists of services in the demonstration site proposals from the states. In reviewing these sources, particular attention was paid to the services eligible for reimbursement under Titles XVIII, XIX, and XX.

A number of existing assessment instruments collect some information an those providing assistance with personal care and household management tasks. This can range from asking the identity of the provider for one task to (in a few instruments) collecting substantial information for several tasks. Havens and Thompson (1971) is an example of an instrument that collects a substantial amount of information an

[33] Havens and Thompson (1971a, 1976a) used a similar strategy of companion surveys of individuals and service providers.

assistance. The data in this instrument include the relationship of the informal service provider to the client, the identity of formal service providers, the amount and frequency of assistance, and the perceived heed for additional assistance. Looking beyond personal care and household management tasks, few instruments inventory service use, although a number include questions on use of selected medical services such as items on hospitalizations or nursing home residence.[34] Of the major instruments, OARS has the most comprehensive service inventory. Moreover, a set of generic service definitions was developed in conjunction with the OARS.

Table VII.2 lists the most recent version of the generic services list developed by this process. The definition for each service is given in Appendix B. Table VII.3 presents the conceptual framework for this list of services; for each service, it indicates the settings in which the service may be provided and the types of providers. The final column of Table VII.3 indicates services that may be provided informally. The potential for informal provision of services is of particular concern with respect to the client assessment instrument because questions must be worded to prevent informal services from being overlooked.

C. Service Utilization Data in the Client Assessment Instrument

1. Alternative Data Collection Strategies

As noted in Section A, all the data on services required by the research need not be gathered by the client assessment instrument. In particular, we plan to limit the data collected from individuals to charges for services. Provider records and possibly third party payer records will be the source for much of these data. It is important to note that the procedures to be used in collecting data from these records are still under development and must be pretested final decisions are made about their feasibility. The implication of this is that treatment of service data within the client assessment instrument is subject to change.

The strategy of collecting service and cost data from sources other than individuals has numerous advantages. Difficulties of recall are avoided and the burden on respondents is much reduced. Furthermore, individuals may simply not know some of the information needed for research purposes. For example, if Medicare or Medicaid is billed directed for a service, individuals may have no knowledge of the charges involved. However, because of the expense, the research budget permits data to be extracted from provider records only in a subset of sites. In the other sites, data on quantity of services must be collected by the client assessment instrument.

[34] Service use inventories are properly not the approach in the needs assessments instruments such as those of Havens and Thompson (1971, 1976) and Branch and Fowler (1975). As Havens (forthcoming) points out, the services utilized by an individual do not necessarily represent either the services that person needs or what a community's service resources are. Unmet needs may exist, community resources may go unused, services may be provided to persons without special needs, and so on.

The basic questions to be asked in all sites would include whether a client has received a service, the quantity of services received, the perceived need for additional services and the identity of the service provider(s). In those sites in which data will be collected from provider records, we would also include questions about out-of-pocket costs associated with the services. Using the information on provider identity collected from the respondents, information on total charges would be collected from provider or third party payor records. Together, the out-of-pocket, and provider record data (possibly supplemented by third party payor data), should provide comprehensive data on the costs of services and who pays for them. The data on service use from the provider and third party records would provide a validity check for the other data collected from respondents.

The recall period for service data in the client assessment instrument must be brief. The quality of information on services that are not received regularly and on out-of-pocket costs, in particular, is likely to decay very rapidly unless diaries or similar devices are used to record services and costs as they occur. We have not proposed such diaries for several reasons. First, keeping diaries would impose a substantial burden on impaired individuals who need assistance to function independently. Second, a number of these individuals will not handle their own financial affairs. In these cases, it would be difficult and expensive to locate the appropriate proxies and persuade them to keep diaries. Third, to foster use of the diary by a substantial portion of the sample, it would be necessary to contact respondents often, preferably by telephone or in-person. This frequent contact would be very expensive yet could not be expected to ensure faithful diary use.[35]

Given the decision to eschew diaries and rely on unaided recall, the recall period must be brief. However, if the period is too brief, many respondents will not yet have received a bill for the services and will be unable to estimate what out-of-pocket costs may be involved beyond the costs covered by Medicare, Medicaid or public programs. We tentatively recommend a recall period of two to three months for out-of-pocket cost data. This is the recall period in the National Medical Care Utilization and Expenditure Survey (NMCUES), which also collected data on out-of-pocket costs for medical services.[36]

There are four advantages to the data collection strategy described above. First, because the same questions using exactly the same recall period will be asked in all sites, a basic data set on service utilization will be generated that is directly comparable across all sites, whether or not provider records are collected there. Second, potentially

[35] The current Medicare Survey involves diaries of medical costs and a monthly telephone survey of unimpaired elderly respondents. Although these conditions are more favorable than those in the demonstration, only about 60 percent maintain their diaries. (Jack Scharf, Health Care Financing Administration, personal communication, June 1980.)

[36] Although originally designed to be two months, the reference period in NMCUES averaged thirteen weeks. There is no evidence of decreased quality across individuals with shorter or longer reference periods (Gail Wilensky, Research Triangle Institute, personal communication, January 1981). Before a final decision is made on the length of the recall period, we plan to pursue this issue further.

inaccurate self-report data on charges for services are avoided by collecting this information from provider and third party payor records. Only out-of-pocket cost data, available from no other source, are collected from individual respondents. Third, the strategy eliminates respondent burden associated with diary use. Fourth, it will allow us to verify respondent reports on service use, because utilization and charge data will be collected from provider records.

A disadvantage of the strategy is that it does not permit construction of a data set with continuous data on service use. Rather, we will have a series of "snapshots" of service use and charges for the two to three months preceding the interview.

2. Informal Delivery of Services

If a respondent identifies an organization as a provider, one can assume that the services are formally provided. However, if a respondent names an individual, further questions or probes will be required to determine whether this person is acting in a formal or informal capacity. We define informal services as those which are regularly provided, which do not constitute part of a provider's job, and which are not part of an organized volunteer activity. By regularly provided we mean that the caregiver makes a practice of performing the service or services. Someone who makes a practice of performing various activities as needed would be classified as an informal service provider, even though any particular service might be performed sporadically.

For each service delivered informally we will also collect, information on the identity of the caregiver and his (her) relationship to the respondent. Questions on the quantity of informal services will refer to the two to last three months to maintain a consistent time frame for all service data.

In addition to questions for each service, we recommend that further information be collected on the characteristics of caregivers. At the end of the services section, respondents will be questioned about the characteristics of up to three informal caregivers. (If more than three informal caregivers are named, respondents will be asked which three provided the most care.) Caregiver-specific rather than service specific questions are appropriate because the same informal caregiver may often provide more than one service, and the questions we wish to ask relate to the general characteristics of the provider, not to the specific service. In Chapter V, we presented the information we recommend be collected on the characteristics of informal caregivers. These include sex, employment status, and relationship. Relationship will be ascertained for informal caregivers providing any service, not just the three providing the most care.

3. Service-Specific Instrumentation

Up to this point in this chapter, we have been discussing our general approach to the collection of service data. This approach represents the maximum amount of data

that would be collected on utilization of service. For many of the services listed in Table VII.2, much less data would be collected.

In Table VII.2 we have attempted to provide a comprehensive list of services. Some of those listed there will be used by the target population only rarely, or are minor services for which costs are minimal (whether or not an individual is charged). We recommend that such services be excluded from consideration in the client assessment instrument. Referring to Table VII.2, these services are:

- vocational rehabilitation
- nutrition services
- reading and letter writing
- employment placement
- sheltered employment
- speech and hearing therapy
- administrative, legal and protective assistance

Another group of services for which a less extensive set of questions will be asked are those which cannot be provided informally. For each generic service, Table VII.3 indicates whether it can be provided informally. Most of the services that cannot be performed by a family member are medical services that require specialized knowledge and extensive gaining and licensing. Several other services listed in Table VII.3 as possible informal services require training and may be performed only rarely by family members or friends.

Services also differ with respect to whether individuals are charged for them. For example, some services such as telephone reassurance and friendly visiting are provided without charge. Of the other services listed in Table VII.3 the following commonly do not involve charges to individuals:

- advocacy, ombudsman services
- emergency services (non-medical)
- telephone reassurance and checking
- sheltered employment
- information and referral
- services planning, coordination and follow-up
- outreach.

The number of services listed in Table VII.3 suggests that the services module will be lengthy, even though some of the services listed will not be considered in the instrument and not all items will be appropriate for the remaining services. However, it is important to note in conjunction with the burden of the services module, that any given individual will have received only a limited number of services and thus only a subset of the questions will be applicable to him or her.

D. Recommendations

Our tentative recommended approach to the data collection on service utilization and costs involves a mixed strategy of data collection from individuals when they are the best source, and from providers and possibly third party payor records when they are the best source. Data on provider charges and third party payor payments, would be collected from provider records in a subset of sites. Out-of-pocket costs would be collected from respondents in these same sites. Service utilization data (including quantity of services, perceived need for services, and the identity of the service provider) would be collected from respondents. In provider records sites, the data on service utilization could be validated against data on service use obtained from those records. In addition, information an the characteristics of informal providers would be collected in a separate section, following the services items.

Because of recall difficulties, a short time frame of two to three months is tentatively recommended for data collected from respondents. To ensure a comparable set of basic data across sites, this recall period would apply to all sites, whether or not provider records extracts were being made there. It would also apply both to formal and informal services.

TABLE VII.1. Settings for the Elderly and Services Inherent in Each Setting										
	Services									
	Shelter	**Monitoring**	**Meal Preparation**	**House-keeping and Chore Services**	**Shopping and Errands**	**Personal Care Intermittent**	**Personal Care Continuous**	**Rehabil-itation**	**Skilled Nursing**	**24-Hour Skilled Nursing**
Hospitals	x	x	x	x	x	x	x	x	x	x
Nursing Homes										
Skilled nursing	x	x	x	x	x	x	x	x	x	x
Intermediate care	x	x	x	x	x	x	x	x	x	
Personal Care and Other Homes										
Personal care	x	x	x	x	x	x	x			
Domiciliary care	x	x	x	x	x	x				
Caretaker Environment										
Foster home	x	x	x	x	x	x				
With relatives	x	x	x	x	x	x				
Congregate Housing	x	x	x							
Independent Housing										
Self and spouse	x									
Self	x									

NOTE: Adapted from Scanlon, DiFederico, and Stassen, 1979.

KEY: x = Service inherent in a setting
Blank = Service not inherent but may be contracted

TABLE VII.2. List of Generic Services	
1. Medical Services 2. Pharmaceutical Services 3. Dental Services 4. Other Medical Services 5. Physical Therapy 6. Occupational Therapy 7. Speech and Hearing Therapy 8. Vocational Rehabilitation 9. Medical Supplies and Equipment 10. Nursing Services 11. Emergency Transportation 12. Physical Fitness, Exercise, Habilitation Therapy 13. Mental Health Services 14. Counseling 15. Personal Care 16. Nutrition Services 17. Advocacy, Ombudsman Services 18. Administrative, Legal and Protective Assistance 19. Emergency Services 20. Escort Services 21. Transportation Services 22. Friendly Visiting, Personal Checking, and Companion Services	23. Telephone Reassurance and Checking 24. Monitoring Services 25. Homemaker, Housekeeping Services 26. Chore Services 27. Meal Services 28. Shopping Assistance 29. Home Repair Services 30. Instruction, Training Services 31. Shelter Services 32. Day Care, Day Hospitalization 33. Hospice Services 34. Financial Assistance 35. Reading and Letter Writing 36. Interpretation and Translation 37. Recreational Services 38. Housing Placement 39. Employment Placement 40. Sheltered Employment 41. Respite Services 42. Outreach Services 43. Information and Referral Services 44. Assessment 45. Service Planning, Coordination and Follow-Up

TABLE VII.3. Conceptual Framework for Services			
Service Category	**Settings**	**Providers**	**Informal Provision**
Medical Services	H, NH, OR, PH, C, O	P = MD, DO, physician's assistant, nurse practitioner ORG = H, NH, C	No
Phamaceutical Services	H, NH, C, OC	P = pharmacist ORG = OC, H, NH, C	No
Dental Services	H, NH, C, O	P = DDS, hygienist ORG = H, NH, C	No
Other Medical Services	H, NH, OR, PH, C, O	P = chiropractor, optometrist, podiatrist ORG = H, NH, C	No
Physical Therapy	H, NH, C, OR, PH, O	P = therapist, nurse, aide, family ORG = H, NH, C, OC	Yes (1)
Occupational Therapy	H, NH, C, OR, PH, O, OC	P = therapist, nurse, aide, family ORG = H, NH, C, OC	Yes (1)
Speech and Hearing Therapy	H, NH, C, OR, PH, O, OC	P = therapist, nurse, aide, family ORG = H, NH, C, OC	Yes (1)
Vocational Rehabilitation	H, NH, C, OR, OC, PH, O	P = therapist, nurse, aide, family ORG = H, NH, C, OC	Yes (1)
Medical Supplies and Equipment Supportive Devices and Prostheses (providing/fitting)	H, NH, OR, PH, C, O	P = orthopedist, prosthetist, brace fitters, etc. ORG = H, NH, OC, C	No

TABLE VII.3. (*continued*)			
Service Category	**Settings**	**Providers**	**Informal Provision**
Nursing Services	H, NH, OR, PH, C, O	P = RN, LPN, aide, family, privately contracted person ORG = H, NH, C, OC	Yes
Emergency Transportation		P = family, privately contracted person ORG = H, OC	Yes
Physical Fitness, Exercise, Habilitation Therapy	H, NH, OR, PH, C, OC, O	P = family, aide, therapist, privately contracted person ORG = H, NH, OR, C, OC	Yes 1
Mental Health Services (therapy)	H, NH, OR, C, O, OC, PH	P = psychiatrist, psychologist, certified therapist ORG = H, C, OC, NH	No
Counseling	H, NH, OR, PH, C, OC, O	P = pastor, social worker, family ORG = C, O, OC	Yes
Personal Care	H, NH, OR, PH	P = aide, family, nurse, privately contracted person ORG = NH, N, OR, C	Yes
Nutrition Services	H, NH, OR, C, OC, O	P = nutritionist, dietitian, family ORG = H, NH, OR, C, OC	Yes
Advocacy, Ombudsman Services	C, O, OC	P = lawyer, legal aide, social worker, family ORG = C, OC	Yes
Administrative, Legal and Protective Services	C, O, OC	P = lawyer, legal aide, social worker, family ORG = C, OC	Yes
Emergency Services (other than transportation)	C, OC	P = family ORG = C, OC	
Escort Services		P = family, privately contracted person ORG = OC	Yes
Transportation Services (other than emergency)		P = family, privately contracted person ORG = NH, OR, OC	Yes
Friendly Visiting, Personal Checking, Companion Services	PH, OR, NH, H	P = family, privately contracted person ORG OC	Yes
Telephone Reassurance and Checking	PH, OR	P = family ORG = OC	Yes
Monitoring Service (full or partial days; with or without therapy)	PH, OR, OC, H, NH	P = family, privately contracted person ORG = H, NH, OR, OC, C	Yes
Homemaker, Housekeeping Services	OR, PH, H, NH	P = family, privately contracted person ORG = OR, OC, H, NH	Yes
Chore Services	OR, PH	P = family, privately contracted person ORG = OR, OC	Yes
Meal Services (includes meal preparation and delivery)	OR, PH, H, NH, OC	P = family, privately contracted person ORG = OR, OC, H, NH	Yes
Shopping Assistance		P = family, privately contracted person ORG = OR, OC	Yes
Home Repair Services	PH	P = family, privately contracted person ORG = OC	Yes

TABLE VII.3. (*continued*)			
Service Category	**Settings**	**Providers**	**Informal Provision**
Instruction, Training Services (health, employment, personal enrichment)	H, NH, OR, C, OC	P = teacher, social worker, therapist, aide, family ORG = NH, OR, C, OC, H	Yes
Shelter Services	H, NH, OR, PH	P = family ORG = H, NH, OR, C	Yes
Day Care (2)	H, NH, OC	ORG = H, NH, OC	No
Hospice Services (2)	H, NH, OR, PH	ORG = H, NH, OC	No
Reading and Letter Writing	H, NH, OR, OC, PH	P = aide, nurse, social worker, family, privately contracted person ORG = OC, NH, OR	Yes
Financial Assistance	H, NH, OR, PH	P = family ORG = OC	Yes
Interpretation and Translation	PH, NH, OR, OC, H	P = aide, nurse, social worker, family, privately contracted person ORG = NH, OR, OC	Yes
Housing Placement	H (discharge), NH (discharge), C, OC	ORG = H (discharge), NH (discharge), C, OC	No
Employment Placement	H (discharge), NH (discharge), C, OC	ORG = H (discharge), NH (discharge), C, OC	No
Sheltered Employment	OC	ORG = C, OC	No
Respite Services (2)	PH, NH, OR, OC	P = privately contracted person, family ORG = C, OC, NH	Yes
Outreach	OC, PH, OR	P = social worker ORG = H (discharge), NH (discharge), C, OC	No
Information and Referral (3)	C, OC, H (discharge), NH (discharge), PH, OR	P = social worker, family ORG = H (discharge), NH (discharge), C, OC	Yes
Assessment (3)	C, OC, H, NH, OR, PH	P = social worker, nurse, physician, family ORG = H (discharge), NH (discharge), C, OC	Yes
Services Planning, Coordination, Follow-Up (3)	C, OC, H, NH, OR, PH	P = social worker, nurse, family ORG = H (discharge), NH (discharge), C, OC	Yes

1. May be provided informally with special training.
2. Not a separate generic service, but combination of other services which may be performed informally.
3. Aspects of channeling care management.

KEY: H = Hospital (inpatient and partial)
C = Clinic
P = Practitioner or Private Person
NH = Nursing Home (SNF, ICF)
O = Private Office
ORG = Organizational Provider
OR = Other Residential Institution
PH = Private Home
OC = Other Community Facilities (e.g., community center, business, government agencies)

VIII. FINANCIAL RESOURCES AND EXPENDITURES

A. Rationale

The National Long Term Care Demonstration Evaluation is designed to address four major issues: (1) the process by which channeling is implemented, (2) the impact of channeling on the use of long term care services, (3) the impact of channeling on the cost, for the government and for society as a whole, of long term care services, and (4) the impact of channeling on individual clients. The data on financial resources discussed in this chapter are directly relevant to the investigation of the last three issues.

Information on financial resources (income, assets, insurance coverage, and program eligibility and participation) is central to the analysis of the effect of channeling on the utilization of long term care services. Of particular interest to policy makers is the effect of channeling on entry into institutions. To analyze the decision to seek institutional care, information on financial resources and program eligibility is critical because these factors play a major role in choosing a care setting. For example, the high cost of institutional care often makes it unavailable to anyone without substantial financial resources or Medicaid eligibility. Individuals of moderate means often spend down their resources to become eligible for Medicaid. In addition, sufficient income to purchase amenities may be an important consideration in the decision to remain in the community.

A principal issue in the analysis of the effects of channeling on the costs of long term care services is the comprehensive comparison of the cost of community-based versus institutional care. It is important to stress the need for comprehensiveness in the cost comparisons because this has been a major flaw in previous studies. There are several types of goods and services (the most obvious of which are food and shelter) subsumed within the basic costs of institutional care. In addition, some goods and services such as transportation) required no function in a community setting are not required (or are required to a much lesser extent) in an institution. To develop a comprehensive comparison of the costs of community-based and institutional care, we must take differential expenditures for such goods and services into account.

To determine the coat of channeling, we must be concerned with its impact on the cost of income transfer programs as well as on programs that directly provide long term care. Different types of assistance are available to those living in the community and to those in institutions. For example, persons residing in public institutions may receive reduced SSI benefits and in many states may not be eligible for supplemental SSI payments (U.S. Congress, 1974). Determination of the cost of channeling requires information on the amount of income assistance received from various transfer programs; overall income data is not sufficient for our purposes.

Finally, economic well-being and perceived economic well-being are clearly important to quality of life. Both objective and subjective measures of well-being may be affected by the demonstration directly through systematic assessment of financial need and coordination of eligibility determination or more generally through provision of needed services at no cost or at reduced cost. In particular, channeling may affect the burden of out-of-pocket costs for medical and long term care expenses.

Up to this point, we have focused on the research needs for collecting data on financial resources. Practitioners also require such information. To develop a care plan, a practitioner needs to understand what financial resources an individual has to help meet his (her) needs. This includes eligibility for public programs as well as income, assets, and insurance coverage. A practitioner will also want to identify a person whose resources are limited, but who is not currently enrolled in one or more public programs so that an eligibility determination can be made.[37]

B. Income, Assets, and Expenditures

1. Financial Resources

Short of obtaining access to records, the most accurate way to collect data on income is to ask an individual whether s/he receives various types of income, and, if so, the amount received. This approach helps ensure that no sources of income are neglected and results in more accurate data. Because accurate information on total income and on transfer program income is important to the research, this is the approach we recommend.

Existing multidimensional assessment instruments vary substantially in their consideration of financial resources, with some including only one or two questions on the topic. Perhaps the most comprehensive considerations of income are found in OARS and COMPASS. Both provide checklists of various types of income and the amount of each type received. However, the OARS checklist is much more comprehensive. It includes earnings, social security, pensions, various types of transfer income, income from assets, and regular contributions from relatives. Information on pensions is important because in conjunction with information on assets and program eligibility, it can be used to estimate future income. OARS also includes information on in-kind income; whether someone else contributes food or housing is ascertained, but not the value of this in-kind income.

Insurance coverage is an especially important resource in the context of long term care. Many multidimensional assessment instruments collect information on insurance coverage under Medicare (Plans A and B), Medicaid, and private insurance

[37] Because of differences across states and programs, eligibility probably cannot be determined by the standard client assessment instrument. However, much of the information required for such a determination will be available from the instrument.

(for hospitalization and doctor bills). We recommend that insurance coverage be included in the client assessment instrument.

Assets receive much less consideration than income in existing multidimensional functional assessment instruments. Using a categorical question, OARS asks about the worth of owner-occupied housing. A question is also included on whether there is a mortgage against the home, but not the amount owed.[38] COMPASS asks about the value of savings accounts but not of owner-occupied housing or other types of assets. The value of one's assets can be quite important in choice of care setting. To analyze this decision, it is necessary to consider liquid and non-liquid assets separately. Non-liquid assets may be difficult to convert to cash and may be associated with considerable expense, (for example, taxes and maintenance expanses on real estate).[39] In order to ensure that some types of assets are not overlooked, we recommend that questions be asked about specific types of assets and that aggregate measures of liquid and non-liquid assets be calculated from the interview data. Because our purpose in gathering asset data is to characterize the general level of wealth in liquid and non-liquid assets, detailed information about specific assets is unnecessary.

Because the value of owner-occupied housing is a major portion of the net worth of many elderly, it is important to obtain relatively more accurate information on this item than on other types of assets. We recommend that those who own their home be asked its market value and the amount of debt on the property, including the amount owed on mortgages or home improvement loans and back taxes. This is the approach taken in the Longitudinal Retirement History Survey of the Social Security Administration. In addition to the value of owner-occupied housing, we recommend that items be included an the value of checking and savings accounts, savings bonds, certificates of deposit, stocks and bonds, and other real estate, estates and trusts.

Questions on income and assets are sensitive; same respondents view them as intrusive and refuse to answer. We have administered batteries of items on income and assets far more extensive than these recommended here. It is our experience that the elderly who manage their own financial affairs are no more likely to refuse such questions than the general population. However, some elderly individuals simply have no knowledge of their financial affairs. We expect this for a substantial minority of the elderly in the demonstration. As discussed in Chapter I, proxy respondents will be interviewed when clients are unable to answer.

2. Measures of Expenditures

The optimal means of measuring expenditures is to use a diary or other memory aid, or, failing that, detailed questions on the different types of expenditures. For example, to ascertain expenditures on food, the Consumer Expenditure Survey includes

[38] Some respondents may take into account the amount owed on the mortgage when they respond to the item on the worth of their home. However, it seems more likely that they will report the market value.

[39] As discussed in the next section, we also recommend that information be collected on the expenses associated with upkeep of one's home.

items on the frequency of grocery shopping, the usual amount of purchase, the amount spent specifically for food, shopping for food at places other than grocery stores, the frequency of such shopping, the usual amount spent, usual monthly expenses for meals in restaurants, and, finally, the approximate value of meals received as a part of pay. Obviously, the need for brevity in the client assessment instrument severely constrains the extent to which we can ask such detailed items. Rather, we recommend that regular or average expenditures be obtained for general categories of goods and services, but that the questions be worded to remind the respondent to include various types of expenses for that general category.

With the exception of mortgage payments or rents, few multidimensional assessment instruments collect information on expenditures. Havens and Thompson (1971), COMPASS, and TRIAGE are three instruments that do consider. expenditures. Of these, TRIAGE collects the most comprehensive data; it includes items on regular or average expenses for housing, household operation, food, utilities, transportation, clothing, leisure activities, life insurance and health insurance, among others. We recommend the general approach of asking average expenditures, varying the period over which the average is obtained according to the expense. For example, rent might be asked on a monthly basis and food expenditures on a weekly basis.

For the research purpose of comparing the costs of institutionalized and community-based care and estimating the demand for certain types of services, not all of the types of expenditures considered in the TRIAGE instrument need be itemized here. We recommend that estimates of regular or average expenses be obtained for:

- housing
- utilities
- household operations (maintenance and supplies)
- food
- transportation
- personal services
- medical costs
- health insurance premiums
- all other insurance premiums
- all other expenses.

3. Subjective Measures of Economic Well-Being

Subjective perceptions of economic well-being are important to overall life satisfaction. Both Campbell, Converse and Rogers (1976) and Andrews and Withey (1976) found concern with standard of living to be one of the specific items most highly correlated with global well-being.

The elderly use various standards to evaluate the adequacy of their financial resources, including comparison of their current and pre-retirement income, and the adequacy of their resources to meet current and long-term expenses (Peterson, 1969;

Chen, 1974). Clearly, objective measures of income and assets do not capture the subjective significance of financial resources.

We recommend that the client assessment instrument include a measure of perceived adequacy of financial resources. This would serve as one measure of the effect of the demonstration on quality of life. In addition, the perception of the adequacy of financial resources may be useful in the analysis investigating decisions about institutionalization, especially because the objective information about net worth that can be collected in the client assessment instrument will necessarily be limited. Finally, information on the perception of the adequacy of financial resources would also help practitioners identify individuals who should receive eligibility determinations for public transfer programs.

Existing multidimensional assessment instruments vary substantially in their consideration of subjective economic well-being. Some include no information on financial resources (objective or subjective); others include a single item on the perceived adequacy of resources to meet current needs. A few include multiple items evaluating different aspects of satisfaction with financial resources. Given the inclusion of subjective economic well-being as an outcome variable for the research, reliance on a single item is inappropriate.

Exhibit VIII.1 presents the subjective economic well-being questions from Havens and Thompson (1971) and OARS, two instruments that devote considerable attention to the issue. The OARS items concentrate on the adequacy of resources for current needs, future needs, and emergencies--issues of particular concern in long term care. We concur with Lawton and Kleban (1979) that the OARS items cover perceived economic well-being particularly well and recommend that they be included in the client assessment instrument.

C. Recommendations

We recommend the collection of data on the amount of income received from various sources including earnings, social security, pensions, various types of transfer income, income from assets, and regular contributions from relatives. In addition, we recommend the collection of data on general level of liquid and non-liquid assets including the approximate equity value of owner-occupied housing, and the value of checking and savings accounts, savings bonds, certificates of deposit, stocks and bonds, other real estate, and estates and trusts.

Turning to expenditure data, we recommend the collection of recall information on usual expenses for housing (including utilities and maintenance), food, transportation, medical costs, personal services, insurance, and all other expenses. These would be asked as general categories because the need for brevity precludes specific detailed items in each category.

We recommend that the client assessment instrument include a measure of subjective well-being; that used in OARS.

In conclusion, we should like to emphasize that previous surveys such as the Longitudinal Retirement Survey of the Social Security Administration have successfully collected detailed financial information from the elderly. Moreover, data have been collected in various assessment instruments at the same level of detail as we are recommending.

EXHIBIT VIII.1.
Havens and Thompson (1971) Items on Perceived Economic Well-Being

ASK a) TO d): (TOTAL AND COMPUTER 5 a) $ x 100/TOTAL = %. ENTER AMOUNT IN EACH CATEGORY FIRST AND THEN %. USE 000 AND 000 IF NO EXPENSES IN A CATEGORY; USE AMOUNT AND 99 IF ALL EXPENSES ARE IN ANY SINGLE CATEGORY. WHERE BOARD & ROOM ARE PAID TOGETHER, DESIGNATE 1/3rd OF WHAT IS PAID TO RENT AND 2/3rds TO FOOD. WHERE PER DIEM RATE QUOTED, DESIGNATE 1/3rd TO RENT, 1/3rd TO FOOD AND 1/3rd TO HEALTH CARE.)

	MONTHLY EXPENSES	AMOUNT	PERCENT	
_____ 9-83.34.35 _____ 9-36.37	a) How much of your monthly income is spent for rent or for house upkeep (MORTGAGE, TAXES, INSURANCE, REGULAR REPAIRS AND MAINTENANCE)?	$_____	_____%	(OF TOTAL MONTHLY EXPENDITURE)
_____ 9-38.39.40 _____ 9-41.42	b) How much of your monthly income is spent for food & clothing?	$_____	_____%	(OF TOTAL MONTHLY EXPENDITURE)
_____ 9-43.44.45 _____ 9-46.47	c) How much of your monthly income is spend for health care including insurance premiums, transportation, medication, drugs, etc.)	$_____	_____%	(OF TOTAL MONTHLY EXPENDITURE)
_____ 9-48.49.50 _____ 9-51.52	d) How much of your monthly income is spent for utilities (LIGHTING, COOKING FUEL, TELEPHONE, HEATING, WATER)	$_____	_____%	(OF TOTAL MONTHLY EXPENDITURE)
_____ 9-53.54.55.56	TOTAL MONTHLY EXPENDITURES	$_____	100%	
_____ 9-57.58.59 _____ 9-60.61	e) Do you have any other major monthly expenditures? If so (Specify) _____ and the amount spent	$_____	_____%	(OF TOTAL MONTHLY INCOME PAGE F-1)

(USE AVERAGE OR TYPICAL MONTH FIGURES IN ALL CATEGORIES)

_____ 9-62

How do you think your income and assets (INCLUDING THAT OF YOUR SPOUSE WHERE APPLICABLE) currently satisfy your needs?

1. Very well
2. Adequately
3. With some difficulty
4. Not very well
5. Totally inadequate

_____ 9-63

IF 3, 4 OR 5 APPLICABLE ASK (a) & b):

(a) How much more money do you need per month to satisfy your needs adequately?

1. Less than $25.00
2. $25.00 to $49.00
3. $50 to $74.00
4. $75.00 to $99.00
5. $100 or more

(b) If you had such additional income, would you spend it on any of the following:

		YES	NO	MAYBE
_____ 9-64	1. More or better housing or house repairs	5	1	3
_____ 9-65	2. More or better food	5	1	3

Havens and Thompson (1971) Items on Perceived Economic Well-Being (*continued*)				
_____ 9-66	3. More or better clothing	5	1	3
_____ 9-67	4. Medical needs	5	1	3
_____ 9-68	5. Recreation and/or other social activities	5	1	3
_____ 9-69	6. Transportation or new car	5	1	3
_____ 9-70	7. Trips and/or holidays	5	1	3
_____ 9-71	8. Other things	5	1	3
_____ 9-72	How does your present economic situation compare with what if was like when you were age 60? 1. Present economic situation much better 2. Present economic situation somewhat better 3. Present economic situation about the same 4. Present economic situation somewhat worse			
_____ 9-73	How do you think your income and assets (INCLUDING THAT OF YOUR SPOUSE WHERE APPLICABLE) will satisfy your needs in future? 1. Very well 2. Adequately 3. With some difficulty 4. Not very well 5. Totally inadequate			
_____ 9-74	Now, I would like to ask you what you thought of this interview. What was your major thought or opinion? _____ 1. Tedious _____ 2. Useful _____ 3. Interesting _____ 4. Vague _____ 5. Too detailed _____ 6. Pleasant _____ 7. Ridiculous _____ 8. Difficult to answer _____ 9. Difficult to understand (LANGUAGE PROBLEM ONLY)			

EXHIBIT VIII.1. (*continued*) OARS Items on Perceived Economic Well-Being	
27.	Please tell me how well you think you (and your family) are now doing financially as compared to other people you age--better, about the same, or worse? [PROBE AS NECESSARY.] 2 Better 1 About the same 0 Worse - Not answered
28.	How well does the amount of money you have take care of your needs--very well, fairly well, or poorly? 2 Very well 1 Fairly well 0 Poorly - Not answered
29.	Do you usually have enough to buy those little "extras"; that is, those small luxuries? 2 Yes 0 No - Not answered
30.	Do you feel that you will have enough for your needs in the future? 2 Yes 0 No - Not answered

IX. BASIC DESCRIPTION INFORMATION

We recommend that the following basic descriptive data be included in the client assessment instrument:

- name
- sex
- birthdate
- race
- ethnicity
- primary language, if other than English
- marital status
- family or household structure
- income
- wealth
- education
- usual occupation
- retirement/employment status
- type of community (urban/rural)
- type of housing
- type of institution.

Information on sex, birthdate, race, ethnicity and marital status are of obvious importance. These are the demographic items included in the National Minimum Data Set on Long Term Care (U.S. National Committee on Vital and Health Statistics, 1979). We would add type of community, education, and usual occupation because these variables (along with others) may be related to service use. All the other data items have been discussed in earlier chapters; they are listed here for the sake of completeness.

Some basic descriptive information items need not be asked but may simply be observed and recorded by the assessor, for example, sex, race, type of community, type of housing, and type of institution.[40] Moreover, many items of basic descriptive information need be asked only once--at the baseline assessment--because they represent fixed characteristics. These items include sex, birthdate, race, ethnicity, primary language, education, and occupation.

It was somewhat arbitrarily decided, for purposes of this report, to discuss basic descriptive information here. In fact, however, these data items can and do relate to more than one area of functioning. Because we are not recommending assessor-completed rating scales to summarize different domains of functioning, we need not be

[40] As discussed in Chapter VI, the assessor would record the name of the institution. Information on its characteristics would be ascertained separately.

concerned that question placement will confound domains. Although confounding across domains is an issue for certain scales, this does not apply to basic descriptive data. Instrument placement of items related to different areas of functioning will be determined by considerations of logic of question order, flow, and ease of administration.

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APPENDIX A. GLOSSARY OF SELECTED ASSESSMENT INSTRUMENTS

ACCESS	Monroe County Long Term Care Program, Inc. Pre-Admission Assessment Form, 1977.
Branch and Fowler, 1975	L.G. Branch and F.J. Fowler, Jr. Health Care Needs of the Elderly and the Chronically Disabled. Massachusetts Department of Public Health, Boston, 1975.
California	California Multipurpose Senior Services Project. Comparison Group Assessment Instrument, August 1, 1980.
CARE	B. Gurland et al. Comprehensive Assessment and Referral Evaluation, 1977.
COMPASS	Hebrew Rehabilitation Center for the Aged and Volunteers for Services to Older Persons. Comprehensive Assessment System for Seniors, August 1978.
Havens and Thompson, 1976	B. Havens and E. Thompson Aging Needs. Manitoba Department of Health and Social Development, 1976.
Manitoba	Manitoba Home Care Program Case Assessment Form. Manitoba Department of Health and Social Development (no date).
OARS	Duke University Center for the Study of Aging and Human Development. Older Americans Resources and Services Multidimensional Functional Assessment Questionnaire, 1975.
PACE II	U.S. Department of Health, Education and Welfare Working Document on Patient Care Management, 1978.
PGC-MAI	Philadelphia Geriatric Center. Multi-Level Assessment Instrument (no date).
SAAP	Pennsylvania Domiciliary Care Program Social Adjustment Assessment Form (no date).
South Carolina	South Carolina Community Long Term Care Project (no date).
TRIAGE	Triage Assessment Form, T.P.-20, November 1977.

APPENDIX B. SERVICE DEFINITIONS AND UNITS OF MEASURES

1.	Medical Services	Diagnostic, therapeutic, surgical, and/or consultation services by a licensed physician, for the purpose of evaluating, treating, and/or monitoring injury, disability, or sickness. Can be provided on in- or out-patient basis.	Visits/Episodes/ Days
2.	Pharmaceutical Services	Filling prescriptions or otherwise making available medications prescribed by physician.	Prescriptions
3.	Dental Services	Diagnostic, therapeutic, surgical, preventative, and/or consultation services by a dentist or dental professional.	Visits
4.	Other Medical Services	Diagnostic, therapeutic, surgical, and/or consultation services performed by or under the direct supervision of a licensed professional for the purpose of evaluating, treating, and/or monitoring injury, disability, and/or sickness. Services may include, but are not limited to those performed by: – Chiropractors – Dentists – Optometrists	Vists
5.	Physical Therapy	Specialized treatment to restore function, relieve pain, and prevent disability following disease, injury or loss of body part.	Hours
6.	Occupational Therapy	Specialized restorative treatment involving use of sensory integration exercises, perceptual-motor techniques, skill practice, and training for independence in activities of daily living and in social skills.	Hours
7.	Speech and Hearing Therapy	Evaluating and treating specific communication disorders.	Hours
8.	Vocational Rehabilitation	Evaluating and training aimed at assisting the client to enter or re-enter the labor force.	Hours
9.	Medical Supplies and Equipment	Supplying and/or fitting devices, supplies, or equipment necessary to carry out therapeutic regime, to compensate for physical disability, and/or correct physical deformity.	Hours/Dollars
10.	Nursing Services	Providing services in accordance with orders or the plan of treatment established by a physician, and intended to assure the safety of the patient and achieve the medically desired result. Services may be provided in an institution or on an outpatient basis, and may be full time or intermittent.	Hours
11.	Emergency Transportation	Emergency transport of injured or acutely ill individuals (to hospital). Service may include transportation with or without medical support services such as oxygen, EKG monitor or doctor-prescribed drugs.	One-way trips

12.	Physical Fitness, Exercises, Habilitation Therapy	Assisting with activities that sustain and/or improve physical and mental health and function.	Hours/Sessions
13.	Mental Health Services	Preventive, diagnostic, therapeutic or rehabilitative services provided to mentally ill patients on an out-patient basis by or under the supervision of a physician or other state-authorized mental health practitioner. Includes individual or group therapy.	Hours/Sessions
14.	Personal Care Services	Assistance in bathing, medication, dressing, toileting, eating, or walking.	Hours
15.	Counseling	Organized provision of advice by someone other than a mental health practitioner or for problems other than mental health.	Hours
16.	Nutrition Services	Evaluating and planning diets.	Hours/Sessions
17.	Advocacy, Ombudsman Services	Pleading and/or otherwise supporting the case of an individual with respect to a provider to ensure the delivery of a service; investigation and resolution of complaints made by, or on behalf of persons who are residents of long-term care facilities.	Hours/Sessions
18.	Administrative, Legal and Protective Assistance	Obtaining or performing legal and/or financial services on behalf of a client to safeguard his/her rights and interests.	Hours/Sessions
19.	Emergency Services	Providing food, clothing, shelter, fuel, and other basic necessities for short periods of time. Transportation not included.	Days/Episodes
20.	Escort Services	Accompanying or personally assisting an individual, by public or private transportation, to assist the individual in accomplishing the purpose(s) of the trip.	Trips
21.	Transportation Services	Transporting clients from one location to another.	One-way trips
22.	Friendly Visiting, Personal Checking, Companion and Services	Personally visiting a client for purposes of expressing interest or comfort, or relieving loneliness; providing companionship; monitoring.	Visits/Hours
23.	Telephone Reassurance and Checking	Placing telephone calls to provide comfort or as an act of friendship, or for monitoring purposes (usually on a daily basis).	Calls
24.	Monitoring Services	Simple custodial supervision that involves assisting individuals to perform activities of daily living associated or unassociated with health condition.	Days
25.	Homemaker, Housekeeping Services	General housework including house cleaning, laundry.	Hours
26.	Chore Services	Providing non-routine services or tasks in a patient's home, such as heavy cleaning, lawn mowing, minor painting, washing windows, rearranging furniture to accommodate wheelchairs or walkers, snow shoveling and various other functions.	Hours
27.	Meal Services	Subsumes both home delivery and congregate meals. Involves the provision of hot or other appropriate meals.	Meals

28.	Shopping Assistance	Shopping for clients for necessities, groceries, and other items. Does not include paying for these items.	Trips
29.	Home Repair Services	Electrical, plumbing, heating, carpentry, or other similar services to a building provided for safety, health, energy conservation, or other purposes. Weatherization and barrier removal included.	Hours/Dollars
30.	Instruction, Training Services	Activities to increase knowledge or skills for personal enrichment or more effective daily living of clients. Includes increasing education or developing skills for employment purposes, in a formal, informal, individual, or group environment.	Hours/Sessions
31.	Shelter Services	Rooming or living arrangements in an institution or home.	Days
32.	Day Care, Day Hospitalization	Supervision and medical, mental health, and nursing care for less than 24 hours a day to assist individuals with an impaired physical or mental health condition.	
33.	Hospice Services	Medical, nursing, mental health and counseling services to assist individuals near death and their families. May be on in-patient or out-patient basis.	Days/Sessions
34.	Financial Assistance	Gifts and transfers of money.	Dollars
35.	Reading and Letter Writing	Reading for pleasure or reading and writing business and personal correspondence.	Hours
36.	Interpretation and	Explaining the meaning of oral or written communication to nonEnglish speaking persons.	Hours
37.	Recreational Services	Services designed to fill leisure time, including sports, crafts, social and other activities, to improve the personal and social adjustment of a client.	Hours
38.	Housing Placement	Subsumes various placement of clients in suitable location or housing situations. May include institutional or non-institutional housing services (and location of furnishings, if necessary). Housing counseling.	Placements
39.	Employment Placement	Various kinds of client placement in employment, including sheltered employment. Job counseling.	Placements
40.	Sheltered Employment	Employment provided for the physically or mentally handicapped or disabled, generally in a special work or industry environment.	Hours
41.	Respite Services	Substitute care provided for workers or for family members caring for clients.	Hours
42.	Outreach Services	Various forms of intervention initiated to identify clients who may require services, and contacting clients to describe available services and benefits, and to encourage participation or utilization of services.	Sessions/ Contacts
43.	Information and Referral Services	Providing information or assistance in effecting linkage with appropriate community resources concerning clients' needs. Includes follow-up with provider.	Contacts/ Referrals

44.	Assessment	Systematic evaluation of an individual's condition, including physical, mental and social health, capacity for self-care, financial resources and physical environment.	Hours/Sessions
45.	Service Planning, Coordination, and Follow-up	Service-related activities such as assisting individuals to identify, locate, and obtain services, and to coordinate and subsequently verify procurement of the required services.	Hours/Sessions

NATIONAL LONG-TERM CARE CHANNELING DEMONSTRATION

REPORTS AVAILABLE

A Guide to Memorandum of Understanding Negotiation and Development
- HTML: http://aspe.hhs.gov/daltcp/reports/mouguide.htm
- PDF: http://aspe.hhs.gov/daltcp/reports/mouguide.pdf

An Analysis of Site-Specific Results
- HTML: http://aspe.hhs.gov/daltcp/reports/1986/sitees.htm
- PDF: http://aspe.hhs.gov/daltcp/reports/1986/sitees.pdf

Analysis of Channeling Project Costs
- HTML: http://aspe.hhs.gov/daltcp/reports/1986/projctes.htm
- PDF: http://aspe.hhs.gov/daltcp/reports/1986/projctes.pdf

Analysis of the Benefits and Costs of Channeling
- Executive Summary: http://aspe.hhs.gov/daltcp/reports/1986/costes.htm
- HTML: http://aspe.hhs.gov/daltcp/reports/1986/cost.htm
- PDF: http://aspe.hhs.gov/daltcp/reports/1986/cost.pdf

Applicant Screen Set
- HTML: http://aspe.hhs.gov/daltcp/reports/1982/appscset.htm
- PDF: http://aspe.hhs.gov/daltcp/reports/1982/appscset.pdf

Assessment and Care Planning for the Frail Elderly: A Problem Specific Approach
- HTML: http://aspe.hhs.gov/daltcp/reports/1986/asmtcare.htm
- PDF: http://aspe.hhs.gov/daltcp/reports/1986/asmtcare.pdf

Assessment Training for Case Managers: A Trainer's Guide
- HTML: http://aspe.hhs.gov/daltcp/reports/1985/asmttran.htm
- PDF: http://aspe.hhs.gov/daltcp/reports/1985/asmttran.pdf

Case Management Forms Set
- HTML: http://aspe.hhs.gov/daltcp/reports/1985/cmforms.htm
- PDF: http://aspe.hhs.gov/daltcp/reports/1985/cmforms.pdf

Case Management Training for Case Managers: A Trainer's Guide
- HTML: http://aspe.hhs.gov/daltcp/reports/1985/cmtrain.htm
- PDF: http://aspe.hhs.gov/daltcp/reports/1985/cmtrain.pdf

Channeling Effects for an Early Sample at 6-Month Follow-up
HTML: http://aspe.hhs.gov/daltcp/reports/1985/6monthes.htm
PDF: http://aspe.hhs.gov/daltcp/reports/1985/6monthes.pdf

Channeling Effects on Formal Community-Based Services and Housing
HTML: http://aspe.hhs.gov/daltcp/reports/1986/commtyes.htm
PDF: http://aspe.hhs.gov/daltcp/reports/1986/commtyes.pdf

Channeling Effects on Hospital, Nursing Home and Other Medical Services
HTML: http://aspe.hhs.gov/daltcp/reports/1986/hospites.htm
PDF: http://aspe.hhs.gov/daltcp/reports/1986/hospites.pdf

Channeling Effects on Informal Care
HTML: http://aspe.hhs.gov/daltcp/reports/1986/informes.htm
PDF: http://aspe.hhs.gov/daltcp/reports/1986/informes.pdf

Channeling Effects on the Quality of Clients' Lives
HTML: http://aspe.hhs.gov/daltcp/reports/1986/qualtyes.htm
PDF: http://aspe.hhs.gov/daltcp/reports/1986/qualtyes.pdf

Clinical Baseline Assessment Instrument Set
HTML: http://aspe.hhs.gov/daltcp/reports/cbainstr.htm
PDF: http://aspe.hhs.gov/daltcp/reports/cbainstr.pdf

Community Services and Long-Term Care: Issues of Negligence and Liability
HTML: http://aspe.hhs.gov/daltcp/reports/negliab.htm
PDF: http://aspe.hhs.gov/daltcp/reports/negliab.pdf

Differential Impacts Among Subgroups of Channeling Enrollees
HTML: http://aspe.hhs.gov/daltcp/reports/1986/enrolles.htm
PDF: http://aspe.hhs.gov/daltcp/reports/1986/enrolles.pdf

Differential Impacts Among Subgroups of Channeling Enrollees Six Months After Randomization
HTML: http://aspe.hhs.gov/daltcp/reports/1984/difimpes.htm
PDF: http://aspe.hhs.gov/daltcp/reports/1984/difimpes.pdf

Examination of the Equivalence of Treatment and Control Groups and the Comparability of Baseline Data
HTML: http://aspe.hhs.gov/daltcp/reports/1984/baslines.htm
PDF: http://aspe.hhs.gov/daltcp/reports/1984/baslines.pdf

Final Report on the Effects of Sample Attrition on Estimates of Channeling's Impacts
Executive Summary: http://aspe.hhs.gov/daltcp/reports/1986/atritnes.htm
HTML: http://aspe.hhs.gov/daltcp/reports/1986/atritn.htm
PDF: http://aspe.hhs.gov/daltcp/reports/1986/atritn.pdf

Informal Care to the Impaired Elderly: Report of the National Long-Term Care Demonstration Survey of Informal Caregivers

HTML: http://aspe.hhs.gov/daltcp/reports/1984/impaires.htm
PDF: http://aspe.hhs.gov/daltcp/reports/1984/impaires.pdf

Informal Services and Supports

HTML: http://aspe.hhs.gov/daltcp/reports/1985/infserv.htm
PDF: http://aspe.hhs.gov/daltcp/reports/1985/infserv.pdf

Initial Research Design of the National Long-Term Care Demonstration

HTML: http://aspe.hhs.gov/daltcp/reports/designes.htm
PDF: http://aspe.hhs.gov/daltcp/reports/designes.pdf

Issues in Developing the Client Assessment Instrument for the National Long-Term Care Channeling Demonstration

HTML: http://aspe.hhs.gov/daltcp/reports/1981/instrues.htm
PDF: http://aspe.hhs.gov/daltcp/reports/1981/instrues.pdf

Methodological Issues in the Evaluation of the National Long-Term Care Demonstration

HTML: http://aspe.hhs.gov/daltcp/reports/1986/methodes.htm
PDF: http://aspe.hhs.gov/daltcp/reports/1986/methodes.pdf

National Long-Term Care Channeling Demonstration: Summary of Demonstration and Reports

HTML: http://aspe.hhs.gov/daltcp/reports/1991/chansum.htm
PDF: http://aspe.hhs.gov/daltcp/reports/1991/chansum.pdf

Screening Training for Screeners: A Trainer's Guide

HTML: http://aspe.hhs.gov/daltcp/reports/1985/scretrai.htm
PDF: http://aspe.hhs.gov/daltcp/reports/1985/scretrai.pdf

Survey Data Collection Design and Procedures

HTML: http://aspe.hhs.gov/daltcp/reports/1986/sydataes.htm
PDF: http://aspe.hhs.gov/daltcp/reports/1986/sydataes.pdf

Tables Comparing Channeling to Other Community Care Demonstrations

HTML: http://aspe.hhs.gov/daltcp/reports/1986/tablees.htm
PDF: http://aspe.hhs.gov/daltcp/reports/1986/tablees.pdf

The Channeling Case Management Manual

HTML: http://aspe.hhs.gov/daltcp/reports/1986/cmmanual.htm
PDF: http://aspe.hhs.gov/daltcp/reports/1986/cmmanual.pdf

The Channeling Financial Control System
HTML: http://aspe.hhs.gov/daltcp/reports/1985/chanfcs.htm
PDF: http://aspe.hhs.gov/daltcp/reports/1985/chanfcs.pdf

The Comparability of Treatment and Control Groups at Randomization
HTML: http://aspe.hhs.gov/daltcp/reports/compares.htm
PDF: http://aspe.hhs.gov/daltcp/reports/compares.pdf

The Effects of Case Management and Community Services on the Impaired Elderly
HTML: http://aspe.hhs.gov/daltcp/reports/1986/casmanes.htm
PDF: http://aspe.hhs.gov/daltcp/reports/1986/casmanes.pdf

The Effects of Sample Attrition on Estimates of Channeling's Impacts for an Early Sample
HTML: http://aspe.hhs.gov/daltcp/reports/1984/earlyes.htm
PDF: http://aspe.hhs.gov/daltcp/reports/1984/earlyes.pdf

The Evaluation of the National Long-Term Care Demonstration: Final Report
Executive Summary: http://aspe.hhs.gov/daltcp/reports/1986/chanes.htm
HTML: http://aspe.hhs.gov/daltcp/reports/1986/chan.htm
PDF: http://aspe.hhs.gov/daltcp/reports/1986/chan.pdf

The Evaluation of the National Long-Term Care Demonstration
Executive Summary: http://aspe.hhs.gov/daltcp/reports/1988/hsres.htm
HTML: http://aspe.hhs.gov/daltcp/reports/1988/hsre.htm
PDF: http://aspe.hhs.gov/daltcp/reports/1988/hsre.pdf

The Planning and Implementation of Channeling: Early Experiences of the National Long-Term Care Demonstration
Executive Summary: http://aspe.hhs.gov/daltcp/reports/1983/implees.htm
HTML: http://aspe.hhs.gov/daltcp/reports/1983/imple.htm
PDF: http://aspe.hhs.gov/daltcp/reports/1983/imple.pdf

The Planning and Operational Experience of the Channeling Projects (2 volumes)
HTML: http://aspe.hhs.gov/daltcp/reports/1986/proceses.htm
PDF: http://aspe.hhs.gov/daltcp/reports/1986/proceses.pdf

DATA COLLECTION INSTRUMENTS

Applicant Screen
HTML: http://aspe.hhs.gov/daltcp/instruments/1981/AppSc.htm
PDF: http://aspe.hhs.gov/daltcp/instruments/1981/AppSc.pdf

Client Contact Log
HTML: http://aspe.hhs.gov/daltcp/instruments/ClConLog.htm
PDF: http://aspe.hhs.gov/daltcp/instruments/ClConLog.pdf

Client Tracking Form
HTML: http://aspe.hhs.gov/daltcp/instruments/1982/ClTracFm.htm
PDF: http://aspe.hhs.gov/daltcp/instruments/1982/ClTracFm.pdf

Clinical Assessment and Research Baseline Instrument: Community Version
HTML: http://aspe.hhs.gov/daltcp/instruments/1982/carbicv.htm
PDF: http://aspe.hhs.gov/daltcp/instruments/1982/carbicv.pdf

Clinical Baseline Assessment Instrument: Community Version
HTML: http://aspe.hhs.gov/daltcp/instruments/1983/cbaicv.htm
PDF: http://aspe.hhs.gov/daltcp/instruments/1983/cbaicv.pdf

Clinical Baseline Assessment Instrument: Institutional Version
HTML: http://aspe.hhs.gov/daltcp/instruments/1983/cbaiiv.htm
PDF: http://aspe.hhs.gov/daltcp/instruments/1983/cbaiiv.pdf

Eighteen Month Followup Instrument
HTML: http://aspe.hhs.gov/daltcp/instruments/18mfi.htm
PDF: http://aspe.hhs.gov/daltcp/instruments/18mfi.pdf

Followup Instrument
HTML: http://aspe.hhs.gov/daltcp/instruments/FolInst.htm
PDF: http://aspe.hhs.gov/daltcp/instruments/FolInst.pdf

Informal Caregiver Followup Instrument
HTML: http://aspe.hhs.gov/daltcp/instruments/ICFolIns.htm
PDF: http://aspe.hhs.gov/daltcp/instruments/ICFolIns.pdf

Informal Caregiver Survey Baseline
HTML: http://aspe.hhs.gov/daltcp/instruments/ICSurvey.htm
PDF: http://aspe.hhs.gov/daltcp/instruments/ICSurvey.pdf

Screening Identification Sheet
HTML: http://aspe.hhs.gov/daltcp/instruments/1982/ScrIDSh.htm
PDF: http://aspe.hhs.gov/daltcp/instruments/1982/ScrIDSh.pdf

Time Sheet

HTML: http://aspe.hhs.gov/daltcp/instruments/TimeSh.htm
PDF: http://aspe.hhs.gov/daltcp/instruments/TimeSh.pdf

Twelve Month Followup Instrument

HTML: http://aspe.hhs.gov/daltcp/instruments/12mfi.htm
PDF: http://aspe.hhs.gov/daltcp/instruments/12mfi.pdf

To obtain a printed copy of this report, send the full report title and your mailing information to:

U.S. Department of Health and Human Services
Office of Disability, Aging and Long-Term Care Policy
Room 424E, H.H. Humphrey Building
200 Independence Avenue, S.W.
Washington, D.C. 20201
FAX: 202-401-7733
Email: webmaster.DALTCP@hhs.gov

RETURN TO:

Office of Disability, Aging and Long-Term Care Policy (DALTCP) Home
[http://aspe.hhs.gov/_/office_specific/daltcp.cfm]

Assistant Secretary for Planning and Evaluation (ASPE) Home
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U.S. Department of Health and Human Services Home
[http://www.hhs.gov]