

A Normative Approach to the Definition of Primary Health Care

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Primary care is the subject of many pronouncements and many recommendations for change in the literature on health care organization and delivery. Heretofore, there has been no attempt to assess the degree of agreement on the meaning of the term. This paper reports on a normative process used to construct 92 statements about important elements of primary care, and to rank these statements according to their relative degrees of importance in primary care. Three panels—nationally recognized “experts” on primary care, consumers, and public health nurses and social workers—participated in the development as well as the ranking of the statements. The rankings of the national experts are discussed in detail, and brief comparisons are made with the rankings of the consumer and public health worker panels. Experts gave a high ranking to the statements concerned directly with medical services and their linkages. All gave attention to equality and patient dignity. Consumers stressed the need to improve access to primary care services. Public health workers emphasized improvement in both access and the quality of the relationship between patients and providers. The overall findings suggest that increasing the base of participation in primary care planning may bring greater attention to patient defined needs, and that broadening of medical care objectives from medical care to a more inclusive health care is not imminent.

Introduction

Primary care is a term used frequently in discussions of medical care. It has been the subject of pronouncements and recommendations calling for changes in health care organization and delivery. Increasingly, attention is being focused on primary care by medical educators and state legislators attempting to enlarge the supply of primary practitioners. However, the definition of the term primary care varies with each spokesperson. There is neither a consensus on priorities nor an agreement on content.

The authors are engaged in a study of the performance of health care organizations delivering primary care. The long-term purpose of this project is to determine what organizational structures would be most effective for the delivery of such care. Because

of the lack of an agreed-upon statement about what primary care is or should be, the first task of the project was to develop a definition of primary care which would represent a wide range of opinion. Although its immediate use was in the design of performance measures specific to the primary care setting, it was hoped that such a definition would lay the groundwork for a more refined operational definition and would also focus more attention on the need to answer other questions such as: How should a primary care service be differentiated from a secondary care service? Who should provide primary care? In what organizational settings?

Prior attempts to define primary health care have sometimes turned to the past to explain what goes on at the primary level—e.g., what the family doctor or general practitioner used to do—or have sometimes tried to define it by exclusion—e.g., every service not provided by a specialist. Other definitions have been more inclusive, approaching the definition by listing the functions primary care must assume. For example:

. . . [P]rimary health care is what most people use most of the time for most of their health problems. Primary care is *majority* care. It describes a range of services adequate for meeting the great majority of daily personal health needs. This majority includes the need for preventive health maintenance and for the evaluation and management on a continuing basis of general discomfort, early complaints, symptoms, problems, and chronic intractable aspects of disease . . . [P]rimary health care describes a locus which should serve the patient as an entry point into a comprehensive health care system . . . [It] should be responsible for assuring continuity of all the care the patient may subsequently need (U.S. Public Health Service, 1970).

[Primary medical care] . . . refers to first-contact care. It is "care" in the sense of "caring about" and "caring for"; it is the care the patient receives when he first approaches the health-services system or formally participates in the process of medical care (White, 1967).

[First-contact care or primary care has the following special features]: 1. There is direct access to the physician or non-physician. 2. The nature of the first-contact care is to assess and manage a mass of unselected and undiagnosed diseases and social problems. 3. The population cared for by the primary physician is usually small (2,000–3,000 persons) and relatively static. 4. The care provided is long-term and continuous, and patient and physician become well known to each other. 5. The diseases and problems en-

countered are those that occur in a small population of 2,000–3,000; there is an inevitable predominance of the common diseases that commonly occur and a scarcity of the rare diseases that rarely happen (Fry, 1973).

Patients in one degree or another need the following when they seek medical attention: 1. Assessment of their total needs before these are categorized by specialty. 2. Elaboration of a plan for meeting those needs in the order of their importance. 3. Determination of who shall meet the defined needs—physicians, general or specialist; nonphysician members of the health team; or social agencies. 4. Follow-up to see that needs are met. 5. All must be done in a continuous, coordinated, and comprehensive manner. 6. Attention at each step must be given to the personal, social, and family dimensions of the patient's problem. 7. Health maintenance and disease prevention are as important as cure and rehabilitation (Committee on Medical Schools . . . , 1968).

[Primary care must]: Serve as the entry, screening, and routing (referral) point for the rest of the *personal health care system* . . . Provide a full range of the basic health care services . . . and provide the services necessary to ensure utilization. Provide the stabilizing human support needed by patients and their families . . . Assume responsibility for the continuing management and coordination of *personal health care* services throughout the entire care process . . . [A primary care system]: serves a small population; is physically close to the community; provides a generalized, holistic response; is easily identifiable and quickly responsive; is able to sort out problems needing referral to the next level of care; is continuous in its attention; coordinates all facets of care; calls for simple approaches; is trusted by the community and its people (Parker, 1974).

Most recently, Alpert and Charney (1973) have summarized primary care's functions as follows:

1. Primary medicine is first-contact medicine . . .
2. Primary medicine assumes longitudinal responsibility for the patient regardless of the presence or absence of disease . . .
3. Primary medicine serves as the "integrationist" for the patient.

While these definitions have much in common, they lack agreement on, or refinement of, the essential ingredients. In this paper we will report on the process and results of developing a consensual definition for primary care.

Research Method

Statement Generation

The first step in developing a normative definition of primary health care was the generation of extensive lists of ideas about its goals and attributes. Several groups were consulted to generate these lists. They were as follows: (1) eight physicians considered by reputation to be experts in primary health care matters;¹ (2) twelve public health social workers and nurses each with an average of five years' work experience in a primary care setting;² and (3) 14 consumers from the San Francisco Bay Area who had been members of health planning boards and health center boards or advisory groups, and 14 consumers who had been active in health programs throughout the southeastern area of the United States. To the extent that this could be feasibly done, the consumers were selected to represent a wide range of age, ethnicity, and socioeconomic status. Both sexes were equally represented in the consumer groups.

Ideas about primary care by these three categories of participants were generated by using the Nominal Group Process, a structured process developed by Delbecq and Van de Ven (1971) which allows for the maximum of creativity in small groups. Briefly, a series of one-day workshops was held in which participant groups were asked the question: "What are the most important goals, responsibilities, tasks and attributes of primary health care systems?"³ Participants were then given approximately 10 minutes to think silently and to write down statements in response to the question. During the next phase, the group members delivered their statements orally, in a round-robin fashion, and the leader wrote

¹This group of physicians has had many years of experience in primary care work—teaching, planning, and research. They were predominantly from northern California. We will refer to this group as an *expert* group. This is merely a convenient descriptive label, however, and use of the term to describe this group does not imply that the other participants in the generation and ranking—public health social workers and nurses and consumers—are not also knowledgeable in certain primary care matters.

²Public health social workers and nurses were included because they so frequently see the failure of health care and its non-utilizers. These social workers and nurses were enrolled in the MPH Program, School of Public Health, University of California, Berkeley.

³This question is representative of the basic question asked of each group. Where necessary, additional direction was given to a group.

them on a board visible to all group members. The procedure continued until each person had exhausted his or her complete list. The group then discussed each statement to be sure that everyone had a clear understanding of its meaning. The combined product of these workshops was a list of 333 statements containing many overlapping or duplicate ideas.⁴

Comparison and Synthesis of Statements

The second step in the process of developing a normative definition was the creation of a single, comprehensive list of ideas about primary health care. Following each workshop, the investigators organized the newly generated statements into categories and removed redundant ideas, global concepts, and the mention of specific procedures. This process of combining and categorizing the workshop statements follows the constant comparative method of qualitative analysis described by Glaser and Strauss (1967).

A final workshop was held with experts at the School of Medicine and Dentistry of the University of Rochester, New York.⁵ At this workshop, the seven participants were given worksheets containing 10–15 exemplary statements for each category. They identified missing concepts and raised points about statements with which they could not agree. Subsequently, the research staff reworked the original categories to incorporate all the comments and suggestions made by this group of primary care experts.

This refinement process produced 92 new statements of varying levels of generality. Some of these refined statements express an overriding or key concept, others express a more specific idea. (See Glossary of Statements in the Appendix.) For example, one general statement says that a primary care organization “assumes ongoing responsibility for individual patient care management and coordination.” A more specific statement, one that deals with only one aspect of patient care coordination, says that a primary care organization “coordinates primary care services with the secondary and tertiary services received by a patient.” Many of the more

⁴The largest number of statements (87) was generated by the *experts*. The two public health nurse and social worker groups generated 33 and 36 statements, and the four consumer groups, 58, 43, 44, and 32.

⁵The Rochester participants were selected because of the important contributions they have made to research and development in primary care.

general statements have a platitudinous ring to them since they tend to express what is commonly valued as good quality in medical care. It was assumed that this characteristic does not make such statements any less real in meaning or make the ideas they express less necessary to primary health care.

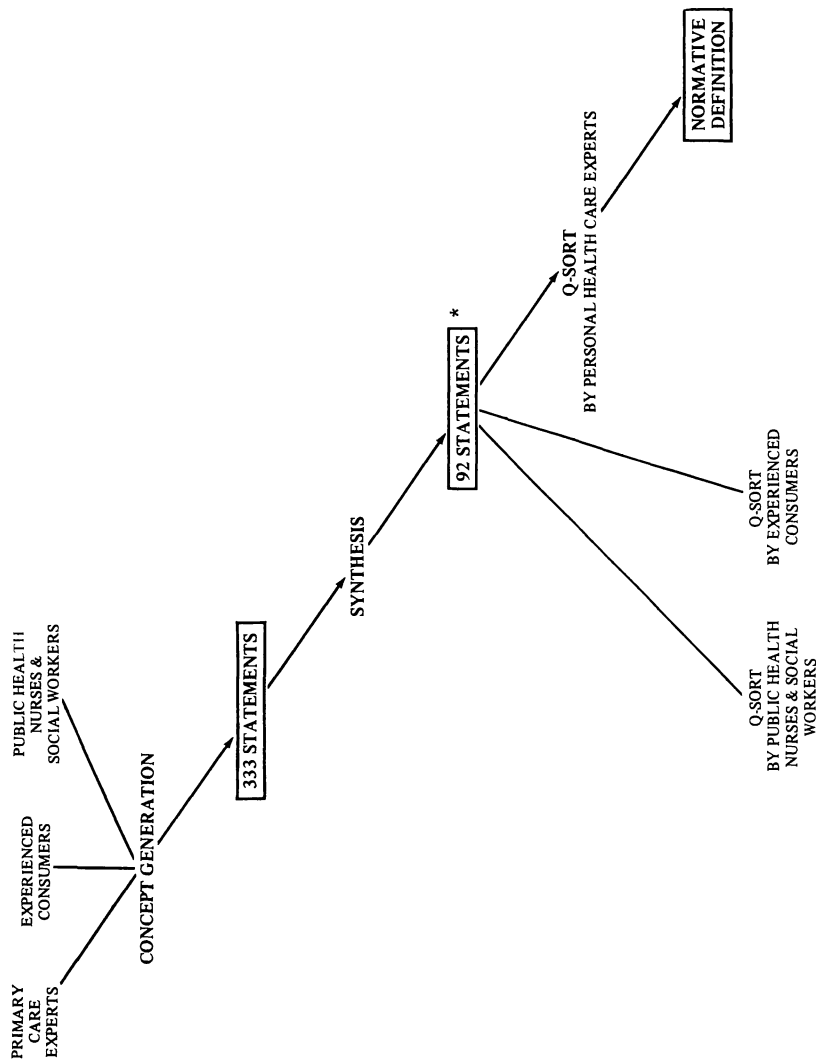
Assignment of Priorities

The third step in constructing a normative definition was the assignment of a priority rating to each of the edited statements. A mailed survey was designed, using the Q-sort method, a standard technique used in attitudinal research (Stephenson, 1953). Each statement was printed on a separate card and sets of 92 cards (in random order) were prepared. Instructions were written, asking respondents to place the statements in five envelopes, each one representing a point along a continuum from *most important* to *least important* "in the functioning of an optimal primary care system." The instructions were to place some statements in each category, but there was also a reminder that each statement had been considered important or it would not have been included. A sixth envelope option was also provided, and respondents could place in the sixth category any statements they considered unimportant or totally inappropriate for primary care organizations.⁶

A panel of 125 health care experts was selected from persons known to be extensively involved in primary health care planning, development, and research.⁷ Following the advice of Starkweather et al. (1975), the expert panel was deliberately chosen for its breadth, balance, and judgment. All of the experts had had many years of experience in health care, and most held academic positions. The largest number (98) were physicians; the remainder were social scientists (16), administrators/researchers (7), and other providers (4). In addition, the survey instrument was sent to the consumers and to the public health workers who had participated in the statement generation workshops. The response rates of the three separate panels are shown by respondent type in Tables 1 and 2. As indicated earlier, the responses of the expert panel are the main focus of the discussion to follow. Figure 1 summarizes the three-step

⁶This option was used very infrequently, by fewer than 10 percent of the respondents.

⁷Here again, the term *expert* is used as a heuristic label, and does not imply that the public health social workers, nurses, and consumers are not also knowledgeable.



*The same Q-Sort was performed by practicing primary care physicians. The results of this study are being reported in a separate publication.

FIG. 1. The Normative Process

TABLE 1

Number of Health Care Experts Surveyed and Number of Responses Received
by Expert Category

<i>Expert Category</i>	<i>Number Surveyed</i>	<i>Non- Responses</i>	<i>Responses</i>
Providers ^a			
Physicians	98	28	70
Nurses	3	0	3
Dentists	1	0	1
Non-providers			
Sociologists	8	1	7
Economists	7	4	3
Other	8	4	4
Total	125	36	89 ^b

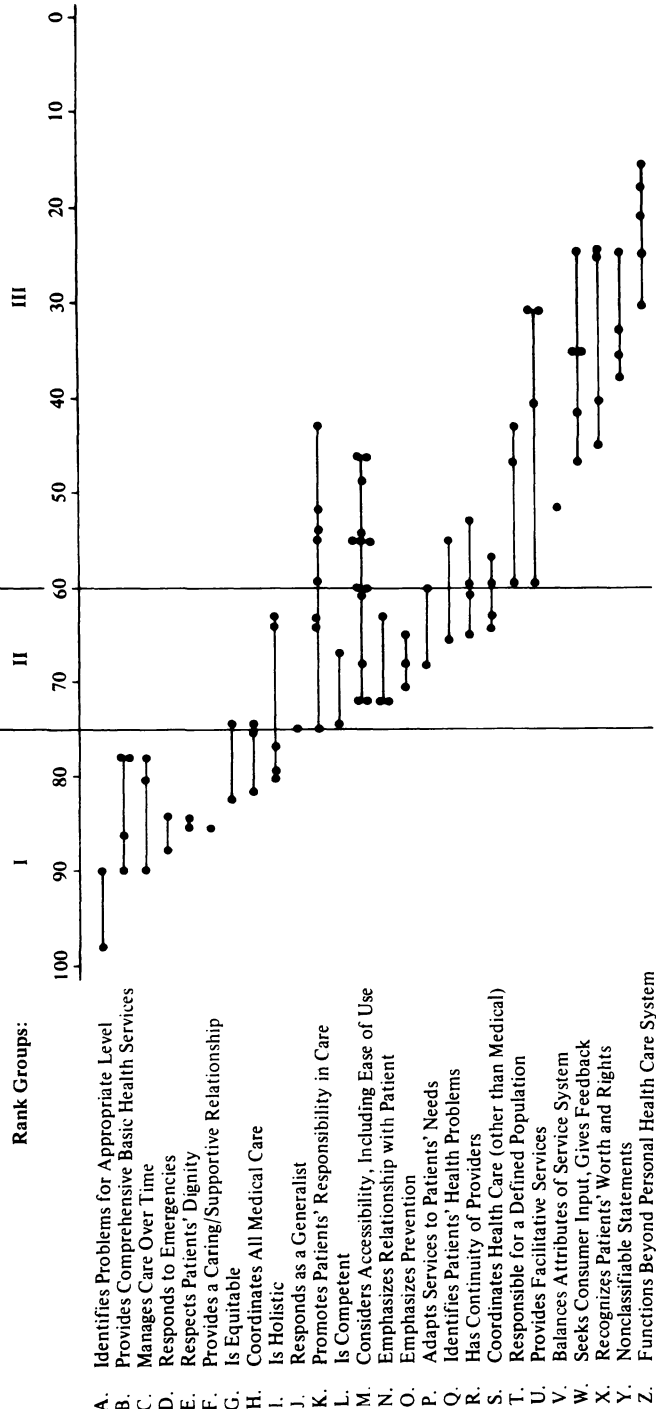
^aIncludes the 14 workshop participants who are provider experts. Of the 14, 13 responded.

^bResponses rate = 71.2%. Two returns were incomplete and four were received after the cut-off date for analysis. The number of experts whose responses were analyzed was 83.

TABLE 2

Number of Workshop Panel Members Surveyed and Number of Responses Received
by Panel Category

<i>Workshop Panel Category</i>	<i>Number of Participants</i>	<i>Non- Responses</i>	<i>Responses</i>
Public Health Nurses and Social Workers	12	0	12
Consumers	28	10	18



NOTE: The Glossary of Statements in the Appendix corresponds with this figure, in which each dot represents a statement.

FIG. 2. Ranking of Primary Care Statement Clusters by Experts

process used to construct a normative definition based on expert opinion.

Results

Using the Q-sort method, the respondents rated each of the 92 statements on a scale of one to five to indicate their judgments of the statement's degree of importance relative to the other 91 statements in the functioning of an optimal primary care system (most important scored 1, least important scored 5). In order to simplify analysis, the ranking scale was dichotomized, and categories 1 and 2 were treated as *high* ranks. All 92 statements were then rank ordered according to the percentage of respondents who placed them in the *high* group. Finally, the statements were grouped according to their content, thereby creating subject clusters. (See Glossary of Statements in the Appendix.)

The findings of the survey are presented in three stages. First, we compare the subject area clusters. Next, these clusters are analyzed in terms of their relationships within larger constellations of logically related ideas about health care. Finally, the rankings provided by the expert panel are compared with those produced by the consumers and by the public health nurses and social workers.

The rank order of subject clusters, based on the judgments of health care experts, is displayed in Fig. 2. The first nine clusters contain the 20 statements ranked *high* by more than 75 percent of the experts. These statements (rank group I) cover the following functions: appropriate sieving between the primary level and other levels of the health care system, providing basic health care services, responding to emergency situations, and managing patient care. Also included in this group of statements are certain attributes of that care: respect for the patient, a caring and supportive relationship with the patient, and a holistic viewpoint in all aspects of care. A summary of the content of these 20 statements is presented in Table 3.

Of the remaining 72 statements, 29 were ranked *high* by at least 60 percent of the experts. These statements (rank group II) may be considered less essential or less critical to the performance of primary health care than the first 20. However, some statements in this group are also more explicit and for this reason may have been judged less important than higher-ranked statements with similar

but more generalized meaning—for example, *Provides time for adequate dialogue to develop between provider and patient* is more specific than *Responds to patients as human beings, not as depersonalized numbers*. Four of these relatively less important statements were included in the first nine clusters and the remaining 21 statements represent an additional 10 clusters: providing a single provider or team, promoting the patient's capacity to be responsible for his/her own health, providing high-quality care, considering the patient's ease in using the system, providing a personalized relationship with the patient, emphasizing prevention, adapting to the special needs and priorities of patients, identifying and assessing individual health needs, assuring stability of providers, and coordinating health care other than medical care.

The last 43 statements were ranked *high* by less than 60 percent of the experts. Nearly half of these low statements (rank group III) are associated with previously mentioned clusters. Six new subjects are introduced by the remainder of the low statements. They are: assuming responsibility for a defined population, adding facilitative services (such as translation and transportation), balancing service-system dilemmas (quality with quantity, efficiency with convenience, etc.), obtaining consumer input and giving feedback to consumers, recognizing patients' worth and rights, and functioning in the community beyond the delivery of personal health services. Several of these categories may be considered controversial. For example, *involvement in community health issues* suggests that primary care providers should step in and take the initiative, when necessary, to meet community health needs including health education. The statements which emphasize the patients' worth and rights may be considered antithetical to the attitudes of many providers because they reflect an egalitarian relationship and even an independent stance of patients vis-à-vis providers. They state that primary care should *demystify medical care* and put *providers and consumers on an equal level*, and should respect *the patient's right to engage in behavior detrimental to his own health*.

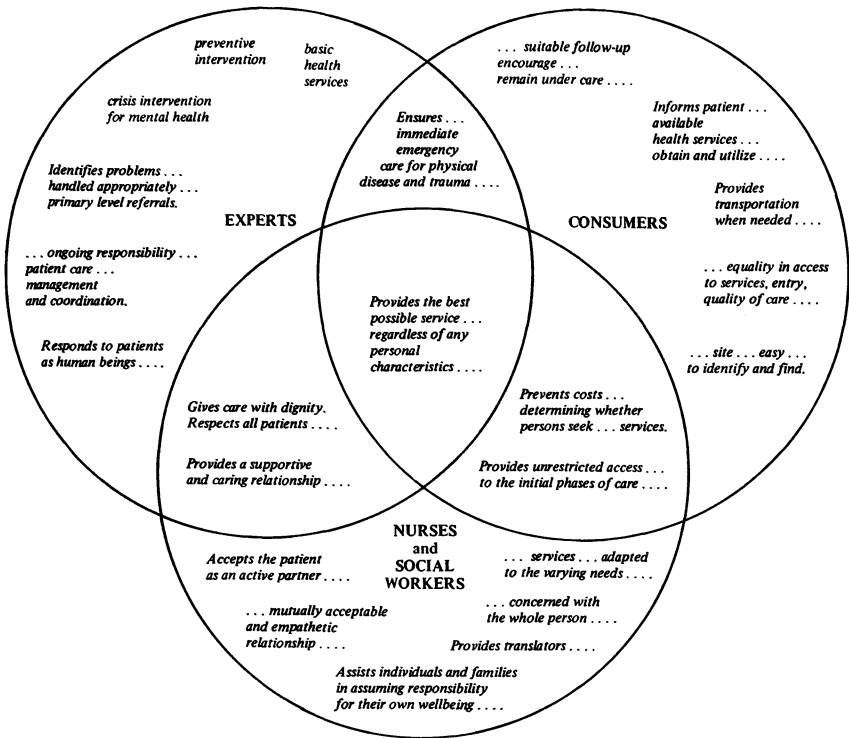
For the second stage of the analysis, certain of the statement clusters depicted in Fig. 2 were further combined to create logical constellations of ideas. The relative differences in the rank of clusters within these constellations are compared to highlight emphases in the experts' opinions. Four of these larger groupings were examined—the delivery of health services, patient care

management and coordination, quality of the patient-provider or patient-system relationship, and consideration for consumer needs. Within the constellation concerned with the delivery of services, basic services and emergency care are ranked higher than the categories prevention and continuing assessment. Within the constellation around the subject of patient care management and coordination, continuity of services is ranked higher than the continuity of interpersonal relationships between providers and patients. Coordination of all medical care ranks higher than the coordination of medical care with other primary health care services such as mental, dental, social, and public health nursing care. In the quality of patient-provider or patient-system relationship constellation, a personalized relationship—e.g., time for dialogue, trustworthiness, acceptance, and empathy—is ranked lower than respect for the patient's dignity or provision of a caring and supportive relationship. Within the constellation concerned with consideration for consumer needs in structuring a health care delivery system, giving consideration to the patient's ease of using the system and adapting the system to patient needs are both ranked higher than adding facilitating services to overcome access barriers or obtaining input from or giving feedback to consumers.

Finally, the expert rankings were compared with those of the consumers and public health nurses and social workers who responded to this survey.⁸ As could be expected, there were differences of opinion. A comparison of their respective *highest*-ranked statements gives some indication of the nature of these differences. Figure 3 shows the minimal overlap in their top 10 statements.⁹ The only statement in the top for all three respondent groups calls for equality in the delivery of services. The consumers agreed with the experts that immediate emergency care is a most important function

⁸We purposely do not emphasize this comparison in our analysis because of the small numbers in the consumer and public health worker groups. Plans are under way to enlarge these sample groups, and thus to allow more conclusive comparisons to be made.

⁹The small number of respondents in the consumer ($N = 18$) and the public health ($N = 12$) groups resulted in many statements having the same percentage of responses in the high category (i.e., tied ranks). Therefore, an exact cut-off between the top 10 statements and all others was not possible and the closest breaking point was chosen. For the consumer responses, the break was at nine statements; for the public health nurses and social workers, it was 11.



*More than 82 percent of the Experts, more than 75 percent of the Consumers, and more than 75 percent of the Public Health Nurses and Social Workers ranked these statements high.

FIG. 3. Statements Ranked Highest by Experts, Consumers, and Public Health Nurses/Social Workers*

of primary care. The public health nurses and social workers agreed with the experts as to the importance of dignity and a supportive and caring relationship. The public health nurses and social workers agreed with the consumers as to the importance of access, placing both financial and 24-hour access at the top, while the experts did not even include these statements in their top 20.

All of the statements ranked *high* by the consumers stress access and equality issues, either directly or indirectly. They did not rank *high* any statements describing patient care management or coordination. In fact, less than 40 percent of the consumers ranked such statements *high* as compared to more than 60 percent of the ex-

perts. Top rankings were not given to any statements suggesting changes in the system or changes in the relationship of consumers and providers. The statements ranked lowest of all by the consumers had to do with *ensuring accountability to consumers*, *improving community health in ways other than through the delivery of personal health care*, and *respecting the patient's right to engage in behavior detrimental to his own health as long as it is independent of the health of others*. All of the statements denoting consumer participation in health care were ranked *high* by less than 50 percent of the consumers.

The public health social workers and nurses, as noted previously, are also somewhat more concerned with access than the experts are, but place overriding emphasis on the nature of the patient-provider or patient-system relationship (particularly its affective components), the responsiveness of the system to the differences in human beings, and on providing all persons with the best possible care regardless of personal characteristics. They are the only group of respondents who are highly concerned with statements that suggest change in the system, particularly the patient's own role in care—e.g., *patient as partner* was ranked *high* by 92 percent compared with only 33 percent of the consumers and 75 percent of the experts, and *assists individuals and families in assuming responsibility for their own well-being* was ranked *high* by 83 percent of the public health workers, 39 percent of the consumers and 63 percent of the experts. They were also more concerned with consumer participation, ranking all such statements higher than did the experts or the consumers. The public health nurses and social workers, however, joined the experts and consumers in not placing a high rank on statements suggesting that primary care enlarge its role beyond personal health care.

Conclusion

The following definition has been created from the statements ranked highest by the experts:

Primary care provides basic services, including those of an emergency nature, in a holistic fashion. It provides continuing management and coordination of all medical care services with appropriate retention and referral to other levels. It places emphasis, when feasible, on the preventive end of the preventive-curative spectrum of health care. Its

TABLE 3

Summary of the Content of Statements Ranked High by at Least 75 Percent of the Expert Respondents^a

Primary Health Care:

- Serves as the place where patient problems are identified and, where appropriate, are retained for care; does not refer unnecessarily to a more complex level of care.
 - Provides basic health services for minor, acute, and chronic health problems throughout the entire process of care and provides preventive interventions whenever possible, including working to retard the progression of disease and disability.
 - Assumes ongoing responsibility for individual patient care and the management of this care by coordinating primary care services with secondary and tertiary levels, encouraging follow-up, and ensuring that critical information about the patient is recorded and easily retrieved.
 - Ensures that immediate emergency care is available for physical disease and trauma and crises arising out of mental health problems.
 - Provides a supportive and caring relationship as an integral part of the treatment process.
 - Responds to patients in a personal way, with dignity and respect.
 - Is equitable in the distribution of care, its quality, and the way patients are treated (as persons).
 - Is holistic in its focus, taking into account the broad array of causative factors and the patient's total life situation.
-

^aArranged from most frequently rated high to least frequently rated high.

services are provided equitably in a dignified, personalized, and caring manner.

The similarity of this definition to those quoted earlier in this paper indicates that previous definitions of primary care have general acceptance. When asked to set priorities, the experts emphasize improvements to the delivery of medical care. The greatest number of experts gave a high ranking to the statements concerned directly with medical services and their linkages. Lower rankings were given, without exception, to statements related to increasing the patients' capacities to assume responsibility for their own care, to access or convenience issues, and to the linkages between medical care and other health care components. Placed lowest of all were the statements suggesting that primary care might venture beyond delivering care to individuals—e.g., developing services presently unavailable in the community, changing hazardous community health conditions, and providing community educational programs.

Consumers and public health workers agree with the experts

about the overall medical role of primary care; all three groups placed in the lowest categories the statements that would shift this fundamental focus. However, the three respondent groups disagreed about the aspects of primary care that should receive emphasis. Consumers stressed the need to improve access while the public health workers stressed improvement both in access and the quality of patient-provider relationships. The differences in ranking observed among the three respondent groups suggest that findings from a normative approach will vary, depending on the breadth of individuals and groups surveyed.

If the priorities set by the three respondent groups are any indication of where priorities on the use of limited health care resources will be set in the future, our findings suggest two important points: (1) that broadening the base of participation in primary care planning may bring about greater attention to patient-defined needs; and (2) that basic changes in primary care objectives, broadening them from medical care to a more inclusive health care, are not imminent.

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APPENDIX

Glossary of Statements, including comparative
importance rankings by experts, consumers, and
public health nurses and social workers

	% Ranking Statements High		
	Experts	Consumers	Nurses/ Social Workers
A. Identifies Problems for Appropriate Level			
Identifies problems that cannot be handled appropriately at the primary level and makes appropriate referrals.	98	50	58
Identifies problems that can be handled appropriately at the primary level, avoiding unnecessary referral.	90	61	58
B. Provides Comprehensive Basic Health Services			
Provides preventive intervention for those diseases which can be prevented.	90	72	75
Provides basic health services for minor/acute illnesses and for chronic health problems, whether physical or emotional.	87	61	58
Works to retard disability and progression of disease.	78	61	67
Functions throughout the entire process of care—entry, maintenance, referral, and exit.	78	39	50
C. Manages Care over Time			
Assumes ongoing responsibility for individual patient care and patient care management and coordination.	90	33	58
Ensures that critical information relevant to ongoing patient care is recorded and easily retrievable.	81	50	50
Assists with suitable follow-up procedures to encourage patients to remain under care when continuing care is indicated.	78	78	67
D. Responds to Emergencies			
Ensures that immediate emergency care for physical disease and trauma is available for patients served.	88	78	67
Provides crisis intervention for mental health problems.	84	44	67
E. Respects Patients' Dignity			
Responds to patients as human beings, not as depersonalized numbers.	86	56	75

	% Ranking Statements High		
	Experts	Consumers	Nurses/ Social Workers
Gives care with dignity. Respects all patients including those on welfare and those with alternative lifestyles.	84	72	92
F. Provides a Caring/Supportive Relationship			
Provides a supportive and caring relationship as an integral part of the treatment process, especially in times of emotional or physical crises.	86	50	92
G. Is Equitable			
Provides the best possible service to those needing care regardless of any personal characteristics (e.g., race, sex, socioeconomic position).	83	78	100
Provides equality in access to services, entry, and in the quality of care received for all patients served.	74	78	75
H. Coordinates All Medical Care			
Coordinates primary care services with the secondary and tertiary services received by patient.	82	39	58
Does not limit health care to disease care; ties together preventive and curative care.	76	67	50
Functions as the one place where all the strands of health care being received by an individual/family can be tied together.	74	39	67
I. Is Holistic			
Focuses on causes (physical, social, environmental, or psychological), as well as on symptoms when prescribing care.	81	61	58
Is concerned with the whole person and all his health problems in the context of the total life situation—his family, community, social setting, and past history.	80	67	92
Identifies underlying problems (psychological or social) that surface as physical complaints.	77	44	58
Maintains continuous "contract" (formal or informal) for health care with patient and/or family, independent of the presence or absence of disease.	64	33	42
Works with the family of the patient under care, when necessary.	63	44	58

	% Ranking Statements High		
	Experts	Consumers	Nurses/ Social Workers
J. Responds as a Generalist			
Ensures that a single provider or team is capable of a generalist response to the patients health problems.	75	39	33
K. Promotes Patients' Responsibility in Care			
Accepts the patient as an active partner in developing a treatment plan.	75	33	92
Informs patient about available health services and how to obtain and utilize them appropriately.	64	83	67
Assists individuals and families in assuming responsibility for their own well-being, encouraging self-monitoring of health status and appropriate self-care.	63	39	83
Educates patients about health problems, their causes, and their solutions (e.g., consequences of certain behavior and of environmental factors).	59	50	58
Assists the patient in using his own personal and emotional resources to develop a positive mental attitude no matter what his physical condition.	55	44	58
Makes each episode of illness or crisis (physical or emotional) a learning experience so patient can prevent reoccurrence or can better respond to next episode.	54	28	58
Promotes the well-being of patients served and their ability to cope with health problems.	52	50	58
Educates patients to value their own health.	43	39	67
L. Is Competent			
Provides the highest quality of technical care that is practical.	74	67	67
Evaluates its delivery of services (e.g., on their technical quality, acceptability to patients and providers, and efficiency).	67	39	50
M. Considers Accessibility, Including Ease of Use			
Organizes services in such a way that they are easy for the patient to use.	72	72	58
Provides unrestricted access (24 hours/day, 7 days/week) to the initial phases of care, i.e., entry, assessment, determination of need, and referral.	72	78	83

	% Ranking Statements High		
	<i>Experts</i>	<i>Consumers</i>	<i>Nurses/ Social Workers</i>
Prevents costs from being the factor determining whether persons seek needed services.	68	89	83
Takes consumer convenience into consideration in determining the hours services are available.	61	67	58
Provides as many primary care services as possible under one roof.	60	67	67
Provides a service site which is easy to identify and find.	60	78	50
Ensures that distance to entry points and basic services does not block access for patients.	55	61	42
Provides services in settings which are comfortable and make patients feel at ease.	55	61	33
Provides home care services for those with conditions which confine them to their homes.	55	72	75
Recognizes that patients' time is valuable and uses it efficiently.	54	50	50
Provides services which the consumer perceives as helpful, safe, and appropriate.	49	22	58
Does not allow waiting time for obtaining appointments to interfere with utilization.	46	39	50
Does not allow waiting time in the health care facility to block utilization.	46	44	42
N. Emphasizes Relationship with Patient			
Provides a trustworthy health delivery system and works to build the trust and confidence of patients in the care they are receiving.	72	56	75
Provides time for adequate dialogue to develop between provider and patient.	72	50	58
Develops a mutually acceptable and empathetic relationship between consumers and providers.	63	33	83
O. Emphasizes Prevention			
Emphasizes preventive measures at every stage of care.	71	56	50
Functions at every level of prevention: health promotion, specific disease prevention, early screening and diagnosis, treatment, and rehabilitation.	68	72	75
Emphasizes keeping people well rather than curing people.	65	67	75

	% Ranking Statements High		
	Experts	Consumers	Nurses/ Social Workers
P. Adapts Services to Patients' Needs			
Provides services that are adapted to the individual's needs and to his particular priorities.	69	44	67
Provides services which are adapted to the varying needs associated with different socioeconomic and ethnic groups and consumers' lifestyles.	60	61	83
Q. Identifies Patients' Health Problems			
Identifies, on an ongoing basis, the patient's health problems, personal health goals, and priorities.	66	44	50
Provides health screening services, on entry as well as periodically, especially for those at special risk.	55	56	58
R. Has Continuity of Providers			
Provides stability of personal relationship between provider(s) and patient.	65	33	33
Keeps at a practical minimum the number of providers a patient sees so that the patient's receipt of services is not fragmented.	61	56	33
Provides a continuing relationship with an individual while he is at the secondary and tertiary level of care.	59	61	33
Assigns the overall coordination of a patient's care to one provider.	53	33	17
S. Coordinates Health Care (Other than Medical)			
Coordinates primary care services with services received from other community service system (e.g., visiting nurse, public health nurse, schools, welfare).	64	50	58
Serves as advocate for patient throughout the entire health care system (beyond primary care) as well as with other related institutions.	63	50	75
Incorporates medical, dental, mental health, and social services into the care provided.	59	50	58
Coordinates all primary care services, i.e., visiting nurse, public health nurse, schools, welfare, etc.	57	44	50

	% Ranking Statements High		
	Experts	Consumers	Nurses/ Social Workers
T. Responsible for a Defined Population			
Assumes responsibility for a defined population (geographic or enrolled). Such responsibility extends to the well and ill, utilizers and non-utilizers.	59	28	50
Is concerned with the consumer before he enters the system—reaching out to assist those not receiving services.	47	50	58
Carries out surveillance on the health status, health needs, and health priorities of the population served.	43	28	25
U. Provides Facilitative Services			
Provides translators when needed by patients.	59	28	83
Provides transportation when needed (e.g., for those with no way to get to care, or for the elderly for whom it poses a burden).	41	78	58
Provides baby-sitting when needed, ie., when the care of children is a barrier to access.	31	39	50
Provides services at a site which is most appropriate to the nature of the problem (e.g., family counseling in home, education in school).	31	39	42
V. Balances Attributes of Service System			
Balances health care services (e.g., quality versus quantity, efficiency versus patient convenience, general needs versus needs of special groups).	52	28	42
W. Seeks Consumer Input, Gives Feedback			
Provides an easily recognized and acceptable method for acting on consumer complaints.	47	28	42
Obtains consumer input in planning, policy development, and decision making.	42	44	75
Ensures accountability to consumers by providing systematic methods of feedback to those served.	35	17	58
Provides the opportunity for those served to assume increased responsibility for their health services (e.g., by involvement in planning and policy making).	35	44	67
Allows the people served to define access and acceptability.	24	22	58

	% Ranking Statements High		
	<i>Experts</i>	<i>Consumers</i>	<i>Nurses/ Social Workers</i>
X. Recognizes Patients' Worth and Rights			
Minimizes the placing of patients in a dependent position.	45	33	50
Discourages the attachment of stigma to certain conditions and their treatments.	40	22	42
Demystifies medical care and puts providers and consumers on an equal level.	25	33	50
Respects the patient's right to engage in behavior detrimental to his own health, as long as it is independent of the health of others.	24	17	42
Y. Nonclassifiable Statements			
Responds to provider's needs, attitudes, and ethical beliefs.	38	33	50
Ensures that type and number of services provided are based on patient's need for care rather than on consumer demands.	36	50	33
Provides consumers with a choice among providers.	33	39	33
Provides controls to avoid unnecessary utilization of services.	24	39	8
Z. Functions Beyond Personal Health Care System			
Develops services for special needs of the group(s) served (e.g., adolescent care, alcoholism services).	31	28	58
Takes responsibility in the community for the mobilization of needed and unavailable personal health care services (other than the services which primary care is providing).	24	39	33
Provides leadership in the community for health-related issues; makes recommendations to groups having influence over environmental, economic, and political factors that may contribute to poor physical and mental health.	21	44	42
Intervenes when necessary to improve the community's health in ways other than the delivery of personal health care (e.g., housing, water, waste disposal).	18	17	42
Provides educational services for the community in order to create an awareness of health, health needs, and health services.	16	39	50

An Epidemiology of Disability among Adults in the United States

SAAD Z. NAGI

This paper presents the findings of an epidemiological analysis of disability among adults in the noninstitutionalized continental United States population. Data were collected through interviews with a probability sample of persons 18 and over, yielding 6,493 completed schedules comprising 80.3 percent of the sample. Distinctions were made among concepts and indicators of pathology, impairment, individual performance, and social performance. Central to the analysis were two dimensions of individual performance (physical and emotional) and two dimensions of disability in social performance (work and independent living). A number of socio-demographic characteristics were included in the analysis.

The results show the relative contributions of pathology and impairment to performance on the individual level, and the relative contributions of all of these factors on social performance, that is, the two dimensions of disability. Through pathology, impairment, performance at the individual level, and the socio-demographic characteristics, it was possible to account for 38 percent of the variance in work disability and 74 percent of dependence-independence in community living. Further explanations are given for variance in work disability. Estimates of the size of populations reporting varying types and severities of disability are also presented.

The Problem

Despite its significance as a health and social problem, it is only recently that disability has attracted attention as an object of epidemiological analysis (Berkowitz and Johnson, 1970; U.S. Department of Health, Education, and Welfare, 1970). This might be attributable, at least in part, to the preoccupation of epidemiologists with the various forms of pathology and impairment, the conceptual confusion that surrounded disability and related terms, and problems in the reliability and validity of available measures. Increasing attention to the problem over the last decade has contributed greatly to the clarification of concepts and measures. Conceptual distinctions were outlined among pathology, impairment, limitations in the performance of the human organism, and disability in performing social roles and activities (Nagi, 1965;

Haber, 1967; Burk, 1967). In addition to the inclusion of disability measures in the National Health Surveys (NHS) administered periodically by the National Center for Health Statistics (1973), questions seeking information about work disability were incorporated in the 1970 Census of the United States (U.S. Bureau of the Census, 1972). National surveys of disability were also conducted by the Social Security Administration (SSA) employing detailed measures (Haber, 1967).

Important as these developments are, many important gaps remain evident in epidemiological knowledge about disability. For example, the thrust of the SSA survey and the items included in the 1970 census were on work disability. Therefore, the populations covered were limited to persons between 18 and 64 who constitute the great majority of the labor force. The census included no questions concerning pathology impairment, or limitations in organismic performance. In the SSA survey, which employed far more developed instruments for identifying these entities, the full range of information was sought only for persons for whom indicators of work disability were reported in a screening phase. The data yielded do not allow for comparisons between vocationally disabled and nondisabled sectors of the population.

The National Health Surveys collect information about pathology and impairment and are not restricted to specific age categories. However, they do not ask questions about performance of the organism nor do they ask about work disability among housewives who are out of the labor force. Finally, available literature shows no significant attempts toward constructing multivariate schemes for explaining variance in rates of disability.

This analysis is addressed to some of these gaps in current knowledge about the epidemiological patterns of disability. The specific objectives are: (1) to further the development of measures of disability and related factors; (2) to identify prevalence rates and distributions of two dimensions of disability—in work and in community living; (3) to compare these rates with others obtained in national surveys; and (4) to construct and test an explanatory scheme for variance in the occurrence of disability. Generally, the presentation of material will follow the order of these objectives.

Concepts and Measures

As has already been mentioned, distinctions among pathology, im-

pairment, limitations in the functioning or performance of the human organism, and disability have become more widely accepted. Central in this report are the latter two concepts—performance at the individual level, and disability in social performance. Although overlapping in some respects, three dimensions of performance are conceptually and analytically separable: physical, emotional, and mental. Physical performance refers to sensory-motor functioning of the organism as indicated by limitations in such activities as walking, climbing, bending, reaching, hearing, etc. Emotional performance refers to a person's effectiveness in psychological coping with life stress and can be manifested through levels of anxiety, restlessness, and a variety of psychophysiological symptoms. Mental performance denotes the intellectual and reasoning capabilities of individuals which have been most commonly measured through problem-solving tests such as the I.Q. An important point to be made in connection with these three dimensions of performance is that their indicators can be found in the characteristics of the human organism itself. Disability, on the other hand, is used here to mean inability or limitations in performing social roles and activities such as in relation to work, family, or to independent living. In contrast to organismic performance, indicators of disability can be found in both the characteristics of individuals and in the requirements of the social roles in question. In this sense, the same types and degrees of limitations in the performance of the organism can lead to varying dimensions and degrees of disability. While paralysis affecting the upper limbs, and therefore the function of reaching and use of hands and fingers, may become disabling to a surgeon, the same physical limitations may not influence a teacher in performing his role. Furthermore, it should be noted that disability in a given role does not necessarily mean disability in another. Not all people with work disability require assisted living, nor is it the case that all persons who need such assistance are also vocationally disabled. The material in this paper is organized around two dimension of organismic performance (physical and emotional) and two dimensions of disability (work and independent living). Indications of pathology and impairment were also sought in the study and will be included in the analysis.

Two Dimensions of Individual Performance

The scope of the survey did not allow for administering meaningful

TABLE 1
Responses to Items Comprising Physical Performance and Emotional Performance Scales
and Their Loading Values in Factor Analysis

ITEM	DEGREE OF DIFFICULTY						TOTAL SAMPLE ^a	SCALE FACTOR LOADINGS	
	None		Some		Great			Physical Performance	Emotional Performance
	N	%	N	%	N	%			
Difficulty standing for long periods	4,199	64.7	1,735	26.7	558	8.6	6,492	0.70	0.39
Difficulty lifting or carrying weights of approximately ten pounds	5,199	80.1	891	13.7	402	6.2	6,492	0.64	0.36
Difficulty going up and down stairs	5,105	78.6	1,001	15.4	385	5.9	6,491	0.79	0.37
Difficulty walking	5,495	84.6	748	11.5	249	3.8	6,492	0.77	0.32
Difficulty stooping, bending, or kneeling	4,771	73.5	1,282	19.7	439	6.8	6,492	0.72	0.35
Difficulty using hands and fingers	5,816	89.6	527	8.1	148	2.3	6,491	0.48	0.27
Difficulty reaching with either/or both arms	5,854	90.2	460	7.1	177	2.7	6,491	0.55	0.29
Nervousness, tension, anxiety, and depression	2,975	45.8	2,857	40.0	658	10.1	6,490	0.36	0.76
Trouble getting to sleep and staying asleep	3,929	60.5	1,968	30.3	592	9.1	6,489	0.34	0.52
Troubled with hands sweating and feeling damp and clammy	4,777	73.8	780	12.1	915	14.1	6,472	0.20	0.40
Heart beating hard even when not exercising or working hard	4,489	69.3	726	11.2	1,267	19.5	6,482	0.45	0.53
Pains, aches, or swelling in parts of the body	4,227	65.1	1,627	25.1	635	9.8	6,489	0.52	0.42
Weakness, tiring easily, no energy	3,411	52.6	2,339	36.0	740	11.4	6,490	0.59	0.61
Fainting spells, dizziness, sick feelings	5,397	83.2	947	14.6	146	2.2	6,490	0.46	0.47
Shortness of breath, trouble breathing even when not exercising or working hard	5,220	80.4	945	14.6	325	5.0	6,490	0.50	0.46

^aTotals do not add up to the 6,493 interviews completed because of non-response to certain items.

tests to measure intellectual functioning. Although questionable in some respects, education will be considered as the best available indicator for this dimension of performance. Measures for physical and emotional performance employed in this survey were in the form of 15 questions for which answers constituted a four-point scale (see items in Table 1). The first seven items addressed physical performance (adapted from Nagi, 1969), the following three (used in Srole et al., 1962; Gurin et al., 1960) addressed psychophysiological reactions as indicators of emotional performance, and the last four items (from Haber, 1967) related to generalized symptoms which were believed to be manifestations of either/or both physical and emotional limitations.

A factor analysis was computed to identify the underlying dimensions and the loading values of the various items.¹ The computation yielded two factors which are labeled "Physical Performance Scale" (PPS) and "Emotional Performance Scale" (EPS). The loading values of the 15 items in relation to the two factors (Table 1) followed the expected pattern: the first seven loaded highly on Physical Performance, the following three loaded highly on Emotional Performance, and each of the last five loaded almost equally on both factors.²

Two Dimensions of Disability

This study focused on disabilities in two of the most significant spheres of social roles and activities—work and independent living. To consider work disability first, an index measuring this dimension was based on the actual work history of respondents and reported difficulties in meeting the requirements of their roles in current and previous jobs. The Work Disability Index (WDI) was constructed

¹The technique used in factor analysis was an "Oblimin Oblique Rotation" as specified in Nie et al. (1970). This type of rotation was used because of an assumed association between physical and emotional performance. The value of delta used in this analysis was equal to zero.

²All items were used in computing each of the two factors. Scores on each item were standardized and then weighted through multiplication by the corresponding factor coefficients. The standardized weighted scores were further adjusted by adding a constant in order to eliminate negative values. Using a delta value equaling zero, the correlation obtained between the two factors for the total sample was $r = .60$. Scores for respondents on the resulting two scales ranged from zero to 7.49.

only for persons between ages 18 and 64. It comprised three levels:

No Work Disability: Persons who are working regularly in jobs (36 hours or more), housekeeping, or school work, and reported no limitations in current or previous work.

Limited in Work Roles and Activities: Persons who are working regularly in jobs, housekeeping, or in school, but reported difficulties in performing their current work or a change in jobs because of disability.

Vocationally Disabled: Persons who are out of the labor market because of being disabled; are below 65 and have retired or left their last employment because of disability; or who cannot perform housekeeping or school work. This category includes a small number of persons who, because of health problems, were working on a limited part-time basis.

The second index measures limitations in independent living and was based on a series of questions addressing "the need for help in looking after personal needs such as dressing, bathing, eating, and other daily activities"; "the need for help in going outside the residence"; and "the need for help in shopping and household chores." This Independent Living Index (ILI) was constructed for all persons in the sample (18 and over) who were grouped into four categories:³

No Limitations: Persons who reported no significant difficulty in walking, going up or down stairs, stooping, bending or kneeling, handling and fingering, reaching, and who were neither blind nor deaf.

Limited but Independent: Persons who reported significant difficulty in walking, using stairs, stooping, bending or kneeling, handling or fingering, reaching, or who were blind or deaf, but who require no assistance in community living.

Needing Assistance in Mobility: Persons requiring assistance in

³Distinctions between the first two categories of this index (No Limitations and Limited, but Independent) are based on responses to items used in constructing the physical and emotional performance scales. We believe it is useful to distinguish people falling within these categories. However, the two categories are combined in the analysis of relations between the Independent Living Index and the two scales of organismic performance. This assures the independence of the concepts and their indicators, and avoids spuriousness in their relations.

mobility outside the home or residence; they were also persons who needed assistance in housekeeping, work, and shopping.

Needing Assistance in Personal Care: Persons requiring assistance in activities of daily living such as clothing, feeding, and personal hygiene.

Pathology and Impairment

Briefly defined, pathology is viewed as a condition of mobilization of the organism's defenses in the event of disease and injuries (Selye, 1956), impairment as an anatomical, physiological, intellectual, or emotional abnormality or loss (Nagi, 1965). An impairment may not be associated with active pathology such as in the case of healed amputations and residual paralyses, or may be associated with pathology as in hypertension and diabetes. The interview schedules used in this survey included items seeking two types of data from which inferences can be made regarding the existence and seriousness of pathology and impairment. The first type of data is in the form of responses to the question: "In general, how would you judge your health to be now? Would you say it is excellent, good, fair, poor or very poor?" The second set of data identifies the health conditions which underlie each of the specific limitations constituting the physical performance and the emotional performance scales.⁴ In the absence of better analytical ways for evaluating the severity of individual and combinations of conditions, the sheer number of conditions mentioned will be used as a rough measure of severity. No clinical examinations were performed in connection with this survey; information concerning pathology and impairment is limited by the knowledge and recall of respondents.

Sampling Design and Data Collection

Data to be reported here were derived from a larger survey of disability and the interaction between organizations engaged in the delivery of human services and related sectors of the population.

The "health status" question was used in a variety of surveys including that of the SSA referred to frequently here. The question about "the underlying health conditions" was used by the National Health Survey.

The survey was conducted in 1972 and included 8,090 households constituting a probability sample of the continental United States, excluding Alaska (see Kish and Hess, 1969). One person (18 or over) in each household was selected at random for personal interviews. The survey yielded 6,493 (80.3 percent) completed interviews; 92 percent of the respondents were either household heads or their spouses. Compared to persons 18 and over reported in the 1970 U.S. Census, this sample includes 5.5 percent more females, 6 percent fewer white males, 5.7 percent fewer single persons, and 2 percent more persons 65 and older. Reasons for the 19.7 percent non-completed interviews were: refusals by designated respondents or on their behalf (11.2 percent), no contacts made with any members of the household (2.8 percent), selected respondents unavailable (2.8 percent), and other miscellaneous reasons (2.9 percent). Data were collected through personal interviews conducted by well-trained interviewers on the field staff of the University of Michigan's Survey Research Center. Table 2 presents the demographic composition of respondents.

Physical and Emotional Performance

Three approaches suggest themselves in creating categories out of continua such as those represented by the sample scores on the Physical Performance and the Emotional Performance Scales. The problem is one of selecting appropriate points for defining the categories. One way to establish these points is to divide the scale into equal intervals. Thus, for example, to create four categories of Physical Performance or Emotional Performance, the full *range of scores* on each scale would be divided in four equal intervals. Another way of categorization is through dividing the *sample* into four equal groups regardless of the points on the scale that define these groupings. While the first approach creates equal scale intervals, the second results in equal categories of people; both represent arbitrarily created classes. A third approach was used in this analysis. Histograms representing the distributions of sample scores were examined in order to identify forms of clustering and therefore the natural points of differentiation among categories. The objective was to arrive at more conceptually meaningful classifications by "carving at the joints" to use Kaplan's (1964) metaphor. Because of

the association between the two scales ($r = .60$), points of differentiation on them were similar. Minor adjustments were made by bringing these points to scores representing the closest round figures. Four categories resulted from this approach to classification; they were labeled and defined as follows:

None or Minimal Limitations.....	Scores 0 to 1.99
Some Limitations	Scores 2 to 2.99
Substantial Limitations	Scores 3 to 3.99
Severe Limitations	Scores 4 to 7.49

Table 2 presents the distributions of limitations in *physical* performance in relation to a number of socio-demographic characteristics. Substantial and severe limitations were reported by 9.7 percent of the respondents. The distributions show differentials for age and education; and to a lesser extent for marital status, racial background, and sex. To be noted are the particularly high rates of "substantial" and "severe" physical limitations among persons 75 and over, and the relatively high concentration of these severer limitations among persons with low formal education and widowed respondents. The higher rates of severer limitations among the latter two categories are in part a function of age—proportionately, more of the widowed respondents and persons with lower education are in the older age brackets. It is also important to note the association between income levels and limitations in physical performance. Underlying this relationship is "work disability" which, as will become evident later, is significantly associated with limitations in physical performance while it contributes greatly to reduction in income (Haber, 1967; Gurin et al., 1960; Nagi, 1969). Finally, the data presented in Table 2 show the strong influence of pathology and impairment, as indicated by the number of health conditions and the evaluations of health status, upon the respondents' levels of physical performance.

In order to assess the combined effects of the various independent variables discussed above, and the amount of variance in physical performance attributable to their collective influence, a regression coefficient was computed. Scores on the Physical Performance Scale constituted the dependent variable in the computations presented in Table 3. Fully 62.02 percent of the variance in this dimension of performance can be explained through the six independent variables introduced to the analysis. As would be expected, in-

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^aTotals vary from the 6,493 interviews completed because of non-responses to certain items.

TABLE 3
Regression Computation for Physical Performance

<i>Variables^a</i>	<i>Multiple R</i>	<i>R²</i>	<i>R² Change</i>	<i>Simple R</i>	<i>B</i>
Number of Conditions	0.6944	0.4822	0.4822	0.6944	0.3285
Health Status	0.7725	0.5967	0.1145	0.6506	0.3283
Age	0.7858	0.6175	0.0208	0.4195	0.0082
Sex	0.7874	0.6201	0.0026	0.1162	0.0976
Education	0.7876	0.6202	0.0002	-0.3289	-0.0043
(Constant)					0.3600
<i>N</i> = 6438					

^aThe influence of "race" does not appear in the computation because of being lower than the cutting point in the program used.

dicators of pathology and impairment accounted for a large proportion of explainable variance (59.7 percent) with socio-demographic variables adding very little explanation. In part, this reflects the association of indicators of pathology and impairment with the socio-demographic characteristics, which limits the additional contributions of the latter variables to explaining limitations in physical performance. A regression coefficient for the influence of the four socio-demographic characteristics by themselves shows that they explain 22 percent of the variance in Physical Performance.

The distributions of limitations in *emotional performance* in relation to other characteristics of respondents are shown in Table 4. They exhibit a pattern similar to that of limitations in physical performance, especially in regard to persons falling in the "severe" categories. With the exception of sex differentials, the strength of relations of emotional performance to other characteristics of respondents are not as pronounced as those of physical performance.

Again, through regression analysis it was possible to account for 45 percent of the variance in emotional performance in terms of relations to the two indicators of pathology and impairment and the four socio-demographic variables shown in Table 5. As in the case of physical performance, most of the variance explained in emotional performance is accounted for by the number of "Health Conditions" and the evaluation of "Health Status." Very little additional variance is explained by introducing the socio-demographic

characteristics. When used independently of the "Health Conditions" and "Health Status," the socio-demographic characteristics by themselves explain 8.5 percent of the variance in emotional performance.

The expected overlap between the two dimensions of human performance (physical and emotional) resulted in 2.4 percent of the respondents reporting "severe" limitations on the two scales, and 7.3 percent reporting "severe" and "substantial" limitations on both. At the other end of the continua, 31.5 percent of the sample indicated "minimal" limitations along the two dimensions of performance. No direct comparison can be made between the distributions of scores discussed above and the findings of other surveys since other studies used the two performance scales constructed in this analysis. However, many of the items have been used earlier.

The relations shown between the scores and the socio-demographic characteristics are generally in directions similar to the results of other surveys (Gurin et al., 1960; Haber, 1967). However, the rates of prevalence of limitations and the strength of associations with socio-demographic variables may vary.

Work Disability

Because of the retirement of large sectors of the employed population at the age of 65, indices related to work disability could be meaningfully constructed only for persons below this age. Therefore, this part of the analysis is confined to the 5,332 respondents in the survey who were 18 to 65. As pointed out earlier, three levels of work disability were identified to include persons who reported "no work disability" (89.4 percent), "were limited in work roles and activities" (4.4 percent), or were "disabled" (6.3 percent). Table 6 presents the socio-demographic organismic performance and health characteristics of persons in the three categories of work disability. To be noted is the higher proportion of the disabled among blacks (more than twice that of whites), especially in view of the much smaller differences between the two racial groups on limitations in physical and emotional performance. This suggests that limitations of equal severity along these two dimensions are likely to affect the employment picture of blacks more adversely than in the case of whites. Also to be noted are the high rates of

TABLE 4
Limitations in Emotional Performance and Selected Characteristics
for Persons 18 and Over

CHARACTERISTICS	LIMITATIONS IN EMOTIONAL PERFORMANCE									
	Total ^a		None or Minimal		Some		Substantial		Severe	
	N	%	N	%	N	%	N	%	N	%
Total Respondents										
18 and over	6,487	99.9	2,195	33.8	2,617	40.3	1,239	19.1	436	6.7
Age										
18-44	3,312	99.9	1,200	36.2	1,404	42.4	571	17.2	137	4.1
45-54	1,083	99.9	376	34.7	401	37.0	217	20.0	89	8.2
55-64	935	100.0	276	29.5	387	41.4	191	20.4	81	8.7
65-74	730	100.0	234	32.1	257	35.2	165	22.6	74	10.1
75 and over	427	99.9	109	25.5	168	39.3	95	22.2	55	12.9
Sex										
Male	2,728	100.0	1,229	45.1	1,004	36.8	364	13.3	131	4.8
Female	3,759	100.0	966	25.7	1,613	42.9	875	23.3	305	8.1
Education										
Below 9th grade	1,343	100.0	379	28.2	448	33.4	327	24.3	189	14.1
9-11	1,259	100.0	386	30.7	472	37.5	276	21.9	125	9.9
12 and above	3,872	100.0	1,427	36.9	1,692	43.7	632	16.3	121	3.1
Family Income										
Below \$2,500	628	100.1	132	21.0	234	37.3	153	24.4	109	17.4
2,500-4,999	953	100.0	264	27.7	340	35.7	232	24.3	117	12.3
5,000-9,999	1,767	100.0	580	32.8	733	41.5	340	19.2	114	6.5
10,000 and over	2,816	100.0	1,091	38.7	1,190	42.3	453	16.1	82	2.9

[illegible]

^aTotals vary from the 6,493 interviews completed because of non-response to certain items.

TABLE 5
Regression Computations for Emotional Performance

<i>Variables</i>	<i>Multiple R</i>	<i>R²</i>	<i>R² Change</i>	<i>Simple R</i>	<i>B</i>
Number of Symptoms	0.6047	0.3657	0.3657	0.6047	0.3016
Health Evaluation	0.6474	0.4191	0.0535	0.5124	0.3065
Sex	0.6629	0.4395	0.0203	0.1993	0.2642
Age	0.6723	0.4520	0.0125	0.1285	-0.0066
Race	0.6732	0.4532	0.0012	-0.0025	0.0960
Education	0.6733	0.4533	0.0001	-0.2060	-0.0030
(Constant)					1.4117
<i>N</i> = 6438					

work disability among the widowed, and the separated or divorced. While the former rates can be partially attributed to the older ages of widowed respondents, the latter cannot be similarly explained. The association of work disability with age, education, income, performance scores, and health indices were to be expected, and confirm the findings of earlier surveys (National Center for Health Statistics . . . , 1973; U.S. Bureau of the Census, 1972; Haber, 1967).

In an attempt to explain variance in work disability, a regression coefficient was computed utilizing eight independent variables.⁵ These included the two performance scales, the two health indices, and four socio-demographic characteristics. As shown in Table 7, 38 percent of the variance in work disability is explainable through the eight independent variables included in the equation. Intercorrelations among the eight variables account for the small additional increments of variance being explained beyond the influence of Physical Performance. A regression analysis using the four demographic variables by themselves showed them independently to account only for 5.8 percent of variance in work disability.

Indications that work disability varies to a large extent independently of physical and emotional performance, and that the

⁵Since the Work Disability Index does not represent an interval scale, the variable was dichotomized in the analysis by grouping together persons in the two categories of "Limited" and "Disabled." Even with this grouping, the number of cases in this category constituted only 566 (10.7 percent) of the sample. This imbalance in proportions was equalized for this analysis by selecting 566 cases at random from the 4,766 persons between 18 and 64 who had "No Work Disability."

addition of socio-demographic characteristics to the regression equation still leaves about two-thirds of the variance in work disability unexplained, raise the important question of what other factors contribute to this form of disability. Answers to this question were sought through comparisons of persons in different categories of work disability while simultaneously controlling for the severity of limitations in physical and emotional performance. The question addressed to the data then was: Given the same degrees of limitations on the two dimensions of performance, why do some people become vocationally disabled and others do not? The analysis revealed three sources of influence. To begin with, there were problems characteristic of respondents, the influence of which was neither fully expressed through measures of performance nor through the socio-demographic attributes. Alcoholism constitutes an example of such problems. While 28 percent of the frequent "problem-drinkers" were among the disabled in work roles, only 6 percent of the respondents reporting infrequent or no problems with drinking were so disabled. The direction of the causality is not entirely clear in this case; while alcoholism can lead to work disability, the reverse relationship is also probable.

Another factor that differentiated vocationally disabled and nondisabled respondents with similar degrees of limitations in physical and emotional performance was the introduction of job adjustments by employers or by the respondents themselves. Information was sought in this survey about modifications in current jobs for employed persons and in last jobs for unemployed respondents. The question was connected to indications of needs for such modifications because of physical, emotional, and mental conditions. Table 8 presents a comparison between persons who were "limited" in work roles and activities but continued to work and the "vocationally disabled" who were out of the labor market in regard to whether or not work modifications were introduced into their employment situations. The distinctions clearly show the association of work modification with continuity in employment. Although reports of work modification, change, and other adjustments were more prevalent among the vocationally nondisabled than the disabled in every level of physical and emotional performance, differences in frequency were greatest when limitations in performance were severe. This is to say that adjustments in work requirements

TABLE 6
Work Disability and Other Characteristics of Respondents
18-64

CHARACTERISTICS	SEVERITY OF WORK DISABILITY									
	Total ^d		No Work Disability		Limited in Work Roles and Activities		Disabled			
	N	%	N	%	N	%	N	%	N	%
Total Respondents	5,332	100.1	4,766	89.4	232	4.4	334	6.3		
18-64 years										
Age										
18-44	3,314	100.0	3,096	93.4	87	2.6	131	4.0		
45-54	1,083	100.0	942	87.0	56	5.2	85	7.8		
55-64	935	100.0	728	77.9	89	9.5	118	12.6		
Sex										
Male	2,285	100.0	2,068	90.5	97	4.2	120	5.3		
Female	3,047	100.0	2,698	88.6	135	4.4	214	7.0		
Education										
Below 9th grade	758	100.0	581	76.7	60	7.9	117	15.4		
9-11	1,034	100.0	890	86.1	60	5.8	84	8.1		
12	1,932	100.0	1,775	91.9	80	4.1	77	4.0		
13 and above	1,603	100.0	1,515	94.5	32	2.0	56	3.5		
Family Income										
Below \$2,500	302	100.1	195	64.6	28	9.3	79	26.2		
2,500-4,999	594	100.0	484	81.5	38	6.4	72	12.1		
5,000-9,999	1,526	100.0	1,382	90.6	63	4.1	81	5.3		
10,000 and above	2,669	100.0	2,489	93.3	94	3.5	86	3.2		

[illegible]

aTotals vary from the 5,332 interviews completed for respondents 18 to 64 because of non-response to certain items.

seem to have been most effective for persons whose physical and emotional limitations were seriously restrictive.

The third set of factors contributing to work disability comprised limitations in specific physical functions, namely, walking, bending, and climbing. Although these functions were incorporated into the scales of physical and emotional performance, the weights these items were accorded in the scales were derived from their loading values on the performance factors rather than their relations to work disability. In this sense, the influence of limitations in these three functions on work disability was not fully expressed through the two performance scales.

The prevalence rates of work disability obtained in this survey can be meaningfully compared to those reported by the National Center for Health Statistics, the U.S. Census, and the Social Security Administration. In these three surveys, the severest category of work disability is variously defined to include people who were identified by the NCHS as "unable to perform major activity," by the Census as being kept "from holding any job at all" because of health or physical condition, and in the SSA and the present survey as "unable to work altogether or regularly." Of lesser severity is a category that generally includes people who are in the labor force but are limited in the type or amount of work they can perform. Percentages of the U.S. population falling in these categories are presented in Table 9. The marked differences in rates reported by the NCHS when compared to those of other surveys are largely due to the exclusion of housewives who are not in the labor force from the question of ability to work.⁶ Findings of the Census, the SSA, and the present survey are fairly similar. The small differences among them can be attributed to variations in age composition, sampling designs, the instruments used in data collection, codification of responses, and in the times at which the surveys were conducted.

The standard error for the proportions of "limited" and "disabled" in the present survey is large because of the small size of these groups in relation to the total population.⁷ However, con-

⁶A comparison of the 1970 Census and the 1973 NCHS surveys for males aged 45-64 shows similar proportions falling in the most severe category of work disability (7.2 percent and 7.6 percent, respectively). See National Center for Health Statistics (1974).

TABLE 7
Regression Computation for Work Disability

<i>Variables</i>	<i>Multiple R</i>	<i>R²</i>	<i>R² Change</i>	<i>Simple R</i>	<i>B</i>
Physical Performance	0.5795	0.3358	0.3358	0.5795	0.1271
Health Status	0.6057	0.3668	0.0310	0.5370	0.0830
Number of Conditions	0.6125	0.3752	0.0083	0.4946	0.0321
Education	0.6148	0.3780	0.0029	-0.3072	-0.0094
Emotional Performance	0.6156	0.3789	0.0009	0.4678	0.0165
Sex	0.6159	0.3794	0.0004	0.0565	0.0192
Age	0.6162	0.3797	0.0003	0.2466	-0.0007
Race	0.6162	0.3798	0.0001	0.0673	0.0136
(Constant)					0.0723
<i>N</i> = 1116					

TABLE 8
Comparison of Respondents Limited in Work Roles and Activities
but Who Continued to Work and the Vocationally Disabled
Who Were Out of the Labor Market or Whether or Not
Work Modifications Were Introduced to Their Employment Situations

<i>Work Modifications</i>	<i>Limited in Work Roles and Activities</i>		<i>Vocationally Disabled</i>		<i>Total</i>	
	<i>N</i>	<i>%</i>	<i>N</i>	<i>%</i>	<i>N</i>	<i>%</i>
Modifications Reported	86	52.8	77	47.2	163	100.0
None Reported	146	36.2	257	63.8	403	100.0
Total	232	100.0	334	100.0	566	100.0

TABLE 9
Comparisons Among the Four Sets of National Data on Work Disability

<i>Survey</i>	<i>Limited (%)</i>	<i>Severely Disabled (%)</i>	<i>Total (%)</i>
NCHS (1969-70) 17-64 years of age	6.7	2.2	8.9
The Census (1970) 16-64 years of age	5.3	5.9	11.2
SSA Survey (1966) 18-64 years of age	4.9	5.9	10.8
Present Survey (1971) 18-64 years of age	4.4	6.3	10.7

TABLE 10
Limitations in Independent Living and Other Characteristics
of Respondents 18 and Over

CHARACTERISTICS	LIMITATIONS IN INDEPENDENT LIVING									
	Total ^a		None		Limited but Independent		Mobility Assistance Needed		Personal Care Assistance Needed	
	N	%	N	%	N	%	N	%	N	%
Total Respondents	6,493	100.0	5,740	88.4	406	6.3	230	3.5	117	1.8
Ages 18 and over										
Age										
18-44	3,314	100.0	3,196	96.4	83	2.5	19	0.6	16	0.5
45-54	1,083	100.0	973	89.8	67	6.2	28	2.6	15	1.4
55-64	935	100.0	749	80.1	112	12.0	49	5.2	25	2.7
65-74	731	100.0	566	77.4	81	11.1	62	8.5	22	3.0
75 and over	430	100.0	256	59.5	63	14.7	72	16.7	39	9.1
Sex										
Male	2,731	100.1	2,466	90.3	168	6.2	60	2.2	37	1.4
Female	3,762	99.9	3,274	87.0	238	6.3	170	4.5	80	2.1
Education										
Below 9th grade	1,344	100.0	1,012	75.3	161	12.0	120	8.9	51	3.8
9-11	1,261	100.0	1,097	87.0	81	6.4	57	4.5	26	2.1
12 and above	3,875	100.0	3,623	93.5	162	4.2	51	1.3	39	1.0
Family Income										
Below \$2,500	629	100.0	422	67.1	88	14.0	84	13.4	35	5.6
2,500-4,999	955	100.0	764	80.0	105	11.0	61	6.4	25	2.6
5,000-9,999	1,767	99.9	1,605	90.8	85	4.8	48	2.7	29	1.6
10,000 and over	2,817	100.0	2,665	94.6	109	3.9	23	0.8	20	0.7
Race										
White	5,546	100.0	4,920	88.7	338	6.1	186	3.4	102	1.8
Black	667	100.0	562	84.3	56	8.4	35	5.2	14	2.1
Other	255	100.0	236	92.6	10	3.9	8	3.1	1	0.4

Marital Status	4,411	100.0	4,032	91.4	230	5.2	89	2.0	60	1.4
Married	550	100.0	466	84.7	48	8.7	30	5.5	6	1.1
Sep./Div.	808	100.0	572	70.8	97	12.0	100	12.4	39	4.8
Widow	721	100.0	668	92.6	31	4.3	11	1.5	11	1.5
Single	3	100.0	2	66.7	0	—	0	—	1	33.3
No data										
# Health Conditions										
None	4,223	100.0	4,210	99.7	9	0.2	1	0.0	3	0.1
1 or 2	1,597	100.0	1,244	77.9	219	13.7	84	5.3	50	3.1
3 or more	673	100.0	286	42.5	173	26.4	145	21.5	64	9.5
Health Status										
Good	4,968	100.0	4,757	95.8	157	3.2	35	0.7	19	0.4
Fair	1,074	100.0	816	76.0	145	13.5	90	8.4	23	2.1
Poor	439	100.0	160	36.4	103	23.5	104	23.7	72	16.4
Limitations in Physical Performance										
Minimal	4,981	100.0	4,935	99.1	42	0.8	1	0.0	3	0.1
Some	873	99.9	681	78.0	160	18.3	24	2.7	8	0.9
Substantial	340	99.9	115	33.8	135	39.7	79	32.2	11	3.2
Severe	293	100.0	7	2.4	68	23.2	125	42.7	93	31.7
Limitations in Emotional Performance										
Minimal	2,195	100.0	2,119	96.5	56	2.6	16	0.7	4	0.2
Some	2,617	100.0	2,407	92.0	140	5.3	45	1.7	25	1.0
Substantial	1,239	100.0	1,003	81.0	120	9.7	81	6.5	35	2.8
Severe	436	100.0	209	47.9	89	20.4	87	20.0	51	11.7

^aTotals vary from the 6,493 interviews completed because of non-responses to certain items.

sistency in these proportions among major surveys (refer to Table 10) provides confidence in their approximation of the true values. The prevalence rates of work disability obtained through the present study lead to the following unweighted estimates:

U.S. Population Between Ages 18 and 64 (1970)	100.0%	112,580,427
Persons Not Limited in Work Roles and Activities	89.4%	100,629,842
Persons Limited in Work Roles and Activities	4.4%	4,898,473
Persons Disabled	6.3%	7,052,112

Independent Living

Disability in living activities was assessed in terms of dependence-independence in performing these activities. It has already been mentioned that an Independent Living Index (ILI) was used to group respondents into four categories in regard to this dimension of disability: (1) not limited in performing these activities; (2) limited, but independent; (3) needing assistance in outdoor mobility and activities such as shopping and housework; and (4) needing assistance in self-care activities such as bathing, dressing, feeding, and the like. As shown in Table 10, these categories included 88.4 percent, 6.3 percent, 3.5 percent, and 1.8 percent of the total sample, respectively. The proportions of all persons with limitations, and particularly those with needs for assistance, are associated positively with age and negatively with educational and income levels. Particularly significant is the dramatic increase in the prevalence of needs for assistance in mobility and self-care for persons 75 and over. Compared with men, close to twice as many women need assistance in both types of activities. In part, this is due to the age structure where the ratio of women to men was higher in the older age brackets. The influence of limitations in physical and emotional

⁷Accepting 95 percent level of confidence, the sampling error for the proportions of the sample with "No Work Disability," the "Limited" and the "Disabled" are 1.0 percent, 5.1 percent, and .8 percent, respectively.

TABLE 11
Regression Computation for Independent Living

<i>Variables^a</i>	<i>Multiple R</i>	<i>R²</i>	<i>R² Change</i>	<i>Simple R</i>	<i>B</i>
Physical Performance	0.8462	0.7161	0.7161	0.8462	0.2093
Age	0.8537	0.7290	0.0129	0.5384	0.0030
Number of Conditions	0.8565	0.7336	0.0046	0.6479	0.0248
Sex	0.8584	0.7368	0.0032	0.1790	0.0664
Race	0.8697	0.7390	0.0022	0.0384	0.0631
Emotional Performance	0.8609	0.7411	0.0021	0.5549	-0.0372
Health Status	0.8621	0.7432	0.0021	0.6679	0.0287
(Constant)					-0.3493
<i>N</i> = 683					

^aThe influence of "education" does not appear in the computation because of being lower than the cutting point in the program used.

performance, and of health indicators, upon independent living is clearly reflected in Table 10.

Fully 74.3 percent of the variance in independent living can be explained through the two performance factors, the two health indicators, and the four socio-demographic variables included in Table 11.⁸ The intercorrelations among the independent variables limit the additional increments of variance explained through the addition of each of the variables beyond physical performance. However, an independent regression computation shows that age, sex, race, and education, by themselves, account for about 31 percent of the variance in capability for independent living.

The relations between indices of Independent Living and Work Disability can only be described for respondents below 65 because the latter index is limited to these age groups. Of the 5,332 persons between the ages of 18 and 64, 4,637 (87 percent) reported no disabilities in either set of roles and activities, and 105 (2.0 percent) in-

⁸Since the Index of Independent Living does not represent an interval scale, the variable was dichotomized by grouping together persons who reported needs for assistance into one category. This category remained relatively small, comprising 347 persons (5.3 percent). In order to equalize the two groups, a sample of 347 was selected at random from the 5,740 persons who reported no needs for assistance and who constituted the other group in the analysis. It should be noted also that grouping the first two categories of this index together eliminates the overlap with indices of individual performance, which distinguished between them, and thus eliminates spuriousness in this step of the analysis.

licated severe disabilities along both dimensions. These persons were disabled as far as work is concerned and also needed assistance in living. Of 152 persons requiring assisted living: nine (5.9 percent) had no work limitations, 38 (25.0 percent) were regularly engaged in full time work but with limitations in roles and activities, and 105 (69.1 percent) were not working because of disability. On the other hand, of the 334 vocationally disabled persons, 105 (33.4 percent) were in need of assisted living. In summary, to a large degree, the two dimensions of disability vary independently, and assisted living is more predictive of work disability than vice versa.

Based on the distributions of levels of dependence-independence in living activities obtained through this survey, and the size of the U.S. population in 1970, the numbers of persons falling in each of the categories of this index can be estimated as follows:

U.S. Population in 1970 (18 and over)	100.0%	131,679,216
Persons Not Limited in Living Activities	88.4%	116,408,232
Persons Limited, but Independent	6.3%	8,233,757
Persons Needing Assistance In Outdoor Mobility, Shopping, and Housework	3.5%	4,664,446
Persons Needing Assistance in Personal Care	1.8%	2,372,781

Summary and Conclusions

This report presented the findings of an epidemiological analysis of disability among adults in the noninstitutionalized continental United States population. Data were derived from a survey of a probability sample of persons 18 and over. Interviews were completed for 6,493 respondents representing 80.3 percent of persons comprising the sample. The conceptual framework was organized around distinctions among the concepts of pathology, impairment, levels of performance of the organism, and disability. Central to the study were indices for two dimensions of performance (Physical and

Emotional), and of disability (Work and Independent Living). A number of socio-demographic characteristics were included in the analysis.

The results showed the relative contributions of pathology and impairment, as indicated by the number of health conditions reported and the respondents' evaluations of their health status, to the levels of physical and emotional performance. Furthermore, it was possible to account for 38 percent of the variance in work disability and 74 percent of dependence-independence in community living through the influence of levels of performance, health conditions, and four socio-demographic characteristics. "Physical Performance" figured prominently in explaining variance in both Work Disability and Independent Living activities. The comparatively weaker role displayed by "Emotional Performance" could be, at least in part, a result of society's tendency to more readily institutionalize persons with severe emotional limitations than those with severe physical limitations. In this sense, the sample of non-institutionalized populations in this analysis represents a truncated distribution of levels of emotional performance with the most severe categories being excluded because of institutionalization. The independent contributions of the four socio-demographic variables (age, sex, race, and education) upon disability were also assessed. They accounted for 6 percent of the variance in Work Disability and 31 percent of that in Independent Living. Age, education, and income levels were most consistent in their relations to health conditions, physical and emotional performance, and the two dimensions of disability.

The degree of independence in variance exhibited by the indices of disability, limitations in physical and emotional performance, and the health conditions of respondents confirm the utility of distinctions made among these concepts. Differences in the amounts of variance in Work Disability (38 percent) and Independent Living (74 percent) explainable through individual attributes demonstrate the sensitivity of indices used in measuring these forms of disability. To a greater extent, work disability depends upon a variety of environmental factors such as the requirements of work roles, the labor-market demands, and the attitudes of employers. The significance of factors in the work environment was illustrated by the influence of job modification and change upon continuing employment on the part of respondents. Finally, it can be concluded that

the consistency in rates of work disability reported in the U.S. 1970 Census, the Social Security Survey of Disabled Adults, and this study attest to the reliability of available measures. Using prevalence rates yielded through this study and the 1970 U.S. Census data for the noninstitutionalized population, estimates were computed for the numbers of people 18 and over who fall within the various categories of work disability and independent living.

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