

**A HEALTH CARE PLAN DECISION
SUPPORT SYSTEM
FOR PEOPLE WITH DISABILITIES**

FINAL REPORT

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Project Officer: Frantz Wilson**

Submitted by:

**Berkeley Planning Associates
440 Grand Avenue, Suite 500
Oakland, California 94610**

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AUTHORS OF THIS REPORT:

Stuart P. Hanson
Berkeley Planning Associates

Quentin W. Smith
The Institute for Rehabilitation and Research

David J. Simon
Menlo Park

PROJECT TEAM:

Berkeley Planning Associates

Stuart P. Hanson
Ann Cupolo
Sasha Gottfried
Susan Haight
Dennis Meehan
Pat Spikes-Calvin

The Institute for Rehabilitation and Research

Quentin W. Smith
Lex Frieden
Joyce Frieden
Kim King
Laurie Redd
Jonathan Strayer, M.D.

Consultants

Lawrence Boyd, Ph.D.
Gerben DeJong, Ph.D.
Jan Hecht, Ph.D.

Consumers

Maureen Donahoe
Robert Mudd

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I. INTRODUCTION

Although the health care reform debate during the 103rd Congress faltered, it represented a major attempt to move the health care marketplace from a provider-driven toward a consumer-driven system. Inspired by that debate, the Agency for Health Care Policy Research (AHCPR) has embarked on a policy initiative to make the health care system more accountable to consumers and to enhance the consumer's role in the health care marketplace. One component of this initiative is a series of Small Business Innovation Research (SBIR) contracts to develop informational products to assist consumers in choosing among different health care plans, providers, and practitioners. Each of the SBIR Phase I projects was to focus on the informational requirements of populations with special needs. The project summarized below dwells on how people with disabilities, particularly those with physical impairments, choose among different health care plans.

The remainder of this report is divided into four sections. Section II describes the public policy issues addressed by this project and the goals and objectives we have sought to achieve in the six months allotted to this effort. Section III describes the methods used to accomplish these goals, namely focus groups discussions, interviews with key informants, literature review, product development, and independent expert review. Section IV summarizes the results including a description of the two products developed during Phase I—a draft guidebook and prototype CD-ROM program entitled *Choosing a Health Care Plan for Independent Living*. In Section V, we address the policy research implications of the project and assess the feasibility of successfully conducting the Phase II and Phase III stages of this SBIR project.

Appended to this report are the instruments and other documents used to conduct the focus groups, key informant interviews, and independent review. Also appended are the draft guidebook and a detailed description of the CD-ROM program. A single copy of the actual CD-ROM prototype accompanies this report.

II. PROJECT BACKGROUND, GOALS AND OBJECTIVES

BACKGROUND

This project is a practical response to the paucity of useful information that people with disabilities need to make thoughtful choices about different health care plans. Our aim is to supply relevant information in such a way that actually changes the way people with disabilities choose among different plans. Accordingly, the ultimate purpose of this project is to create *well-informed* consumers of health plans. By consumers, we mean end users of health care services rather than institutional purchasers and other intermediaries.

In the classical economic theory of "perfect competition," the independent well-informed consumer plays a central role in the competitive health care marketplace by judiciously choosing among similar products based on their price and quality. In the current health care marketplace however, several factors directly undermine the role of the well-informed consumer (Weisbrod, 1983). This project responds to these factors and takes into account additional market conditions that indirectly influence consumer decision-making.

First, *different health care plans do not offer standardized benefits*. Without a homogenous product, effective price competition is difficult to achieve. Consumers must compare apples with oranges rather than apples with apples and oranges with oranges. Needless to say, health care plans are far more complex than fruit. Sweetness, flavor, and texture are nothing compared to deductibles, copayments, annual and lifetime maximums, physician reputation, convenience, and curtesy. Indeed, to switch metaphors, health care plans often are characterized as moving targets, impossible to pin down as to coverage. This presents a serious obstacle to providing reliable and valid information to consumers.

Second, *insufficient information exists that indicates what would happen if health care coverage is not purchased compared with what would happen if it was obtained*. AHCPR currently supports Patient Outcome Research Team (PORT) research to assess the efficacy of specific medical treatment procedures, and shared decision-making programs (Kasper et. al., 1992) have been developed to involve the patient in making treatment decisions. Report cards based on

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mortality data and consumer satisfaction comparison ratings attempt to fill this gap. Unfortunately, the reliability and validity of these data are frequently challenged (GAO, 1994), although efforts have begun to standardized consumer satisfaction ratings (RTI, 1995) and set national accreditation standards (NCQA, 1994). Other information such as malpractice records exists, but is not available (with some good reasons) to the general public.

Third, ***decision-making is often relinquished to agents who are sellers and providers of health care coverage.*** Or some sellers, like company benefit managers, represent interests other than the end user of the health care plan. As we describe in our guidebook, marketing representatives, intentionally or not, often mislead individuals about coverage availability; brokers represent a limited number of plans from which they receive commissions; and company benefit managers must pay heed to the financial needs of the firm as well as the interests of the employee. The important issue here is that while consumers and payers may have overlapping concerns, these groups also have unique and differing perspectives on health care.

In addition to these direct factors, several conditions in the health care marketplace indirectly but substantially exacerbate the problems consumers face in making thoughtful choices about health care plans (DeJong and Sutton, 1994). First, in the health care industry, providers and payers rather than consumers set prices. Second, the prevalence of experience rating forces health plans to compete on the basis of risk and price rather than quality. Experienced rated health care plans design their coverage package and set prices to appeal to low users of health care services and discourage enrollment by high user of services such as individuals with disabilities. Third, the absence of risk or case-mix adjustment fails to reflect the different utilization rates of consumers. Without risk adjustment, plans have little incentive to enroll high user groups such as people with disabilities. Fourth, consumers are underrepresented in the governance of the health care system. The boards of private health care plans are dominated by physicians and business people. Even accrediting agencies like the National Committee on Quality Assurance do not substantially involve consumers in setting standards and evaluating health plans.

This analysis helped us the shape the goals and objectives of this project. It also led us to formulate two principles that would guide us in designing the decision support system. Foremost, we sought to create information that is based on the actual experiences of people with disabilities who have direct experience with specific health care plans. We believed that people want to hear how other similarly situated individuals evaluate the consequences of choosing a health care plan. While this seemed key, we also believed that people would prefer a wide range of information

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from their peers. As we perceived it, our job was to identify key data and transform these data into useable information by distilling it and packaging it in engaging ways.

PROJECT GOALS AND OBJECTIVES

The goal of this SBIR project is to develop a ***Decision Support System*** to help people with disabilities, particularly those with physical disabilities, choose health care plans that best meet their needs. Given the scarcity of resources, especially during Phase I, we decided to focus on individuals between the ages of 18 and 65 with severe mobility impairments. Examples of specific conditions include:

- | | |
|----------------------|------------------------|
| ! amputations | ! post polio |
| ! cerebral palsy | ! spina bifida |
| ! cystic fibrosis | ! spinal cord injuries |
| ! multiple sclerosis | ! head injuries |
| ! muscular dystrophy | ! stroke |

Persons with these conditions tend to have a common constellation of health problems such as decubitus ulcers, urinary tract infections, respiratory tract infections, and osteoporosis. We envision expanding the information system to other disabilities at a later date.

The Decision Support System, tentatively entitled ***Choosing A Health Care Plan for Independent Living***, includes both "low tech" products such as brochures, guidebooks, and workbooks, as well as a "high-tech" products such as a videos and an interactive CD-ROM program. In their final form, these products will be available in a variety of accessible formats including braille, audiotape, closed-captioning, and voice-activation. While each product is designed to stand alone, they are linked by common content. For example, both the draft guidebook and the prototype CD-ROM program developed in Phase I contain anecdotes of how health plan information can mislead consumers into believing that services they thought would be available actually are not. In the guidebook this information is conveyed in text; whereas in the CD-ROM program it is convey in a narration presented as a radio call in show. An identical glossary was created for both products. A brochure version of the guidebook will be developed during Phase II.

II. Project Background, Goals and Objectives

During Phase I, we focused our efforts on producing two major products: (1) a detailed guidebook including worksheets for assessing the cost and adequacy of different health plan and a glossary of terms, and (2) a CD-ROM program presenting a wide array of information ranging from a physician's perspective on the health care needs of individuals with physical disabilities to the personal experiences similarly situated people have had in choosing a health care plan. The guidebook is designed for a national market. The CD-ROM is designed for the Bay Area health care market. We will address issues of depth and breadth of product applications in Chapter V.

To accomplish the goals of this project, we sought to complete three major objectives:

- (1) ***Determine the information needs of people with physical disabilities.*** This objective addressed how people with disabilities assess the key features (price, benefits, restrictions, etc.) of a health care plan, relate these elements to their own health care needs, and assess quality of care. Specific research questions included:
 - (a) What are the salient factors people with disabilities consider in choosing a health care plan?
 - (b) What are the trade-offs people with disabilities consider in choosing a health care plan?
 - (c) What sources of information do people with disabilities use in choosing a health care plan?
 - (d) What formats do people prefer?

To achieve this objective, we relied mainly on focus group interviews with persons with disabilities. These focus groups were conducted in the Oakland, California, and Houston, Texas in order to vary consumers input from a highly competitive and richly developed and predominantly managed care marketplace (Oakland) to a less developed, fee-for-service dominated environment (Houston). We also conducted key informant interviews with a national sample of health care and disability experts including individuals with disabilities.

- (2) ***Validate the content of the decision support system.*** This objective aimed to develop a decision support system that has a high likelihood of improving consumer awareness and

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fostering independent decision-making among people with physical disabilities. Specific questions included:

- (a) What factors should we consider in optimizing the reliability, comprehensiveness, accuracy, objectivity, and usefulness of the decision support system?
- (b) What outcomes should we expect to observe from consumers exposed to the guidebook and CD-ROM program?

To answer these questions, the project team conducted open-ended key informant interviews with researchers, policy experts, and disability advocates/consumers.

- (3) ***Develop a prototype of the decision support system.*** Early in the project, we realized that we did not have sufficient resources to develop a diversity of low- and high-tech products. Accordingly, we focused our efforts on developing a substantial "low-tech" guidebook and a comprehensive CD-ROM product. One measure of the success of this project is how success the project team has been in producing prototype versions of the guidebook and CD-ROM program. Specific research questions included:
 - (a) Can we demonstrate the feasibility of developing a decision support system consisting of "low tech" and "high tech" products?
 - (b) What are the substantive and technical strengths and weaknesses of the decision support system, particularly the "high tech" prototype?

For several reason, we decided to allocate scarce project resources to obtaining an independent review of the technical and substantive aspects of the CD-ROM version of ***Choosing A Health Care Plan For Independent Living***. Because the content of the CD-ROM duplicates some parts of the guidebook, independent review of both products would be redundant. Furthermore, we anticipate that AHCPR reviewers would have the expertise to evaluate the guidebook, but few would have the expertise to assess the technical merits of the CD-ROM program. Finally, even though the technology will soon become widely available, we perceived that not all AHCPR reviewers could readily view the CD-ROM program. Thus we hired ***independent*** consultants to provide a detailed review.

In the next chapter we describe the methods used to achieve these objectives.

III. PROJECT METHODS

OVERVIEW

In this chapter, we describe the methods used to pursue the project objectives described in Chapter II. We conducted focus groups and key informant interviews to understand how people with disabilities think about health care choices. In addition, we conducted key informant interviews with a national sample of researchers, policy experts, product developers, and advocates in the fields of health care and disability. Based on input from these sources, we drafted sections for a written guide to choosing a health care plan and drafted scripts and other materials for use in the CD-ROM and engaged in an iterative process combining the content and technical aspects of each products. The most challenging aspect of this process was blending of content and format of the CD-ROM. At the end of the project, we sought an independent review of the CD-ROM from disability and computer technology experts.

To ensure against geographic and market provincialism, focus groups were conducted in Oakland, California and Houston, Texas. Differences between the population of the two states are shown in Table III-1. State and national population data shows that a lower percentage of Texans have completed high school than have Californians and all U.S. residents. However, the percentage of Texans who have completed college is equal to that of the entire U.S. population. On the one hand, the rate of severe work disability and mobility difficulties are about the same for both states, while the rate of self-care difficulties is higher in California. On the other hand, the rate of need for assistance in Instrumental Activities of Daily Living (IADL) or ADL is higher in Texas.

Differences in the health care markets in Texas and California are shown in Table III-2. This table indicates clearly that Health Maintenance Organizations (HMOs) are far more prevalent in California than in Texas, but that Preferred Provider Organizations (PPOs) are more prevalent in Texas. These data suggest that Californians are more likely to be oriented toward

Table III-1
DISABILITY RELATED POPULATION CHARACTERISTICS

CHARACTERISTIC	CALIFORNIA	TEXAS	U.S.
Number of People in 1000s (*)			
All Ages	29,760	16,987	248,710
Over 16	22,150	12,311	186,887
16-64	19,164	10,696	157,324
65+	2,986	1,161	29,564
Percent Completed High School (*)	76.2	72.1	75.2
Percent Completed College (*)	23.4	20.3	20.3
Rate of Severe Work Disability			
Per 1000 Aged 16 -64, 1990 (**)	37.4	38.1	41.9
Rank	29	28	-
Rate of Difficulty in Mobility			
Self-care Per 1000 Aged 16-64 (**)			
Mobility	21.3	21.3	21.9
Rank	30	20	-
Self-care	38.0	34.0	34.3
Rank	9	18	-
Rate of Need for Assistance in IADL or ADL per 1000 Aged 16 and older (***)			
Rate	34.1	42.8	40.4
Rank	29	19	-

Source: State Estimates of Disability in America, Disability Statistics Report, National Institute Disability and Rehabilitation Research, March 1993

(*) 1990 U.S. Census

(**) 1980 U.S. Census

(***) National Health Interview Survey 1988-90

**Table III-2
HEALTH CARE MARKET CHARACTERISTICS**

	CALIFORNIA	TEXAS	U.S.
HMO Market Penetration (June 1994)			
Population	31,279	17,487	257,816
Penetration (%)	36.9	14.4	20.3
Rank	4	26	-
Enrollment in 1000s	11,529	2,517	52,369
Total HMOs	41	26	546
Enrollment Change 1993-94 (%)	9.9	8.3	6.7
HMO Enrollment by Type - June 1994			
Group (N)	5,534	972	14,405
(%)	48.0	38.6	27.5
IPA (N)	3,088	1,545	26,256
(%)	26.8	61.4	50.1
Network (N)	2,465	0	6,696
(%)	21.4		12.8
Staff (N)	442	0	5,012
(%)	3.8		9.6
PPOs per State			
Owned	54	66	1,395
Rented	19	21	585

Source: Marion Merrell Dow, Managed Care Digest, Update Edition, 1994

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HMOs than are Texans. Conversely, Texans are less likely to experience health care through a HMO and more likely, we believe, to belong to a PPO or fee-for service plan.

Aware that this orientation might bias the results of the focus groups, we were careful to take it into account during the analysis of focus group data. We were also concerned that the guidebook, which was developed by the Houston-based study team, would be oriented toward fee-for-service and PPO plans, while the CD-ROM developed in California would reflect HMO experiences. To avoid these biases, the two principal investigators exchanged draft versions of the guidebook and CD-ROM scripts, talked frequently via the telephone, and had two extended face-to-face work session in Houston to resolve issues of perspective.

FOCUS GROUP DISCUSSIONS

In order to learn more about how people with physical disabilities choose among different health care plans, BPA and ILRU conducted focus group discussions in Oakland and Houston, respectively. These group discussions addressed four broad topics related to choosing a health care plan, namely:

- (1) What are the salient factors that people with physical disabilities consider in choosing a health care plan?
- (2) What issues arise among people with physical disabilities in obtaining quality health care as defined above?
- (3) What sources of information do people with physical disabilities rely on in selecting a plan? and
- (4) What formats (brochures, videos, computer software, etc.) are preferred?

Two focus groups were conducted at each site. One group was composed solely of women while the other group was composed of men and women. All individuals had physical disabilities (e.g. paraplegia, multiple sclerosis, etc.) and/or chronic illnesses (e.g., diabetes, enlarged heart, etc.). The Houston groups, however, had more participants with severe mobility impairments than did the Oakland groups. All participants resided in the East Bay area of Northern California (Berkeley, Oakland, Hayward, etc.) or the metropolitan Houston area.

Each group was recruited using an identical protocol (see Appendix A: Focus Group Telephone Screening Instrument, Participant Recruitment, and Moderator's Guide). Recruitment activities included posting of notices in Independent Living Centers and other organizations for people with disabilities such as Easter Seals. We also used word-of-mouth and advertised at wheelchair manufacturing and repair shops.

In Oakland, meetings were held on at BPA's meeting room facilities. ILRU sponsored groups were held at a centrally located hotel in Houston. Each group was moderated by an individual with a physical disability. Training of the moderators and assistant moderators was provided by the Principal Investigator, and detailed protocols were used to insure uniformity (See Appendix A).

At 5:45 PM, prior to each meeting, participants were asked to complete a short questionnaire assessing their demographics characteristics and how they rated the quality of health care they have received under their current health care plan. The 17 quality of care items were derived from several sources including health plan satisfaction surveys and a survey of disabled employees conducted by ILRU. A light dinner buffet was provided to all participants and the formal discussion began at 6:10 PM. Participants were given \$25 each and reimbursed for extraordinary transportation needs. Each group was audio-taped. Immediately following each focus group, the principal investigator or co-principal investigator debriefed the moderator and assistant moderator. A summary of each group was prepared based on notes from the debriefings, flip chart recordings from each session, and the audio-tapes.

Our original plan was to conduct two rounds of focus groups in each site, partly to guard against the occurrence of "bad" groups and partly to explore new questions that might arise in the first round of discussions. However, we found this unnecessary. Each group was conducted without major problems, results from each group tended to be confirmed by the results from the other groups, and many of these results resonated with results obtained from other focus groups of consumers conducted by the National Committee on Quality Assurance and the AHCPR-Research Triangle Institute consumer satisfaction survey design project (see Chapter IV).

KEY INFORMANT INTERVIEWS

We contacted experts in the fields of disability, health care, and disability advocacy in order to explore several key technical issues and to confirm the insights provided by focus group

III. Project Methods

participants. We provided each expert with a synopsis of the project and description of the goals and components of the CD-ROM version of the Decision Support System (see Appendix B). Specific discussion topics included:

- (1) Salient factors someone with a physical disability should consider in choosing a health care plan?
- (2) What kinds of information someone with a disability would consider most useful in choosing among competing plans?
- (3) Suggestions about any existing material we should review?
- (4) Suggestions for making the product stimulating, objective, and useful?
- (5) Should we take strong positions on what health care plans are good and bad for people with disabilities?
- (6) How can this product be designed to help consumers protect themselves against misinformation provided by health plans and other behaviors that are not in the best interests of people with disabilities?

We compiled a list of approximately 20 individuals gleaned from the academic and trade literature on health care and disability and 20 leaders in the disability arena. In exchange for their mailed-back comments, we promised to send them a summary of this report, and to acknowledge their input without implying endorsement of any product (see Appendix C). We also promised to contact by phone those persons who did not return a written response. When circumstance allowed, the Principal Investigator conducted in-person interviews with a small number of these experts. Of the 40 individuals contacted, 24 provided some kind of response.

PRODUCT DEVELOPMENT

The development of the draft guidebook and prototype CD-ROM program was an iterative process in which substantive issues were considered in terms of the ability of the media (print or CD-ROM) to communicate the essential meaning of the issues derived from the focus groups and

key informant interviews. While these source provided essential ideas for form and content of the CD-ROM, several questions remained:

- (1) What should be the specific style of each product?
- (2) What title best captures these aims?
- (3) How should the content be arranged? and
- (4) What icons, graphics, and other presentation techniques are most appealing?

To answer these questions, we brainstormed among ourselves and, when necessary, conducted informal interviews with technical experts and a small number of focus group members and other experts in the disability field.

We based the guidebook on important features of a health care plan and the issues people with disabilities encounter in choosing a plan. We developed definitions of important health care terms and concepts that should help to resolve plan coverage, price, and quality questions in terms of consumer needs. We also designed worksheets to resolve differences between: (1) service needs and plan coverage, (2) quality needs and quality delivered, and (3) costs and resources. After several drafts, these issues were translated into a draft document answering a series of questions that a typical but highly skeptical consumer might ask about health care plan.

The CD-ROM program also began with drafting preliminary descriptions of each component of the program. Initial ideas were inspired by comments made by focus group members and from feedback from our sample of experts. For example, both experts and consumers recommended that it would be very useful to have a physician's views of the health care issues people with physical disabilities are likely to encounter over the life course. A series of medical questions was then generated and a script was prepared for video-taping a physician. These descriptions were circulated among key members of the project team for comments.

Perhaps the most challenging aspect of this process was the technical feasibility of specific ideas for each component of the CD-ROM. For example, we had planned to prepare several videos of persons with disabilities discussing their reasons for choosing their particular plan. We also wanted to include other video segments in the program. However, the current CD-ROM

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technology severely limits the number of video minutes in a given CD. Thus we were forced to reduce the number of video segments and limit their length. As we encountered these limitations, we gradually began to get a clear idea of what we could accomplish in a prototype CD-ROM program given the current level of resources.

INDEPENDENT REVIEW

Given the advance nature of CD-ROM technology, it was imperative to obtain an independent assessment of our prototype. Accordingly, we asked three experts to review the CD-ROM program and submit criticisms and comments to AHCPR based on their expertise (see Appendix D). Each expert was asked to assess the CD-ROM program on the following terms:

- (1) ***Comprehensiveness.*** Please assess the comprehensiveness of the product in addressing the information needs that people with disabilities have or should have in choosing a health care plan. Are there other areas that should be addressed? What areas need more emphasis?
- (2) ***Accuracy and Consistency.*** How accurate is the information presented in the program? Are there glaring errors or misstatements? Is the information internally consistent?
- (3) ***Objectivity.*** To what extent is the information presented in the program objective and unbiased? How do you think HMOs, PPOs and other plans will react? How do you think the disability community will react? Will a typical user discern a bias that will discourage her or him from using the product?
- (4) ***Accessibility.*** Please assess the tone, content, formats, and other aspects of the program with respect to its "user-friendliness."
- (5) ***Entertainment Value.*** Do you think that this program is stimulating? How would you make it more interesting and fun to use?
- (6) ***Impact.*** Does this product have the potential to affect the decisions people make about health care? How should that impact be measured?

- (7) ***Weaknesses.*** From your perspective, what are the overall weaknesses in this CD-ROM project?
- (8) ***Strengths.*** Overall, what are the strengths of this CD-ROM product?
- (9) What other comments and criticism do you have?

By the end of the project, two of the three experts had responded. Comments from the third reviewer will be included with the Phase II proposal. In the following chapter we present the results of our project efforts.

IV. RESULTS

OVERVIEW

In this chapter, we present the results of the research activities (focus group discussions and key informant interviews) and briefly describe the development of the prototype guidebook and CD-ROM developed during Phase I. We also provide the comments and criticisms of the CD-ROM submitted by our independent reviewers. A draft copy of the guidebook may be found in Appendix F. (A single copy of the CD-ROM version including disk and accompanying documentation has been submitted to the AHCPR project officer.) A detailed description of each component of the CD-ROM may be found in Appendix E.

FOCUS GROUPS

GROUP COMPOSITION

Table IV-1 displays the demographic and health characteristics of the focus group participants as well as how they rate the quality of care received from their current plan. The percentage of all focus group participants with college educations was much higher than the rate for each state and the U.S. (see Table III-1). Although the participants from the two sites were similar with respect to age, gender, and marital status, the Houston participants were more educated and self-reportedly healthier. As we expected, an important difference between the two sites was that no one in the Houston groups belonged to an HMO, while no one in the Oakland groups subscribed to a fee-for-service plan. Participants in the Houston women's group reported much higher satisfaction with their health care plan and rated the quality care received higher than any of the other group participants.

**Table IV-1
FOCUS GROUP PARTICIPANT CHARACTERISTICS**

CHARACTERISTIC	OAKLAND		HOUSTON	
	MIXED N=9	WOMEN N=7	MIXED N=7	WOMEN N=9
Age				
Mean	41.7	42.4	36.0	46.2
Range	29 - 65	32 - 56	22 - 52	32-57
% Female	60%	100%	57%	100%
% White	100%	80%	100%	100%
% Single	67%	80%	85%	50%
Education				
% BA or higher	33%	60%	57%	100%
Dependents				
Mean	0.11	1.4	0	0.63
Range	0 - 1	0 - 3		0-2
Health (*)				
Mean	2.07	2.20	3.83	3.38
Range	1 - 3	1 - 3	3 - 5	1-5
Health Plan				
Private HMO	78%	100%		
Private PPO			29%	33%
Private FFS			14%	67%
Medicaid/Medicare	22%		57%	
Cumulative rating of quality of care (***)				
Mean	2.66	2.88	2.87	3.74
Range	2.12 - 3.18	2.24 - 4.00	1.53 - 4.71	3.00 - 4.71
Overall Satisfaction (**) of Current Plan				
Mean	2.79	2.60	3.0	3.71
Range	2 - 4	2 - 3	1 - 5	3 - 5

* Compared to other persons your age, how would you rate your own health?
Poor (1) Fair (2) Good (3) Very Good (4) Excellent (5)

** Overall, how would you rate the medical you have received under this plan?
Poor (1) Fair (2) Good (3) Very Good (4) Excellent (5)

*** 17 dimensions of quality of health care See Questionnaire:
Poor (1) Fair (2) Good (3) Very Good (4) Excellent (5)

FACTORS AND TRADE-OFFS IN CHOOSING A HEALTH CARE PLAN

Participants identified five types of factors they considered important in choosing a health care plan. These factors are summarized below:

Costs factors included premiums and deductibles, hidden and out-of-pocket costs. Costs, especially out-of-pocket expenses, were a major concern of virtually all groups, although participants whose employer paid premiums, were less concerned than unemployed or employed and uncovered persons.

Accessibility factors included accessibility of physician' office, the availability of a low examining table, out-of-area coverage, no pre-existing condition restrictions, and the availability of the primary care physician. Individuals in fee-for-service plans were primarily concerned about pre-existing condition restrictions.

Adequacy factors included the availability of competent resources and equipment; coverage for durable medical equipment (especially wheelchairs, prostheses, and orthotics) alternative care (e.g., acupuncture, chiropractic), emergency coverage for durable medical equipment; and a variety of other services such as preventive care, psychiatric care, and attendant care. Attendant care, considered by many disability experts to be the cornerstone of maintaining one's functional capacity and independence, was not afforded a high rank by many participants. While they frequently or continuously required personal assistance, many participants simply assumed that health care plans are not responsible for this kind of care. They expected the health care plan to pay for home-based personal assistance in conjunction with an episode of acute illness such as pneumonia, but did not expect the plan to pay for non-acute personal assistance services.

Quality of Care factors covered many of the same factors identified in the literature including continuity of care, timeliness, respect and courtesy, accuracy of information, etc. What may distinguish these participants for non-disabled consumers is the urgency of factors like quickness of assessment, waiting, delays in obtaining durable medical equipment, the physician's expertise in the specific disability, and the doctor's ability to listen to the consumer (especially when the doctor is not familiar with the disability). More than a few participants articulated that it was just as important that the primary care physician understood health problems like respiratory illnesses than it was for she/he to be an expert in a particular condition such as muscular dystrophy.

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Other factors mentioned by our participants included reputation/prestige, open-mindedness and flexibility of professional staff, and problems with getting approval/referral especially for basic needs such as durable medical equipment. Many people agreed with the sentiment that the best health care plan is "a plan where you don't have to fight." As other research indicates, participant attitudes toward their own health care took on more negativity as the discussion shifted from general satisfaction over time to specific instances of care. One horror story begat another. In two groups, participants seemed divided between those who viewed these negative anecdotes as exceptions and those who believed them representative of the plan. One woman characterized her plan as "horrible" with respect to the treatment she received for her brain injury, and "wonderful" when it came to diagnosing and treating potential breast cancer. Thus, for a problem like breast cancer that any woman might have, treatment was very competent and gracious; for a disability, especially one often perceived as resulting from irresponsible behavior, treatment was disorganized and stigmatizing.

In identifying what they consider to be important components of quality of health care, participants in each group distinguished between what they considered to be ideal health care delivery, what they considered to be desirable health care in the real world, and what care they actually expected to receive. When asked to explain the difference, many participants told us that they were so used to inadequate care that they just did not think it was possible to have access to high quality and adequate care. This included services such as personal assistance and durable medical equipment which generally are designed to maintain functional capacity.

As the discussions of salient factors and trade-offs in choosing a health care plan evolved, a spectrum of health care plan savviness emerged among participants in each group. Many members, especially women, were sophisticated consumers of health care. For them, issues such as whether the health plan covers abortions, permitted referrals for acupuncture and other alternative services, and provide specialized information on menopause and estrogen treatment played an important part in how they assessed the quality of care received. These people offered articulate advice about choosing a health care plan: "ask a very detailed question about an obscure service need such as acupuncture and see how they handle it," and how to maximize services: "make two back-to-back appointments with the same physician. This way you'll have enough time to get onto the examining table and be able to ask the doctor questions afterward."

These individuals were very adept at getting what they wanted from their health care providers using a combination of screening skills for provider selection and knowledge of system

operations to exert pressure on providers and payers in order to obtain services and products needed to maintain their health. Notwithstanding this apparent adroitness in obtaining needed services from a system that generally provides for few options, there were significant problems cited by group members. One participant receiving COBRA coverage from her most recent employer reported that because she could not obtain health care coverage from any other provider in the Houston area, she was forced to relocate to another area of the state.

Others belonged to a less sophisticated group of consumers with respect to exposure to choice of health care plans. As one participant put it, "I really have a lot of work to do. I really don't know anything about how to choose a health care plan." The lack of savvy was more prevalent in the Houston groups where choices are more limited and a significant number of participants had spent years enrolled in Medicare and/or Medicaid. We concluded that our efforts to design products to assist individuals in selecting health care plans need to be relevant to people who have not been faced with choices before and may have relatively little understanding of the influence of various factors on the quality, adequacy, and accessibility of health care services.

Despite the differing levels of knowledge and sophistication, each group agreed that cost was the most important factor influencing their choice of health care. For those in traditional fee-for-service plans, costs were followed by inclusion or exclusion of pre-existing conditions, provider experience with disability, coverage of personal assistance services and durable medical equipment, and range of covered services. Participants who are enrolled in HMOs were not concerned about pre-existing coverage and tended to rank range of covered services above all factors except costs. These findings are similar to findings obtained in focus groups with consumers conducted by the National Committee on Quality Assurance (Shelton, personal interview, 1995).

SOURCES OF INFORMATION

Without question the consensus among all groups was that the best information on health care plans could be obtained from persons with disabilities similar to one's own who also had experience with the plans under consideration. Any information generated by groups or methods that did not include significant involvement of people with disabilities was suspect, including information from company benefit managers, well-meaning relatives and friends, and co-workers without disabilities. Furthermore, participants preferred information based on the actual experiences of other similarly situated persons over didactic information even though the latter

IV. Results

may be provided by disability-specific consumer organizations like Independent Living Centers and the Muscular Dystrophy Association. At the same time, however, other sources of information were perceived as useful. Such input included marketing brochures, newspaper articles, contact with health plan staff, and health fairs. In *conjunction* with information and advice from peers, these additional sources were not only viewed as useful but also as necessary. We interpreted these comments as a demand for a diversity of reliable and valid data.

PROBLEMS WITH PLAN-PROVIDED INFORMATION

Focus group members clearly had difficulty with the information that was provided to them by the health care plan itself. Several individuals complained often of lack of forthrightness and quite bitterly of misinformation. Participants identified several aspects of a health plan for which they wanted detailed, accurate, and timely information, namely: (1) how the plan deals with workers' compensation claims, (2) track records of how they have treated people in the past, (3) what plan facilities provide what services, (4) availability of medication without additives, (5) access to medical records, (6) right to sue, and (7) evidence of gross negligence. Once again, these comments reflected demand for reliable, comprehensive, and accurate information.

KEY INFORMANT INTERVIEWS

One purpose of the key informant interviews was to confirm information provided by focus group participants. Although there was general agreement between experts and consumers with respect to salient factors people with disabilities should consider in choosing a health care plan, our experts raised additional concerns and framed focus group issues in different terms. Expert respondents emphasized access to speciality care along with the range or completeness of benefits. Some respondents added that being assigned to a specialist (e.g. pulmonologist) as a primary care physician was more important than allowing easy access to specialists. Reasoning like this led many respondents to identify choice of physician as a critical factor in choosing a plan. Some experts were able to cite specific data such as "women with disabilities see specialists more often than able-bodied women and they use emergency rooms more often, probably due to barriers to primary care."

It was in the area of information requirements that our key informants provided the most valuable advice. Like focus group members, key informants identified the need for same types of plan information (premiums, coverage, restrictions, etc.) and the need for subjective ratings based

on the experience of people with disabilities. But they also emphasized the need for external objective ratings (e.g. NCQA type accreditation) that takes into account the unique needs of high users of health care services. And like our focus group participants, the experts expressed a strong concern for reliability and validity, albeit from a professional, research-oriented perspective.

What our key informants made very clear, however, was just how difficult it is to achieve even minimum levels of reliability and validity. Many respondents emphasized the importance of standardizing plan comparisons and avoiding methodological biases by administering the same assessment tools in the same way. Likewise, in the analysis, developers of informational sessions should use consistent decision rules and (in the case of ratings and report cards) control for differences in health status. Others took a more philosophical approach, commenting that "health care is a moral enterprise so 'objectivity' may be impossible," and "just present the facts as best they can be determined. There are a lot of gray areas."

The key informants were strongly opinionated about whether the decision support system should take strong positions on what health care plans are good or bad for people with disabilities. Answers ranged from "Yes, to a great extent," to "be careful, unless you feel absolutely solid about comparability of data," to "I don't think it is at all appropriate. There is no 'best' plan for all individuals with disabilities." While the range of responses was wide, the most common response was simply to provide as much relevant information as possible for the user to make up his or her mind. When warranted, specific problems can be raised about specific plans as long as there are data to support the claim. This appeared to bring us full circle to the reliability and validity problems discussed earlier.

Finally, we inquired about what outcomes we should expect from someone who uses the decision support system. Some expressed skepticism that such an intervention would really motivate people to change. Others thought that the information would motivate people to change plans and that one could observe measurable indications such as reduced out-of-pocket expenditures and increased satisfaction with health care received. Still others suggested self-reported satisfaction with the information system and testing individuals along the line of a health insurance IQ test.

PRODUCT DEVELOPMENT

During the product development stage of the project, our goal was to develop *examples* of a range of informational materials under the rubric of **Choosing A Health Care Plan for Independent Living** that, in conjunction with other "low tech" and "high tech" products, are intended to reach a wide range of people with disabilities. The print-oriented guidebook and multimedia CD-ROM are not finished products. Rather, they are stylized examples of more fully developed and beta-tested products we will complete during Phase II. Much work remains to be completed. In this section we describe the two prototypes developed during Phase I.

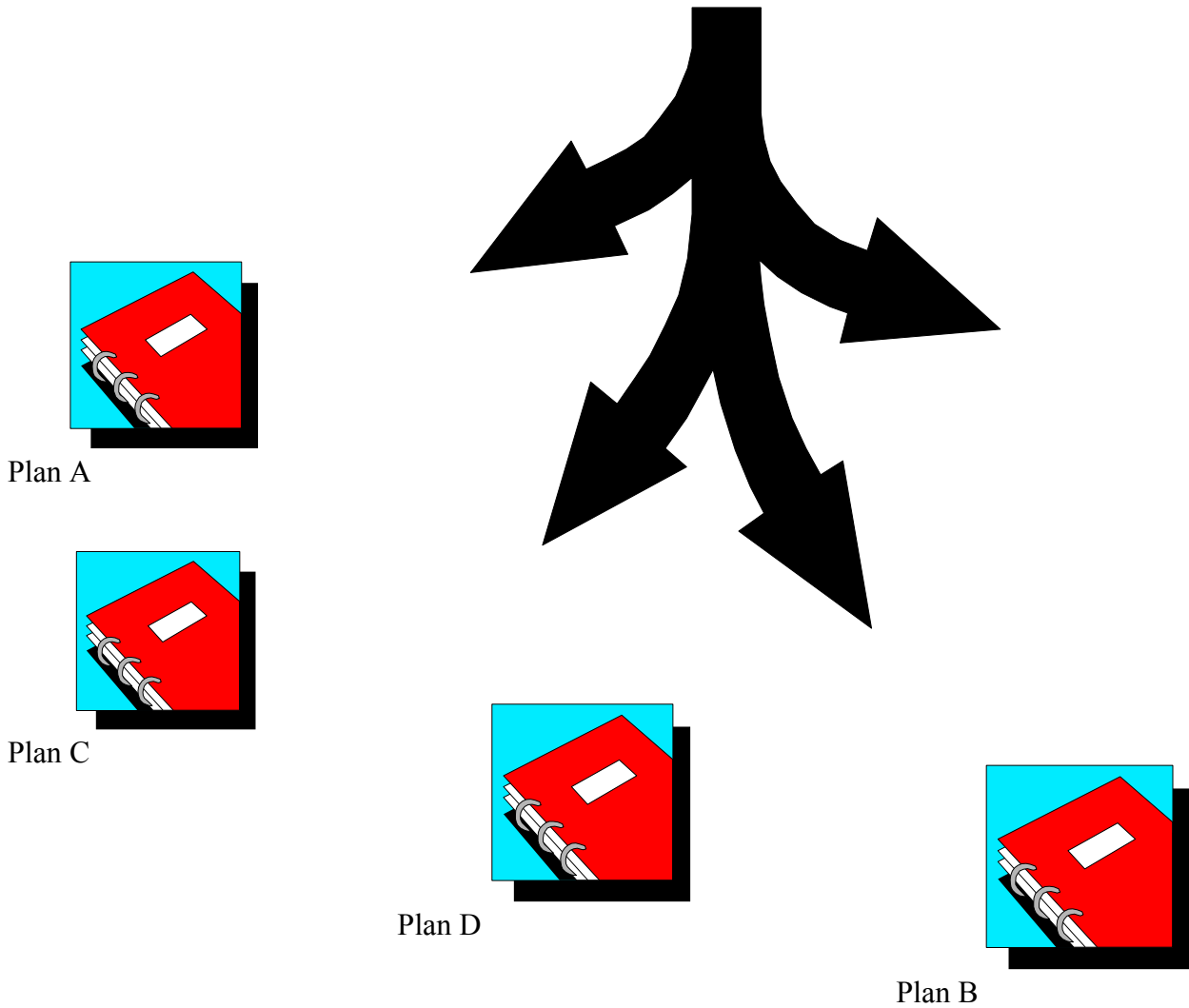
GUIDEBOOK VERSION

A complete draft version of the guidebook version of **Choosing A Health Care Plan for Independent Living** is provided in Appendix F. Figure IV-1 displays the cover page of the guidebook. It depicts the reality that many people with disabilities face choices in health care. Overtime, we believe that more and more persons with disabilities, even those with the most severe disabilities who qualify for Social Security Insurance (SSI) and Social Security Disability Insurance (SSDI) may be empowered to choose among different health care plans.

Figure IV-2 displays the table of contents of the guidebook version of **Choosing A Health Care Plan for Independent Living**. The guidebook consists of four sections. Section One is a question and answer discussion of health care plans based on major topics raised during the focus groups and by key informants. We strived to provide examples and facts while offering advice and examples questions that consumers should heed or ask of market representatives and other purveyors of plans. The question and answer technique is intended to engage readers in an inquiring and skeptical process of discovery.

**Figure IV-1
GUIDEBOOK COVER PAGE**

**Choosing a Health Care Plan for Independent Living:
A Guide for People with Physical Disabilities**



**Quentin W. Smith
Stuart Hanson
Lex Frieden**

Figure IV-2

CHOOSING A HEALTH CARE PLAN FOR INDEPENDENT LIVING

Table of Contents

Section One: Questions and Answers About Health Care Plans

- Purpose of Guide
- What is in the Guide
- Why the Guide is Needed
- Different Types of Health Care Plans
 - Indemnity (Fee-for-Service) Health Care Plans
 - Preferred Provider Organizations
 - Health Maintenance Organizations
- Getting Answers to Questions
- Things to Consider in Choosing Plans
- The Costs of Health Care Plans
 - Premiums
 - Deductibles
 - Coinsurance and Copayments
 - Cost Sharing and Services
- Planning for Other Health-Related Expenses
 - Medically Necessary Services
 - Usual and Customary Charges
 - Other Cost Issues of Concern
 - Dollar Limits on Coverage (Lifetime Maximum Cap)
 - Other Things to Consider that Affect Health Care Costs
- Evaluating Cost Considerations and Range of Services
- Types of Services and Products that are Covered Under Different Plans
- What Your Health Care Plan Won't Cover
 - Exclusions and Limitations
 - Restrictions on Selection of Health Care Professionals
 - Is the Plan with the Most Comprehensive Services Always Best?
- Getting Information on the Quality of Services Available Through Different Plans
- Other Sources of Health Care Plan Information
 - Independent Living Centers
 - Rehabilitation Hospitals
 - Disability Service Organizations
 - Disability and Technical Assistance Centers (ADA)
- The "Bottom Line" on Health Care Plan Choices

Section Two: Worksheets for Assessing Health Care Plan Choices

Section Three: Glossary of Health Care Plan and Selected Disability Terms

Section Four: Contact Information on State Insurance Departments

Section Two provides worksheets for consumers to assess the cost and adequacy of their health care plans. This sections helps the consumer to examine specific features of a health care plan. Section Three is a glossary of important term in the health care field. Section Four provides contact information on state insurance departments. These agencies are usually the primary regulatory agency to which consumers should direct complaints.

CD-ROM VERSION

The prototype CD-ROM version of **Choosing A Health Care Plan for Independent Living** was designed to provide interactive access to a wide range of information on choosing a health care plan. The CD-ROM program is designed to work on both Apple and PC platforms. Figure IV-3 displays the opening screen of the program—a picture of an idealized study carrel such that one might find in the most modern of libraries. The carrel contains a TV screen, a boombox radio and tape player, a set of books, a clipboard upon which are several topics, and a light switch which allows the user to exit the program. After the program credits and disclaimer role through the TV screen accompanied by music, a narrator welcomes the user and tells she/he that moving the arrow over any item on the screen will cause a brief explanation of the contents of that item to appear on the TV screen. By double clicking on the item, the user can enter a specific subprogram. A narrator then explains how to use each subprogram. To exit any given subprogram, the user may double click on the EXIT sign.

For the prototype, we opted for a study carrel scenario. We considered two alternative metaphors/scenarios, namely (1) a modern marketplace or an aisle in a supermarket, and (2) A booth at a health fair. During Phase II we will have the opportunity to develop these scenarios and submit them to focus groups for guidance.

Below is a brief description of the contents of each item in the study carrel.

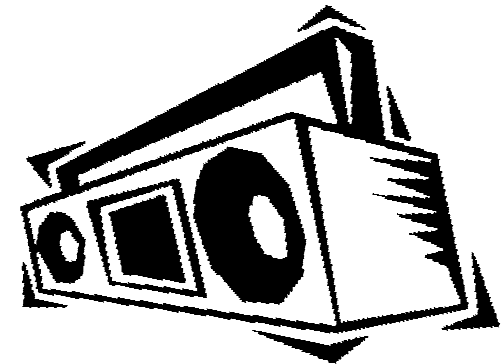
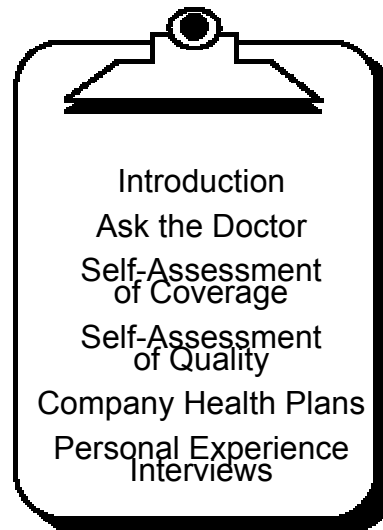
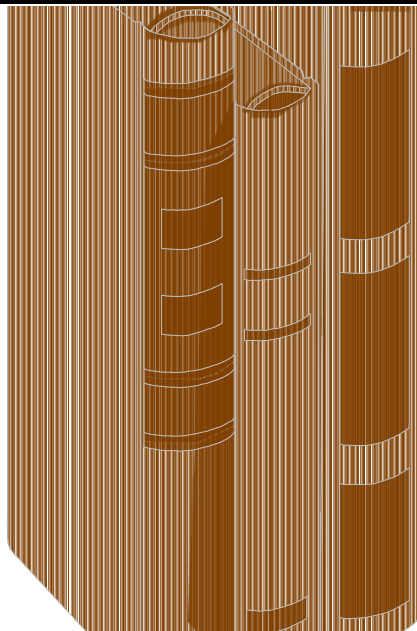
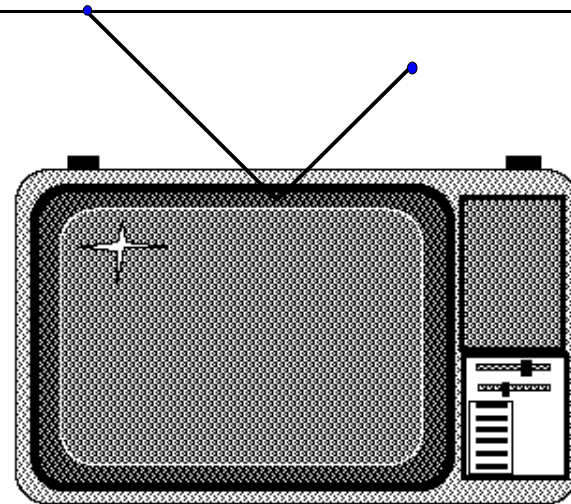
- ! Credits/Disclaimer:** authors, acknowledgements, credits, and a warning that people should consult a medical professional about medical problems.

Figure IV-3
CHOOSING A HEALTH CARE PLAN FOR INDEPENDENT LIVING
CD-ROM VERSION

[OPTIONS]

[PLAN INFO]

[MENU BAR]



! Books:

Glossary: Same as glossary in printed guidebook version.

Legal Guide: Questions and Answers regarding one's rights to health care benefits and employment under the Americans with Disabilities Act of 1990.

Resource Guide: Books and other material related to health care and disability.

Bibliography: A list of academic and popular literature on health care, consumer choice, and disability.

! Radio: Health Plan Talk Radio Questions and Answers: a talk format designed to raise common questions about health plans based on real questions, complaints and advice consumers might have about choosing a health care plan and making the best of the situation once one has enrolled.

! Clipboard:

Introduction: A five-minute video of Lex Frieden, Vice President of The Texas Institute for Rehabilitation and Research and former chair of the National Council on Disability. Lex argues why it is important for people with disabilities to become well-informed consumers of health care plans.

Ask the Doctor: A ten-minute video of Dr. Jonathan Strayer of the Baylor College of Medicine in Houston, Texas. Dr. Strayer answers questions about the health care needs of people with physical disabilities over the life course. The user may select from a menu of questions addressing the health care needs of specific age groups and those of men and women.

Self Assessment of Coverage: This series of questions asks the user to indicate what health care services they needed during the last twelve months and whether the user's health care plan covered (full, partial, or not at all) that service. A "coverage quotient" bar at the bottom of the screen keeps a running total of the percentage of health care needs covered.

IV. Results

Self Assessment of Quality: A series of questions mostly drawn from the AHCPH-sponsored prototype national survey of consumer satisfaction with health care. This component asks the user to rate his/her current plan on 19 dimensions of quality of care (Poor to Excellent). Upon completing the questionnaire, the user may then view a bar chart of his/her ratings ("My Plan"). The user may also see how other people with disabilities rate their plan. In the prototype we show two other ratings: Rob's plan (PruCare) and Maureen's plan (Kaiser North). In the fully developed product we will add many more personal ratings as well display averages.

Comparing Personal Experiences: Videos of two individuals (Rob and Maureen) with disabilities answering specific questions about their reasons for choosing their current plan. The user may view the entire video of each individual or may opt to hear the answer to specific questions. In the more fully developed product, we will provide more of these personal experience videos including videos of people who have disenrolled due to cause.

Comparing Health Plan Ratings: This component uses charts to compare the benefit structure of a typical HMO, PPO and FFS plan. It also reports the accreditation rating of various plans in the region (limited currently to HMOs reviewed by the Nation Committee on Quality Assurance). We also provide a chart comparing the consumer satisfactions rating developed by the Bay Area Business Group on Health for the specific plans in the prototype. Definitions of the terms used in the charts are provided as are explanation of how NCQA accredits plans and how BBGH measures consumer satisfaction.

! **Menu Bar:** At the top of the study carrel is a "Menu Bar" from which different menu may be "pulled down" by double clicking on the item.

Options: This feature allows the user to select a closed-captioned, Spanish translation, or voice activated version of the CD-ROM program. The current prototype does not yet have these features. These and other techniques to make the CD-ROM more accessible will be added to future versions of the program.

Plan Info: Brief descriptions of specific health plans. Current list includes Aetna (PPO), Health Net (HMO), Kaiser North (HMO), PruCare of California (HMO),

TakeCare (HMO), John Alden Life (FFS), and Employers Health Insurance (FFS). These blurbs are based on marketing material provided by the plans. They are not intended to be comprehensive or necessarily accurate. We are just passing on how each plan describes itself.

! **Documentation:** A complete set of written documentation is provided with the CD-ROM including:

- (1) Limitations and Known Defects
- (2) Getting Started
- (3) Technical Notes

INDEPENDENT REVIEWER COMMENTS

The CD-ROM and accompanying documentation were evaluated by two independent reviewers: Lawrence Boyd, Ph.D., an expert in computer technology and disability; and Gerben DeJong, Ph.D., a well-known expert in disability policy, health care, and consumer choice. Dr. Boyd also asked a colleague, Dr. Jan Hecht, of the Department of Special Education at the University of Southern Connecticut, to provide additional input. Dr. Hecht, who is visually impaired, is an expert in adapting computers to individuals with sensory and physical impairments.

Dr. DeJong's comments did not arrive in time to be submitted with this report. His comments will be submitted as part of the Phase II application.

V. CONCLUSIONS

OVERVIEW

In this chapter, we summarize the major research findings and product development results of this project. We also discuss the implications of the findings for consumer choice research and the feasibility of conducting further product development under Phase II of the SBIR program.

SUMMARY AND IMPLICATIONS OF MAJOR RESEARCH FINDINGS

Based on focus group interviews conducted in Oakland and Houston, people with physical disabilities share common priorities in choosing among different health care plans. First, they share a common hierarchy of concerns at the top of which are the costs (premiums, copayments, deductibles, and hidden out-of-pocket expenses). For those with experience mainly in fee-for-service plans, the cost factor is closely followed by concerns about pre-existing condition restrictions, followed by the range of covered services with emphasis on durable medical equipment and personal assistance. Quality of care, while viewed as necessary, ranked last in this hierarchy. Participants who are enrolled in HMOs were not concerned about pre-existing condition exclusions, but otherwise share the same hierarchy of values in choosing a health care plan.

While there seems to be nothing surprising about these findings, what stood out was the urgency expressed in the need for durable medical equipment and personal assistance. Without them, participants reported that their health status and functional capacity would worsen, and they would find it difficult to fulfill their social roles as husband, wife, lover, friend, and worker.

Despite these expressions of concern, it is remarkable that many participants looked fatefully at choosing a health care plan. Many expressed disbelief that choice is genuine. And most members distinguished between what is ideal (e.g., personal assistance as a health care cost), desirable (full vs. partial coverage for durable medical equipment), and real (only partial reimbursement for durable medical equipment and no custodial personal assistance). Many people, matter-of-factly, did not expect any health care plan to provide what they really need.

V. Conclusions

Another major finding is the clear expression of the need for reliable and valid information upon which to base their decision to subscribe or enroll in a given health care plan. For focus group participants, reliable and valid information meant information based on the experiences of people like themselves. At the same time, other sources of information, including professional assessments of quality of care, were welcomed and often highly valued, as long as this information is consumed *in conjunction with* the real life experiences of one's peers.

Expert feedback also emphasized the need for reliable and valid information, and just how difficult it is to achieve. Our experts seemed to be telling us that many informational products and services including popular guidebooks, consumer ratings, and other services have poor reliability and questionable credibility. We should be careful to develop valid and reliable measures of quality of care, administer them with the same rigor that a well-designed consumer survey is administered, use consistent decision rules in the analysis of the data, and control for different levels of health care utilization and other factors.

SUMMARY AND IMPLICATIONS OF PRODUCT DEVELOPMENT RESULTS

During Phase I, the project team designed and developed one "low tech" and one "high tech" component of a decision support system to help people with physical disabilities choose health care plans. The "low tech" product is a complete guidebook consisting of questions and answers about choosing health care plans, worksheets, a glossary of important terms, and a resource guide. The "high tech" product is an interactive CD-ROM program consisting of text, narration, videos, a radio program, and self-assessment exercises.

Although the guidebook and CD-ROM are not flawless, we feel that they are substantial, valuable, and practical contributions to the goal of enhancing consumer choice among people with disabilities. We have demonstrated that useful "low-tech" and "high tech" products can be developed with limited resources that not only respond to the information needs of people with disabilities as articulated by our focus group participants, but also can be prepared in engaging and interactive formats. For these reasons, we have met or exceeded every objective and goal of this Phase I project.

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