

Designing Accessible Managed Care Services for People with Physical Disabilities: Consumer Suggestions Within an Emergent Design Process

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ABSTRACT. Persons with physical disabilities have difficulty accessing health care. This has become more pronounced with the emergence of managed care and other efforts to limit growing healthcare costs. In responding to a state's Medicaid office interest in designing accessible health services, a consumer-based evaluation including a series of nine focus groups (96 participants) was conducted using an emergent design method. Our inductive analysis approach identified difficulties and provided the basis for recommending strategies to improve access. Two sets of consumer recommended strategies consistently were expressed during this process: (1) initiating one-to-one advocacy to improve local service coordination and (2) performing person-centered planning at enrollment in a managed care plan to facilitate appropriate and prompt access. These access strategies formed the basis for a later intervention design. *[Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <<http://www.HaworthPress.com>>© 2004 by The Haworth Press, Inc. All rights reserved.]*

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Providing services within a managed care environment to people with significant physical disabilities often necessitates complex coordination and educational approaches. While managed care providers are concerned about providing care that is accessible within a limited budget and developing responsive networks of care, consumers with disabilities frequently need or desire services beyond the scope of newly initiated health plans. In order to design health services that would address these conflicting desires, a cooperative approach was initiated involving persons with physical disabilities and representatives from the state's health planning agency. Investigating this issue included gathering of information from healthcare literature, perceptions of consumers with disabilities enrolled in managed care, and suggestions from key informants.

The convergence of themes between the literature and the beliefs of consumers was assessed during a series of nine focus groups. This review lead to two implementation issues being studied:

- Requisite training/skill building for a broad population of Medicaid beneficiaries with disabilities that includes self-advocacy and supports coordination within a managed care environment.
- Local advocacy roles in brokering and coordinating Medicaid and non-Medicaid services to persons with severe physical disabilities.

Three themes emerged from this initial review: accessing health care/remaining healthy, improving the quality of care, and advocacy and education. Below, these three themes are discussed.

Accessing Health Care/Remaining Health: People with disabilities have traditionally experienced difficulty accessing health care. Inaccessibility and lack of fulfillment with health plans is reflected by frequent complaints concerning access, cost, and quality of services. An Independent Living Research Utilization-Houston ILRU (1998) study found that access was the cause of a complaint by 26.7% of those questioned, cost/finance by 23.7%, and quality of care by 11.0% for persons with physical disabilities. It further estimated that 63.2% of these complaints were specifically related to their disability. Identifying and measuring satisfaction is further compounded by the lack of choice and

frequency of services (Wolf-Branigin, Daeschlein, Cardinal, & Twiss, 2000), and consumer satisfaction of Medicaid participants in managed care (U.S. Department of Health and Human Services, 1996). The latter study further indicated that 55% of the health maintenance organizations (HMOs) had never conducted consumer satisfaction surveys of people on their Medicaid plans.

The financial benefits of addressing primary health issues of people with disabilities at an early stage have long been known (Batavia, DeJong, Halstead, & Smith, 1988; Smith & Ashbaugh, 1995). Reducing the incidence of secondary conditions by providing appropriate rehabilitative services and equipment produced substantial cost savings while early resolution of primary health care problems significantly reduced costly hospitalizations. Providing services such as a personal assistant was viewed as one method of significantly reducing inpatient and long-term care expenditures.

Improving Quality of Care: A common theme espoused is that health is not only the absence of disease, but good quality of life (ILRU, 1998). To strive for this quality of life, it is suggested that consumers take increased responsibility for their health situation. This could be achieved through advocacy and peer support services where information about healthy living is provided and understandable, and when sufficient information to make good health care choices is available. Batavia et al. (1988), and Smith and Ashbaugh (1995) further recommend that health plans should maximize consumer's long-term health status by improving functioning and independence via preventative and primary care.

Advocacy and Education: Addressing primary health by providing prevention, early detection, informed intervention, and access to physicians knowledgeable of their health care needs plays a vital role. The importance of assuring proper health care through governmental plans is further documented as 36.2% of people with a severe disability receive health care through Medicaid or Medicare plans.

Following this review and discussions with key informants of advocacy and professional organizations, six themes were identified as the basis for focus group discussions.

- Prompt health care reduces costs of treating secondary conditions.
- Consumers with disabilities have information and referral needs centered upon managed care.
- People need information and supports to make good healthcare decisions.

- People have worries and concerns about health care options made available to them.
- Barriers may occur if an assessment instrument determines medical/service needs.
- A person's disability affects his/her health and access to health care.

These six themes formed the recommendations for designing managed care services.

METHOD

Population and Sample

The 96 focus group participants represented a range of people with physical disabilities. To assure that people most likely to be affected by this transition to Medicaid managed care were represented we used purposive sampling. Because managed care plans have been phased into various parts of the state at different times, some of the beneficiaries had six months experience with managed care services. Therefore, some of the opinions may reflect a limited view.

The most frequently self-reported disabilities were related to having cerebral palsy, a spinal cord injury, post-polio syndrome, and multiple sclerosis. One-third of the participants reported that they had a cross disability. The sample was 49% male and 51% female, with ages ranging from 20 to 67 (median age 38). Ninety-four of the 96 respondents indicated that they were currently enrolled in a managed care plan with 95.7% having received services.

Focus Groups and Key Informants

This phase of the project used a design evaluation approach (Gardner, 2000). Questions posed to the focus group participants went through a series of revisions with the input of a variety of consumers, professionals, and organizations. Participants were requested to respond in the context of their recent experiences with managed care health plans. Following completion of a field test, focus group questions were revised and reordered.

The size for eight of the groups ranged from six to thirteen; one focus group had 24 participants. The mean focus group size was 10.7. A consistent protocol was used throughout. At the beginning of each focus group, the facilitator provided a brief overview of the project and stated that four questions would be asked with additional prompts to elicit further detail. Each group lasted approximately two hours. Immediately following these groups the facilitator asked staff for additional comments and insights. Key informants were included to obtain additional detail on various issues. Debriefing was available for these staff at the conclusion of each group. A total of 17 key informants participated. The following questions were posed to each group.

1. What problems do you experience obtaining health care?
2. What could be done to improve the quality of health care you receive?
3. How has your disability affected your ability to get health care?

Has access to a doctor been restricted?

Has access to a specialist been restricted?

Has access to an equipment supplier been restricted?

4. What kind of information has been given to you about staying healthy?

About preventing other illnesses?

About other conditions or complications?

Data Analysis

Summaries were written following each focus group. Using an inductive analysis and creative synthesis analytic strategy (Patton, 2002), trends from each summary were identified whether or not the six themes had been stated at each meeting. Frequency of responses was solely based on whether an issue was addressed within a group, not by individual responses. This approach assumed that if other members in a group heard a response, they would not have to repeat it.

RESULTS

The results related to each of the six themes are discussed below:

1. *Prompt health care reduces costs of treating secondary conditions.*

Physicians who did not accept people with certain disabilities into their practice were a major concern. Furthermore, participants frequently stated that accessing specialists was confusing and often not approved by the primary care physician. Because primary care physicians are limited in the number of enrollees, participants in four focus groups stated that they had to wait three to five months for appointments. Similar waiting periods to schedule an appointment with specialists were also noted. Several of the groups expressed that they would prefer to have a specialist as their primary care physician.

2. Consumers have information and referral needs centered upon managed care.

While there appeared to be a dearth of information on staying healthy provided by the managed care organizations, a few of the more established health plans appeared to satisfactorily address this issue. Many individuals indicated that physicians provided limited information. On more than one occasion, participants stated that they believed there was a lack of information because health providers believed the person "could use a vice (i.e., smoking, overeating, substance abuse) to help them deal with their disability." People who participated in this study viewed this attitude, on behalf of the health care providers, with disdain.

A popular belief among the participants and the Centers for Independent Living (CIL) key informants was that a centralized knowledge base could be used by consumers to facilitate the prevention of secondary conditions. It was further expressed by these individuals that such a knowledge base could be used to inform people with disabilities, who were not currently involved with neither the CIL network nor a managed care organization, about preventing and reducing secondary conditions. Suggested topics for the knowledge base included:

- Education about prescriptions
- Depression and substance abuse as common secondary conditions
- Information on working through the managed care process

3. People need information and other supports to make good health care decisions.

Participants believed that people not involved in the CIL network were less likely to have sufficient supports to obtain information for making

good health care choices. This phenomenon was further evident within the focus groups as individuals appeared to benefit from information exchanges on managed care access and knowledge with the other beneficiaries. Many individuals stated the Internet was their best source of information on disability related issues, and suggested that managed care providers similarly use this resource. Information concerning services either provided or funded by the managed care organizations was often not available. A few participants viewed this as an intentional attempt to limit expenditures.

4. People have worries and concerns regarding the health care options available to them.

Consumers from all focus groups generally thought they knew more about their disability than their primary care physicians. While this concern was expected due to a wide network of support in which the sample was involved, participants believed many physicians were unwilling to spend an adequate time understanding their disability. An additional concern was the frequency of being shifted from a physician who was more knowledgeable of their disability (prior to managed care being implemented) to a physician with more time constraints (following managed care implementation).

5. Barriers occur when an assessment instrument determines medical/service needs.

When participants were asked to respond to the possibility of implementing a brief screening/assessment tool, most responses were negative. The following concerns were most prevalent.

- Afraid of quick answers by a nurse or general practitioner (primary care physician) without taking into consideration the opinions of specialists
- Such an instrument would be used to label or exclude people
- Disbelief that an adequate assessment could be performed with only three to five questions
- Too many types of disabilities to make such an instrument practical

6. *A person's disability affects his/her health and access to health care.*

Another theme centered on participants being uncomfortable about the rates paid to physicians under managed care plans. There was a belief that these lower rates lead to less qualified providers. Others stated that many physicians needed high volume to maintain income streams. These trends were less frequently mentioned in urbanized regions. All participants indicated that their disability affected their health care access. The issues focused on access to specialists who had knowledge of their disability, limited ability to purchase durable medical equipment, transportation to services, managed care staffs' lack of sensitivity, and problems obtaining specific services. These services most frequently included dental care, optical examinations, and mammograms. Specific comments, which were nearly universal across groups, included:

- Restricted access to physicians, specialists, and equipment
- Physical inaccessibility to medical offices and equipment
- Durable medical equipment not correctly sized, hard to get, and improperly fitted
- Keeping a physician knowledgeable of their disability as their primary care physician
- Limited access to continue preventative health care (e.g., optical and dental)
- People who cannot advocate for themselves having problems getting access
- Plans infrequently use sign interpreters
- Exams may not be thorough if the person with a disability is unable to express him/herself

All focus groups reinforced the idea that the most comprehensive prevention is prompt access and treatment. Table 1 highlights current issues participants had with managed care plans relative to the two components relating to this study.

STRATEGIES FOR PROGRAM DEVELOPMENT

Two sets of strategies recommended by consumers dominated the process; initiating one-to-one advocacy and person-centered planning at time of enrollment in a managed care plan. It was believed that local service coordination would best be provided via one-to-one advocacy

TABLE 1. Consumer Concerns

Consumer Competency	Local Service Coordination
Consumers not educated on plan options	Personal assistant frequently needed at medical appointments
One-to-one advocacy services not provided regarding: <ul style="list-style-type: none"> • Getting control of your health care • Working through the system. • Using behavioral health benefits 	Health facilities and equipment were often physically inaccessible; including medical offices, optical exams, radiology, mammograms and other services
Consumers not knowledgeable of what their plan covers (e.g., transportation, exams)	Health plans did not employ physicians and other staff who were knowledgeable of disabilities
Consumers unaware of their rights as consumers	Specialists experienced in disability are not used as primary care physicians
Information on staying healthy not consistently available	Plans not providing information consistently on staying healthy
Consumers unable to communicate with systems, particularly during evening hours	Insensitive or impatient telephone personnel identified

organizations. Strongly linked to these recommendations was that a patient "bill of rights" be implemented. It was resolutely suggested that such a revised rights system should be unlike the practices that community mental health agencies currently follow throughout the state. Most consumers did not feel they were in partnership with their health care provider.

Remaining Healthy/Avoiding Secondary Conditions: Focus group participants appeared knowledgeable on avoiding secondary conditions. The problem centered more on their ability to receive timely referrals to specialists and appropriate durable medical equipment. The use of advocacy services would be valuable in further educating people with disabilities on avoiding these conditions. Accessing behavioral health services (especially treatment for depression and substance abuse) has been difficult under managed care for participants. A RAND (1998) study, found overall quality of care for depression provided by managed care plans was less than optimal, while plans that increased mental health benefits had substantial long-term reductions in mental health costs.

Additional recommendations on staying healthy included a request that managed care organizations subsidize membership to barrier-free health clubs and implement a patient's "bill of rights." All consumers should be made aware of this, including the appeals processes and other

educational information. The final recommendation for avoiding secondary conditions was to use specialists, particularly psychiatrists, as people's primary care physicians. Focus group participants expressed a level of confidence that these specialists better understood the complexities of their disabilities and the resultant care necessary.

Careful Use of Assessment Tools: Focus groups indicated that great caution should be practiced if an assessment instrument is used to identify which health plan best serves an individual. Participants wanted assurances that such an instrument would be administered only after the individual was admitted into the plan. If administered prior to admission, it was perceived that this might only serve as a means for keeping people with disabilities out of managed health care plans.

Advocacy Services: Groups expressed that peer support would provide the most valuable resource for individuals first encountering the managed care system. The groups further indicated that this is particularly evident with people who have a recently acquired disability. An additional recommendation is to develop a patient bill of rights. Such a bill may include suggestions made by Miller (1998) including:

- Assuring personal and medical privacy
- Managed care organizations using accurate advertising
- Avoiding deceptive language
- Maintaining traditional scientific ethics
- Medical professionals practicing only in their area of expertise
- Avoiding conflicts of interest
- Assuring informed consent is practiced
- Knowing what the real costs of health care are

Educational Services: Improving educational services is a strong complement to improving consumer competency. Focus group participants and key informants provided several consistent recommendations in this area including:

- Provide disability specific information
- Assist new enrollees with enrollment forms and choosing the plan that best meets their health care needs
- Provide a comprehensive list on what is and is not covered (be specific so people with disabilities can choose right plan)
- Address transportation better by informing people that the health plans should be providing assistance
- Provide advocates to explain process

Improving Quality of Care: Participants indicated that a demonstration using specialists as primary care physicians would be the best method to improving quality of care. This single change would address several concerns of current consumers, including simplifying and improving access to specialists, having a physician knowledgeable of their specific disability, and reducing waiting times for appointments. Strategies to improve managed care services are summarized in Table 2.

TABLE 2. Summary of Strategies

Activity	Strategy Description
Provide advocates	<ul style="list-style-type: none"> • Implement a peer support program
Improve access to specialists	<ul style="list-style-type: none"> • Encourage health plans to reimburse specialists who treated individuals prior to managed care enrollment
Treat consumer with respect	<ul style="list-style-type: none"> • Train people who operate telephones to be respectful • Allow sufficient time at medical appointments
Improve access to services	<ul style="list-style-type: none"> • Have specialists as primary care physicians • Improve telephone and other communication systems
Have access to dental services	<ul style="list-style-type: none"> • Provide education on availability of dental care through traditional Medicaid. Identify dentists who have accessible offices
Provide consistent information on staying healthy	<ul style="list-style-type: none"> • Have approach where consumer and provider act in partnership for the responsibility of remaining healthy • Information provided by health plans must be understandable
Educate about secondary conditions	<ul style="list-style-type: none"> • Expand Internet access on disability education • Consumers and health plans work in partnership to provide accurate and timely information
Reduce secondary conditions	<ul style="list-style-type: none"> • Provide timely care and access to specialists. • Advocate for behavioral health benefits • Provide properly fitted and correct equipment
Encourage consumer empowerment	<ul style="list-style-type: none"> • Link to Recipient Rights department. Process for complaints needs to be provided to consumers • Have person-centered planning available at enrollment
Use assessment tools cautiously	<ul style="list-style-type: none"> • Assure assessment tool is only used following enrollment • Use instruments sensitive to persons needs

DISCUSSION

Obtaining the input of persons receiving health services is vital to successful implementation of managed care services for persons with disabilities. We attempted to provide planners and funding sources with consumer centered information addressing the medical supports and needs of this population within a cost efficient framework. Given the person's knowledge of his/her disability and the newness of these health provider models, the utility of the person's input is vital.

Participants recently enrolled in managed care experienced difficulties and delays in obtaining health services. They reported that physicians from whom they had been receiving health care prior to implementation of managed care were often not on the panels for the managed care organizations in which they are presently enrolled.

Access to specialists previously used by the individuals with whom they felt comfortable remained a concern. Referrals to specialists who did not accept Medicaid was a frequently identified problem especially in relation to the limited incomes of participants. When assigned to a Medicaid managed care plan, people were often unable to maintain continued services with the same specialists.

Receiving a referral from their primary physician to see a specialist was repeatedly identified as a problem. This issue was further exacerbated by the difficulty in receiving referrals to female physicians. While much of this access to specialists can be explained by the logistical issues centered on newly created systems, consumers repeatedly stated that their access to specialists was better prior to managed care. To address this issue, providers should review their panels to assure that a sufficient number of specialists are on their panels that are knowledgeable of the unique interactions and problems related to various disabilities.

There was near universal agreement among the focus groups that obtaining health care was currently more difficult than before managed care. People were nearly evenly split on whether they chose the plan with which they were currently enrolled, or had been automatically enrolled because they did not select a particular plan.

A strong convergence between the six themes identified in the literature and consumer input occurred, with the exception centered on consumer lack of control. The greatest dissonance between consumers and the literature was the degree to which people with a disability knew how to avoid secondary conditions. Most people indicated that they knew how to avoid secondary conditions, however, receiving the necessary care or equipment was beyond their control. Preventing these conditions needs to become an educational priority for the managed care organizations by providing timely referrals to specialists and equipment. Table 3 summarizes these themes and evaluation findings.

TABLE 3. Evaluation Findings

Expected Theme	Evaluation Finding
Prompt health care reduces costs of treating secondary conditions	<ul style="list-style-type: none"> • Participants supported this theme, people know how to avoid secondary conditions, however, some plans did not provide prompt service • Behavioral health services, especially depression and substance abuse treatment, were difficult to obtain
Consumers with disabilities have managed care related information and referral needs	<ul style="list-style-type: none"> • Few primary care physicians were knowledgeable of disabilities. Those that were usually did not participate in the managed care options available to participants • Participants were interested in having specialists as primary care physicians
People need information and supports to make good health care decisions	<ul style="list-style-type: none"> • Adequate or understandable information was often not provided to consumers at time of enrollment • Telephone contact with care system was frequently frustrating
People have concerns regarding the health care options available to them	<ul style="list-style-type: none"> • Focus group participants frequently expressed suggestions that an advocate could guide them through the complicated process of choosing among options
Barriers occur if assessment tool used to determine needs	<ul style="list-style-type: none"> • Participants expressed concern that such an instrument would be used to deny admission or would be too brief to provide sufficient information
A person's disability affects his/her health and access to health care	<ul style="list-style-type: none"> • In most parts of the state transportation and the physical layout of medical facilities remain barriers

REFERENCES

- Batavia, A. I., DeJong, G., Halstead, L. S., & Smith, Q. W. (1988). Primary medical services for people with disabilities. *American Rehabilitation*, 14(4), 9-12, 26-27.
- Gardner, F. (2000). Design evaluation: Illuminating social work practice for better outcomes. *Social Work* 45(2), 176-182.
- Independent Living Research Utilization-Houston (1998). *Empowerment in managed health care: People with disabilities in a changing health care environment*. Houston: ILRU.
- Miller, I. (1998). *Eleven unethical managed care practices every patient should know*. Commack, NY: The National Coalition of Mental Health Professionals and Consumers, Inc.

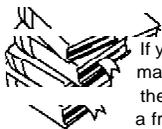
- Patton, M. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.
- Rand Corporation (1998). *Improving the quality and cost-effectiveness of treatment for depression*. Santa Monica, CA: Research Highlights.
- Smith, G., & Ashbaugh, J. (1995). *Managed care and people with developmental disabilities: A guidebook*. Alexandria, VA: National Association of State Directors of Developmental Disabilities Services.
- U. S. Department of Health and Human Services. (1996). *HMO customer satisfaction surveys*. Washington, DC: Office of the Auditor General.
- Wolf-Branigin, M., Daeschlein, M., Cardinal, B., & Twiss, M. (2000). Differing priorities of counselors and customers to a consumer choice model in rehabilitation. *Journal of Rehabilitation*. 66(1), 18-22.

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