Meeting information needs to facilitate decision making: report cards for people with disabilities[1]

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Abstract

Background Several states within the United States offer low-income adults with disabilities a choice of health plans. No states issue comparative 'report cards' specifically for adults with disabilities.

Objective To explore conceptualizations of quality, information needs, and report card preferences from the perspective of people with disabilities.

Research design Eight focus group interviews were conducted in 2003. Existing report cards for California, Maryland, Michigan and Texas were shared for feedback.

Subjects 34 women and 15 men with various behavioural, physical or sensory disabilities in Oregon, California, Virginia, Maryland and the District of Columbia.

Results Quality was mostly defined in terms of choice and disability sensitivity of service providers. Respondents identified various obstacles to receiving appropriate health plan and service information. All beneficiaries were keenly interested in the comparative health plan report cards, but did not think the report cards provided enough pertinent information, especially with regard to provider ratings, accessibility, disability competence and reasons for participating in the Medicaid program.

Conclusions Existing comparative report cards omit several major content domains important to people with disabilities. Organizations providing decision support to people with disabilities should cultivate novel avenues for distribution, such as food banks, libraries and places of worship.

Introduction

A growing number of states in the United States are offering a choice of delivery systems to adult Medicaid (people with low incomes) beneficiaries who have disabilities or complex medical needs.[1] As public reporting of provider groups and health systems becomes more widely available in the United States,[2] a few states preparing and distributing Medicaid

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'report cards' to help beneficiaries select the health insurance plan that is the best match for their needs.[3] A major data source for the report cards is the Medicaid Consumer Assessment of Health Providers and Plans Survey (Medicaid CAHPS®), fielded by 60% of the states. Report cards range from a one-page chart (e.g. Michigan, Maryland, Wisconsin) to multi-page booklets (e.g. California, Texas). Typically, report cards include information on quality indicators such as customer service, access to needed care, health screenings, preventive health care and specialist services for, for example, diabetes. An online search tool that allows users to locate report cards for various public and private health plan types can be found on the website of the National Committee for Quality Assurance (NCQA).[4] Some states supplement the CAHPS® survey data with information compiled from Medicaid claims or medical records. Yet, studies suggest that most consumers have trouble articulating 'quality' and do not use the existing report cards to make their enrolment decisions.[5,6]

O'Day et al. were among the first researchers to investigate how people with disabilities assess health plan quality.[7] They conducted 11 focus groups of 57 adults with disabilities in Phoenix, Philadelphia and Washington, DC in 1999. The participants had mobility impairments arising from spinal cord injury (SCI), cerebral palsy (CP), multiple sclerosis (MS) or rheumatoid arthritis (RA). O'Day et al. found that people with mobility impairments resulting from the studied conditions desired information about the same content areas as people without physical disabilities – but additional content was desired on the reliability of transportation to medical appointments, the ability to use an experienced and knowledgeable specialist as a primary provider, and accessible buildings and examination equipment. The objective of the present study was to explore perceptions of quality health care, access to health information and report card preferences from the perspective of Medicaid beneficiaries with disabilities not limited to MS, SCI, CP or RA.

Method

We used a qualitative approach to explore perceptions and experiences with regard to quality, information access and report card content/format. Focus group methodology was selected to generate a substantial amount of data in the most efficient way while empowering participants to share their views, concerns and experiences.

Participant selection

Participants were recruited through announcements distributed by Centers for Independent Living in Washington, DC, San Bernardino, CA, Baltimore, MD, Portland, OR and Arlington, VA. The inclusion criteria were: age of 18–64 and current Medicaid enrolment, entitled through disability. People who were institutionalized or unable to follow a topical discussion in English were excluded.

We determined the prevalence of disabling conditions among those who met the inclusion criteria based on unpublished data from the Center on Disability Statistics at the University of San Francisco. We used the weighted average prevalence to determine the desired distribution of diagnoses across our target participants. Each study site tried to recruit a participant mix that mirrored this distribution. We offered meeting times on a weekday evening, on a weekend and during a weekday to maximize the opportunity for participation.

Focus group topic guide

The topic guide highlighted subject areas in need of further research previously identified in the literature on use of consumer health quality report cards: types of health-care providers typically seen; defining 'good' health care; perceived availability and accessibility of comparative information about quality of health-care services; sources of information about quality of health-care services; retrieval of information (e.g. Internet, newsletters); actual use of the information; completeness of information;

reaction to content, format, layout and level of detail of Medicaid report cards distributed during the focus group.

Data collection

We conducted seven focus groups in fully accessible facilities at local Centers for Independent Living in four US states (three Portland, OR; two San Bernardino, CA; one Virginia; one Maryland) and one in the District of Columbia. We arranged transportation for participants who requested assistance. The length of the focus group discussions varied between 90 and 120 min. Each participant received a cash stipend of $20.

The group discussions were conducted by an experienced moderator and an assistant. We obtained written informed consent, basic demographic information and signed HIPAA documents from each participant. The MedStar Institutional Review Board in Washington, DC approved the study protocol and all forms. Each of the resulting eight focus groups consisted of six to nine participants, which is consistent with recommendations.[8]

Data management

We audio-recorded each session. Transcribers who were not part of the data collection team transcribed the tapes. We supplemented the transcripts with notes taken by the assistant facilitator during each discussion and our debriefing notes.

Data analysis

We analysed data by coding the transcribed focus group notes with N*VIVO qualitative data analysis software.[9] Data analysis involved the work of two independent analysts. First, two analysts imported interview transcripts into N*VIVO and used the debriefing notes to form initial coding categories. They used constant comparative coding to identify a set of thematic codes. We refined the coding categories as topics emerged and arranged them in a hierarchical structure. Thirty-nine free nodes (codes) were subsumed under three tree nodes: (i) defining quality health care; (ii) access to information and (iii) evaluation of report cards. Themes that were cross-cutting states were selected for in-depth exploration. Theses themes are presented in this paper.

Results

Sample characteristics

Table 1 summarizes participant characteristics. Participant data show that we generated a sample with quite diverse demographic characteristics in terms of age, ethnic background and disability. More than two-third of the participants were female. Nearly, one-quarter of the respondents indicated multiple disabling conditions. One respondent listed five (Arthritis, Bipolar Disease, Spinal Infection, Cancer, Epilepsy) indicating substantial functional impairment.

Defining quality health care

Focus group participants identified three characteristics of quality health care: care coordination, choice and disability competence.

Care coordination and communication
We coded 'care coordination' as any attempt to coordinate care or make referrals. In both Portland and San Bernardino, many respondents complained about a lack of care coordination and insufficient communication among providers, health plans and beneficiaries. In some cases, this affected the continuity of care. Participants viewed on-going and proactive communication as a key component of effective care coordination:

> You know what would be really great is once in a while a phone call. 'How are you feeling today? Have you had the flu lately? How's your knee? As a reminder, don't forget you have your doctor appointment on such and such a date. And you know we all got together and talked about it and we think this is going to work out really well for you'. That would be a plus for me.

Table 1 Characteristics of study participants (*n* = 49)

	n (%)
Female	34 (69)
Male	15 (31)
Age (years)	
20–29	4 (8)
30–39	12 (24)
40–49	20 (40)
60–65	8 (18)
Undisclosed	1 (2)
Race/ethnicity	
Native American/Indian	5 (10)
Asian/Pacific Islander	4 (8)
Hispanic	1 (2)
Black, non-Hispanic	19 (39)
White, non-Hispanic	15 (31)
Other/undisclosed	5 (10)
Highest educational level	
< 12	10 (20)
12 (high school)	10 (20)
Some college	18 (37)
4-year degree	6 (13)
Graduate course work/degree	3 (6)
Undisclosed	2 (4)
Disabling (primary) diagnosis	
Arthritis	7 (14)
Asthma	3 (6)
Blind	5 (10)
Cardiovascular and cerebrovascular (e.g. hypertension, stroke)	4 (8)
Cerebral palsy	2 (4)
Diabetes	2 (4)
Epilepsy	4 (8)
Mental health/psychiatric (e.g. anxiety, depression, PTSD)	11 (22)
Multiple sclerosis	2 (4)
Traumatic brain injury	2 (4)
Other	7 (14)
Multiple	22 (45)
Median number of years lived with disabling condition (IQR)	20 (32)
Median number of hours of weekly assistance (IQR)	0 (16)

Choice

We coded choice as 'the ability and/or opportunity for the beneficiary to select Medicaid services and providers'. Most participants across study sites viewed having a choice of doctor or clinic as very important. Participants said that choice gave them an opportunity to select an understanding provider who was accessible by public transportation. However, many participants did not know they had the right to choose, or believed that no realistic choices were offered: *In private insurance, you can choose. In Medicaid, its public, and … you get no choice. They assign you where you go and you're not given any information….* Many indicated that 'others', primarily hospital staff, made the choice for them: *So they just told me, here's your doctor….*

Disability competence and sensitivity

We defined and coded 'disability competence' as knowledge about the social consequences of disability and clinical expertise.[10–12] Nearly all focus groups emphasized the importance of disability competence. Participants pointed out that people with disabilities might have multiple health issues masked by the primary disabling condition, and that providers should acknowledge their own professional limitations and refer to specialists when necessary.

Respondents were concerned about the lack of sensitivity among health plan personnel and provider staff, even well-meaning ones:

> The most frustrating part [is] when you're trying to explain to somebody that you have this problem. I think its humiliation more than anything for you, when you meet a new person and you have to go into all the details of all your difficulties and all your problems. They strip you of your humanity, of your self-worth and that's a horrible thing. In order to get benefits you have to almost destroy yourself and that's terrible. If they just had somebody more sensitive there….

One participant felt that certain tests to establish service eligibility were degrading and inappropriate. *Why do they have to give me an IQ test to meet my needs, like I need a wheelchair or whatever? What difference does it make, whether I'm a genius or retarded?*

Access to information

We coded statements that addressed aspects related to receiving or not receiving information, both in terms of information content and format.

Participants from all states said the information they get from authorities was not the kind of practical information they needed. Several groups wanted an up-to-date list of Medicaid providers who are knowledgeable about their disability.

Participants also said Medicaid program information should be available in alternate formats: *One thing I know is that the blind, and even the deaf, they are not informed because those who give out the paperwork have not bothered to look at their cases and see whether they're blind or deaf or have a special need.*

Study participants had very different experiences with receiving information in a format they could use. People who had access to multiple information modalities such as the Internet or Braille, or information sessions offered by churches or other community groups, perceived themselves as well informed. People who tried to use computers at public libraries but did not have access to screen readers or large computer displays felt that their information access was insufficient.

Several participants seeking information from their health plans or public assistance agencies reported negative experiences with complex telephone trees and in-person visits:

> A lot of these phone lines, the mailboxes are full or they're not in the office and you leave a message. It gets kind of frustrating, so we end up having to mail to people, or you end up going down there. That's another issue because you know the lines are long....They need to do away with the automated telephones and go back to human beings.

Evaluation of report card content

We presented several Medicaid report cards to the focus groups. Michigan and Maryland report cards were double-sided tabloid size sheets with summary HEDIS and CAHPS measures.[13] The California Quality of Care Report Card was a 20-page booklet for medical group practices and health plans around the entire state.[14] The Texas Star report card was a 40-page document providing detailed county-specific results from the CAHPS® survey.[15]

General reaction

Participants were keenly interested in the state Medicaid report cards we presented and many people wanted to keep them: *These report cards are the most interesting thing I've seen. This is the kind of thing I like to see. It's tangible. This is the best thing I've seen put together in a long time. I appreciate seeing these report cards. I'd like to see more and more.*

Most participants preferred an easy-to-use report card that would provide them with a quick assessment of relevant content areas. Some participants were overwhelmed by the more detailed report cards, particularly individuals who had not graduated from high school or who had learning disabilities such as dysgraphia or dyslexia. They advised that report cards should include visual markers to make them easier to navigate, and to include written percentages as well as graphs: *If I can't understand percentages, which I don't, I can see a visual. The black amount is bigger than the 13% over here in the all-white section, so I like that, the visual of being able to understand what's going on.*

Some participants said they would like something about twice as long as the one-page tabloid chart. Others felt that detail was important and that the tangible characteristics such as paper weight, added to the credibility of the numbers.

Some participants felt the star rating system of the Michigan report card was confusing and they said they did not know what it signified or how stars had been allocated. *What does it signify here with the stars? Did this doctor get 3 stars like a 4-star general?* Others had trouble understanding how the composite measures had been derived, even though the report cards included an explanation: *What does it mean when a doctor gets a low score on doctor communication? Does that mean he's had complaints about not being able to talk to him?*

Content

Most participants said they wanted disability-specific information. Participants were interested in provider-specific ratings, not just health plan ratings. They stressed the need for up-to-date information on provider characteristics, availability, disability competence and reasons for participating in Medicaid. Participants also felt that there should be information on how providers and plans coordinate care, and about the physical accessibility of doctors' offices and availability of assistance during a health examination, such as transfers in and out of wheelchairs.

Distribution

We asked participants for their advice on the best way for making report cards available. They suggested free newspapers, Centers for Independent Living, the monthly or quarterly Medicaid eligibility mailing, food banks, telephone hotlines, the Internet, doctors' offices, bulletin boards in schools and community colleges, front desks of assisted housing facilities, National Federation of the Blind, state libraries for people with sensory disabilities, state ombudsman, churches, county disability offices and the Rehabilitation Services Administration (RSA). They told us that different people had different trusted information sources. Distributing report cards through only one or two mechanisms would miss many concerned beneficiaries.

Discussion

The respondents in our study identified several quality indicators related to health services that were particularly important to them. These included access to a well-coordinated system of generalist and specialist health-care services as well as providers who are 'disability competent and sensitive'. This finding supports earlier research.[16,17] Timely, accurate and comprehensive information about the availability, affordability and quality of coordinated and competent services is critical to the health of people with disabilities. However, as our findings indicate access to reliable information is hampered by various factors. Information may be perceived as irrelevant or may only be available in formats that are unsuitable. Telephone support frequently requires not only patience but also the ability to navigate complex telephone trees. Written information such as health plan report cards may exclude those with dyslexia and dysgraphia.

Current Medicaid report cards, which are designed for the typical Medicaid beneficiary (low-income elderly and women with children) also omit important content areas that are germane to people with disabilities. None of the report cards we reviewed and circulated to our focus groups contained information on benefit coverage, for example. This leads us to conclude that few beneficiaries with disabilities find the existing report card content helpful when selecting health plans or doctors.

Farley-Short et al.[18] concluded that Medicaid beneficiaries care most about access and convenience, while the privately insured emphasize provider quality and costs. Our interpretation is that the privately insured have already met their access needs and are more receptive to taking action on the basis of the type of information collected by CAHPS® surveys.

Our findings also confirm previous research by Hibbard et al. regarding the format of the report cards.[19–21] In several controlled studies of the elderly or people without disabilities, it is clear that format can enlighten or confuse. The responses of our focus group participants to the state-of-the-art report cards we presented, suggest that more targeted information outreach needs to be done for people with disabilities.

One of the 'biasing' influences on the study were State-level changes in coverage of prescription, loss of benefits and other health-related services that had been introduced one month prior to the interviews in the Oregon Medicaid program. The increase in out-of-pocket expenses and confusion about what was still covered clearly influences some of the responses obtained in focus groups in Portland, OR.

We make two recommendations on the basis of this study. First, when preparing report cards

for Medicaid beneficiaries with disabilities, states should combine information on specific benefit coverage and disability-related services with content that focuses on health care encounters and service delivery processes in a single document.

Secondly, the document should be available in multiple formats, easy to understand and distributed through multiple venues. Beneficiaries with disabilities want the currently reported general measures, supplemented with a second page of disability-specific measures. These measures need not be extensive but should be reported with graphs, numbers and narrative. Broad and creative distribution through multiple media channels and community outlets will make it more likely that information is actually received.

Knowledge derived from this study needs to be embedded in what is already known about how individuals arrive at decisions based on structured reporting tools.[22]

Acknowledgments

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