

**Adults with
Disabilities in Medi-Cal:
The Beneficiary Perspective**

*Prepared by
Center for Disability Issues and
the Health Professions*

September 2003

Report

The Medi-Cal Policy Institute, established in 1997 by the California HealthCare Foundation, is an independent source of information on the Medi-Cal and Healthy Families programs. The Institute seeks to facilitate and enhance the development of effective policy solutions guided by the interests of the programs' consumers. The Institute conducts and commissions research, distributes information about the programs and the people they serve, highlights the programs' successes, and identifies the challenges ahead. It collaborates with a broad spectrum of policymakers, researchers, providers, consumer representatives, and other stakeholders who are working to create higher-quality, more efficient Medi-Cal and Healthy Families programs.

Adults with Disabilities in Medi-Cal: The Beneficiary Perspective

September 2003

Brenda Premo

June Isaacson Kailes

Erin Schwier

Curtis Richards

Center for Disability Issues and the Health Professions

Acknowledgments

Founded in 1998, the Center for Disability Issues and the Health Professions (CDIHP) at the Western University of Health Sciences grew out of a need to strengthen relationships between the diverse disability community and health care professionals. CDIHP's goals are to: improve the capacity of health care providers to meet the needs of people with disabilities; increase the number of qualified individuals with disabilities who pursue health care careers; support people with disabilities in becoming more vocal and active participants in their health care; and conduct and disseminate research on community-based health, education, prevention, and health care services for people with disabilities. The primary researchers for this project were Brenda Premo, director of CDIHP; June Isaacson Kailes, associate director; Erin Schwier, policy fellow; and Curtis Richards, senior policy advisor.

The Center for Disability Issues and the Health Professions wishes to acknowledge and thank all of the community-based organizations—independent living centers, other disability service organizations, and health providers—for their invaluable assistance in locating and recruiting participants for our focus groups. A complete list of these organizations appears as Appendix C. Rhys Burchill was also quite helpful in the recruitment effort.

CDIHP extends a special thanks to Juan Garcia, Kathleen Riel, and Diana Hewitt for their assistance in setting up and conducting the focus groups in their respective areas. We would also like to extend a note of appreciation for the professional assistance of our focus group facilitators, Bill and Vicki Bruchner, Lynda Dickey, Monique Jansma, Heidi Keiger, and Leslie Birchell. The project advisory committee, a complete list of which appears in Appendix A, played an invaluable role in shaping the content of the questions for the focus groups.

CDIHP owes a deep gratitude to the Medi-Cal Policy Institute for undertaking this project and actively pursuing the opinions of disabled Medi-Cal participants, and particularly to our project liaison, Lucy Streett. Without Lucy's persistence, guidance, and support, this project would not have been possible in such a short period of time.

The California HealthCare Foundation (CHCF), based in Oakland, is an independent philanthropy committed to improving California's health care delivery and financing systems. CHCF's Medi-Cal Policy Institute seeks to facilitate and enhance the development of effective policy solutions for Medi-Cal and Healthy Families with a particular interest in identifying and understanding options for improving enrollment and retention, access to care, and the quality of care provided to people served by these public programs.

Copyright © 2003 California HealthCare Foundation
ISBN 1-932064-53-2

Medi-Cal Policy Institute
476 Ninth Street
Oakland, CA 94607
tel: (510) 286-8976
fax: (510) 238-1382
www.medi-cal.org

A project of the



Additional copies of this report and other publications can be obtained online at www.medi-cal.org.

Contents

Executive Summary	1
I. Introduction	5
Background	6
Methodology	7
II. Findings: Priority Areas for Consideration	13
Overall Findings	13
Awareness and Perceptions of Managed Care	13
Finding a Physician	15
Provider Knowledge and Sensitivity	16
Access to Health Facilities and Medical Equipment	17
Access to Information	18
Benefits	19
Grievance and Appeals Processes	23
III. Conclusions	25

Appendix A: Project Advisory Committee Members	29
Appendix B: Consolidated Focus Group Topic Guide	31
Appendix C: Community-Based Organizations Assisting in Focus Group Participant Recruitment	37
Appendix D: Focus Group Screening Questions	41
Notes	45

Executive Summary

Background

Medi-Cal provides health care coverage to nearly three quarters of a million Californians with disabilities. Care is delivered to this population through one of two primary delivery systems: traditional fee-for-service and managed care. To date, there has been a lack of information about how well the program is doing at delivering health care services to people with disabilities through either delivery system. In light of recent proposals to expand Medi-Cal managed care for people with disabilities, the Medi-Cal Policy Institute (MCPI) commissioned the Center for Disability Issues and the Health Professions to conduct a series of focus groups in order to solicit direct input from people with disabilities and their families who will be most affected by any major policy changes in the Medi-Cal program.

Twelve focus groups were conducted throughout the state with a total sample of 85 participants. Focus groups were conducted in fee-for-service counties, mandatory managed care counties, and voluntary managed care counties. Each focus group was constructed to include consumers with one primary type of disability, such as deafness or mental illness, in an attempt to compare experiences between fee-for-service and managed care for Medi-Cal beneficiaries with different types of disabilities. Although the qualitative nature of the focus group research and the small number of participants precludes any ability to draw statistically significant conclusions for the entire population of Medi-Cal beneficiaries with disabilities, the study nonetheless provides important insight into this population's experiences with the Medi-Cal program.

Findings

Based on input from the study focus groups, there appear to be significant problems in both the Medi-Cal fee-for-service and managed care delivery systems in providing services to beneficiaries with disabilities. Focus group participants in both systems displayed an almost universal

lack of understanding, and sometimes outright confusion, about Medi-Cal benefits, services, and grievance procedures. Across the board, participants reported difficulty finding physicians and adequately accessing services, programs, and facilities. Nearly all participants reported difficulty in locating a primary care physician, but it appears to be slightly easier for those in managed care plans to find a primary care physician. All focus group participants, regardless of service model, expressed difficulty with locating specialists.

One of the most striking findings was the lack of consistency in quality that was reported by participants in different counties and different health plans. Participants with similar conditions in similar delivery systems (such as fee-for-service or managed care) reported vastly different experiences, depending on where they lived and where they received care. There was also a great deal of variation reported by members of different health plans within a single county. Based on the focus group findings, some health plans appear to be better developed and more successful in addressing the health care needs of people with disabilities than others.

Focus group participants identified three main categories of barriers:

1. Information Barriers

- In general, focus group participants demonstrated a distinct lack of awareness of and understanding about Medi-Cal managed care.
- Most participants in both the fee-for-service and managed care delivery systems exhibited a significant lack of understanding about the scope of covered benefits and services. For example, many participants expressed confusion about which drugs are covered by Medi-Cal and complained that their providers had often prescribed medications that were no longer covered by the program.
- Participants in the two focus groups with deaf consumers reported by far the biggest challenge related to accessing information about their health coverage, but nearly all participants indicated that the information they received about their health coverage was difficult to understand.
- Most focus group participants demonstrated a lack of understanding about where to turn if they had problems with the Medi-Cal system and little knowledge that they had the right to file an appeal if their claim had been denied.

2. Access Barriers

- Locating a physician that is willing to accept Medi-Cal was reported as being very difficult throughout the state and finding a specialist was reported as especially difficult. As a result, consumers reported frequent use of hospital emergency rooms and urgent care clinics.

- According to most focus group participants, the health care providers they were able to access did not adequately understand their disabilities, and medical technicians and office support staff, in particular, lacked knowledge of and sensitivity about people with disabilities.
- Difficulty accessing facilities and medical equipment was a resounding issue across all focus groups and was particularly problematic for beneficiaries with physical disabilities.

3. Coverage Barriers

- Most focus group participants expressed frustration with the scope of several benefits, including durable medical equipment, pharmacy, dental care, and transportation.
- Maintenance, repair, and replacement of durable medical equipment were repeatedly raised in the physical disability focus groups as areas of significant concern.
- Many participants, particularly those in fee-for-service groups, reported that care coordination services were not available to them and that they sought the assistance of community-based organizations to help them advocate for needed services.

Recommendations

Some of the barriers identified through this study may be unique to the Medi-Cal program, while others are likely to be indicative of problems that all people with disabilities experience, regardless of the type of health insurance they have. For example, it may be more difficult for Medi-Cal beneficiaries with disabilities to find providers knowledgeable about their conditions than it is for those who have employer-sponsored coverage because only about one-half of physicians in California participate in Medi-Cal. Other issues, such as difficulty finding accessible medical offices and equipment, are problematic throughout the health care industry. Nonetheless, each of these barriers must be addressed to improve the delivery of care for Medi-Cal beneficiaries with disabilities.

Based on the findings from the focus groups, CDIHP offers several recommended steps toward improving the current Medi-Cal delivery system for people with disabilities.

1. Qualified people with disabilities and their families need to be involved in the Medi-Cal policy process.
2. Improvements in current Medi-Cal benefits and services need to be made to close gaps that adversely impact beneficiaries with disabilities.

3. There is much to be learned from the experiences of the health plans currently participating in Medi-Cal and from the experiences of other state Medicaid programs about improving information and outreach, benefit design, and service delivery for beneficiaries with disabilities. Best practices should be defined, identified, shared, and adopted, and new approaches should be piloted.
4. Outreach efforts should be increased to educate people with disabilities about Medi-Cal managed care options, covered benefits and services, and the grievance and appeals processes.
5. Quality of care outcome measures and access standards and guidelines need to be developed to address the specific needs of people with disabilities.
6. Instruction, licensure, and certifications standards should be adopted for health care providers in cross-disability awareness and sensitivity.
7. Existing public and private health care research surveys and projects need to incorporate disability-related issues. Research projects should be developed in consultation with and, when possible, conducted by qualified people with disabilities.

Until the entire Medi-Cal system has been evaluated for its ability to more appropriately serve people with disabilities, the debate about the benefits and shortcomings of managed care compared to fee-for-service cannot be resolved.

I. Introduction

In January 2002, the California Legislative Analyst's Office (LAO) proposed that the state consider significantly expanding Medi-Cal managed care for people with disabilities as part of the solution to close the state's then \$20 billion budget gap. Although the California Legislature did not adopt the LAO proposal, the proposed concept raised questions about the current Medi-Cal delivery system for people with disabilities and the implications of serving more of this population under managed care.

The Medi-Cal Policy Institute funded the research for this report in an effort to address the absence of information about the first-hand experiences of people with disabilities served in the Medi-Cal program. Although it is often thought of as a program for low-income women and children, Medi-Cal provides health coverage for a large number of people with disabilities. Medi-Cal is an important safety net for those with the most significant disabilities who have low incomes or are unable to work. People with disabilities make up roughly 13 percent of the Medi-Cal caseload and nearly 44 percent of total Medi-Cal expenditures.¹ However, despite the importance of Medi-Cal to Californians with disabilities, there is a lack of information about how well the program is delivering care to this population.

In response, MCPI commissioned the Center for Disability Issues and the Health Professions at Western University of Health Sciences to conduct a series of focus groups with Medi-Cal beneficiaries with disabilities. The goal of this project was to provide information to policymakers on the experience of care for people with disabilities enrolled in Medi-Cal in order to improve the current delivery system and to inform the debate about whether and how to expand Medi-Cal managed care to this population.

On February 27, 2003, MCPI sponsored a meeting entitled "Medi-Cal Managed Care for Working-Aged Persons with Disabilities: Current Status and Future Directions," which was held in Sacramento. The purpose of this meeting was to provide a forum in which policymakers,

program administrators, representatives from health plans and provider organizations, consumer advocates, and researchers could participate in a productive, informed discussion of the implications of expanding Medi-Cal managed care for people with disabilities. The findings from this project, along with findings from related research projects funded by MCPI, were presented at the meeting.

Background

Medi-Cal is an essential source of health insurance for more than six million Californians.² More than 767,000 of those, or 12.5 percent, qualified for the program due to a disability. An indeterminate number of additional people with disabilities qualify for Medi-Cal due to a factor other than their disability, such as being elderly or part of a low-income family.³

Medi-Cal services are delivered through either the fee-for-service (FFS) or the managed care delivery system. Under FFS, which is sometimes called “straight” Medi-Cal, a beneficiary can go to any provider who is willing to see a Medi-Cal patient. That provider submits a claim for reimbursement to the state after each service or visit (such as office visits, medical procedures, and prescriptions) at a rate established by the Medi-Cal program. Slightly fewer than half of all Medi-Cal beneficiaries in California receive coverage through the FFS system.⁴

A significant proportion of Medi-Cal beneficiaries have been shifted from FFS into managed care. As part of legislation implementing the 1992–93 Budget Act, the California Legislature gave the Department of Health Services (DHS) broad authority to expand managed care in California with the goals of improving beneficiary access to care and containing costs in the Medi-Cal program. In 1993, DHS issued a strategic plan to move the Medi-Cal program toward managed care. A decade later, more than half of all of Medi-Cal beneficiaries (about 52 percent) are enrolled in some form of managed care for their physical health care in one of the three primary managed care models that operate in 22 counties.⁵

Although enrollment in managed care is mandatory for low-income families in all 22 counties where managed care is offered, it is only mandatory for people with disabilities in 8 counties. In other words, enrollment in managed care is voluntary for people with disabilities in the remaining 14 counties. Statewide, about 158,000 (21 percent) of the total number of non-elderly Medi-Cal beneficiaries with disabilities are enrolled in managed care plans.⁶

Under Medi-Cal managed care, a beneficiary is enrolled in a health plan. That health plan has a contract with the state and receives a predetermined per member per month rate, which is referred to as a “capitation rate,” to provide all needed services. Managed care beneficiaries choose a primary care provider and typically need authorization from that provider to see a specialist.

Medi-Cal Managed Care is delivered primarily through three models in California: (1) County Organized Health Systems (COHS); (2) Geographic Managed Care (GMC); (3) and Two-Plan Model:

- Under COHS, enrollment in a single county-run plan is mandatory for nearly all Medi-Cal beneficiaries and occurs concurrently with enrollment in the Medi-Cal program. Counties negotiate their contracts with the California Medical Assistance Commission, which is an independent state board under the California Health and Human Services Agency, and are paid on a capitated basis. COHS operates in eight counties, including: Orange, Monterey, Napa, San Mateo, Santa Barbara, Santa Cruz, Solano, and Yolo Counties.
- In GMC counties, the state contracts with a number of commercial managed care plans and pays for services on a capitated basis. Enrollment is mandatory for low-income families linked to the cash assistance program known as CalWORKs. Beneficiaries with disabilities may enroll voluntarily. GMC operates in Sacramento and San Diego Counties.
- In the Two-Plan Model, Medi-Cal beneficiaries may choose one of two managed care plans. One of the plans is intended to be a public entity known as a “local initiative,” and the other plan is a commercial health plan. Some counties have not established a public plan and instead have contracts with two commercial plans. As with GMC, CalWORKs-linked beneficiaries are required to enroll in a health plan, while beneficiaries with disabilities may enroll on a voluntary basis. The Two-Plan Model operates in 12 of California’s largest counties, including: Alameda, Contra Costa, Fresno, Kern, Los Angeles, Riverside, San Bernardino, San Francisco, San Joaquin, Santa Clara, Stanislaus, and Tulare Counties.

In addition to the managed care system for physical health care, mental health services are provided separately in all 58 counties through mental health managed care plans that contract with the state Department of Mental Health.⁷

Methodology

Focus Group Content

The question guides for the focus groups were developed under the guidance of a small, broad-based advisory committee that included representatives from the disability community, health care providers, and state health policy analysts. The advisory committee served to assure neutrality in the design of the topics to be discussed and the questions to be asked. A list of committee members is provided in Appendix A.

This study was not intended to measure beneficiaries’ perceptions of the overall value of Medi-Cal, but to assess the consumer experience in different delivery models (managed care and fee-for-service) within the program. To this end, the question guides focused on six topic areas:

1. Consumer understanding and awareness of managed care;
2. Finding a physician;
3. Provider knowledge and sensitivity;
4. Accessibility of health facilities and medical equipment;
5. Knowledge of and satisfaction with benefits; and
6. Adequacy and availability of grievance and appeals processes.

Questions used to guide the focus groups are provided in Appendix B.

Focus Group Distribution

In January and February of 2003, 12 focus groups were conducted throughout the state with a total sample of 85 participants. Groups were conducted in fee-for-service counties, mandatory managed care counties (COHS), and voluntary managed care counties (Two-Plan and GMC). Each group was intended to focus on one of five primary types of disability, such as deafness or mental illness, in an effort to discuss similar barriers and needs. However, it was expected that most of the participants in each group would have multiple disabilities and would identify with issues affecting many disability groups. The primary disability participant types included:

- People with physical disabilities who require the use of durable medical equipment (DME) and supplies such as wheelchairs, canes, portable oxygen, and catheters;
- People who are deaf;
- People with mental illnesses;
- People and caregivers of adults with developmental disabilities; and
- People with chronic illnesses.

Finally, the focus groups reflected a geographically diverse set of counties. Table 1 displays the distribution of the focus groups.

Table 1. Focus Group Distribution

County	Fee-for-Service-Only Counties	Voluntary Managed Care Counties	Mandatory Managed Care Counties
Alameda		Physical / DME	
Los Angeles		Mental Illness	
Orange			Developmental (with caregivers)
Riverside		Deaf	
Sacramento		Deaf	
San Bernardino		Physical / DME	
San Diego		Mental Illness	
San Francisco		Chronic Illness	
San Luis Obispo	Chronic Illness		
Santa Barbara			Chronic Illness
Santa Cruz		Physical / DME	
Ventura	Developmental (with caregivers)		

Note: All groups had participants with multiple disabilities.

Participant Recruitment

Methods of convenience sampling and snowball sampling were used to collect potential focus group participants.⁸ These methods were chosen primarily because of the limited timeframe in which these focus groups had to be conducted and in order to attain the specific disability groups targeted for participation. Participants were recruited through local community agencies that serve as support networks and resource organizations for the disability community and through the local health care plans. A list of the agencies that assisted with recruitment is provided in Appendix C. Agencies were provided with screening questions to help identify appropriate participants. The participant screening guide appears in Appendix D. Nonprofit community-based organizations were offered an incentive of \$55 per focus group participant. Focus group participants received a \$50 honorarium, lunch, and, when needed, specific accommodations such as transportation to and from the focus group facility.

Table 2 documents the number of focus group participants by county and by type of Medi-Cal service delivery system. The number of participants who were enrolled in either fee-for-service or managed care was nearly evenly split. That is, of the 85 total participants, 45 were enrolled in Medi-Cal fee-for-service, including 32 from managed care counties, while 41 were enrolled in managed care.

Table 3 displays the ethnicity and gender distribution of each of the focus groups. More than half of the participants (58 percent), or 49 of 85, were female while 42 percent, or 36 of 85,

Table 2. Number of Focus Group Participants

County	Fee-For-Service-Only Counties	Voluntary Managed Care Counties		Mandatory Managed Care Counties	TOTAL
		Fee-For-Service	Managed Care		
Alameda		4	2		6
Los Angeles		6	3		9
Orange				4	4
Riverside		7	1		8
Sacramento		5	4		9
San Bernardino			4		4
San Diego		6	3		9
San Francisco		4	3		7
San Luis Obispo	9				9
Santa Barbara				9	9
Santa Cruz				8	8
Ventura	3				3
TOTAL	12	32	20	21	85

Table 3. Demographic Distribution of Focus Group Participants

County	Gender		Ethnicity					
	Male	Female	Caucasian	Latino	African American	Asian	Native American	Other
Alameda	1	5	3	1	1	0	0	1
Los Angeles	2	7	6	3	0	0	0	0
Orange	2	2	3	0	1	0	0	0
Riverside		8	6	1	1	0	0	0
Sacramento	5	4	4	4	0	0	0	1
San Bernardino	1	3	2	0	1	0	1	0
San Diego	5	5	4	4	1	0	0	1
San Francisco	7		NA	NA	NA	NA	NA	NA
San Luis Obispo	5	4	6	3	0	0	0	0
Santa Barbara	5	3	6	1	0	0	1	0
Santa Cruz	3	5	2	6	0	0	0	0
Ventura		3	2	1	0	0	0	0
TOTAL	36	49	44	24	5	0	2	3

Note: Ethnicity data for San Francisco is not available.

were male. Ethnicity data was unavailable for participants in the San Francisco focus group. For the 78 participants for whom ethnicity data was available, 56.4 percent were Caucasian, 30.8 percent Latino, 6.4 percent African American, and 2.6 percent Native American. None were Asian, and 3.8 percent identified themselves as “Other.”

Moderation and Transcription

Each two-hour focus group was led by one professional facilitator and one CDIHP researcher. The facilitator moderated the discussion, asking the questions on the topic guide and completing the questions in the allotted time, while the CDIHP researcher served as a disability content expert in order to probe deeper into questions that needed further development. Appendix B contains a consolidated focus group topic guide used by the facilitators in each session.

Audiotapes were subsequently transcribed. From each of the transcripts, a chart of participant responses by topic area and questions within those topic areas was recorded and analyzed for frequency, similarity, and differences of answers. Totals were compiled for each group, and then answers from similar disability groups were compared. Responses were then compared across all groups. Although each individual’s needs were different, for purposes of the study, it was important to identify general responses and anecdotal responses to specific questions. The transcripts served to augment the observations of CDIHP facilitators at each focus group as the basis for analysis.

Project Limitations

There are several important limitations to this project that are worth noting. First and foremost, the project was designed and implemented under an extremely tight timeline. The project was launched in October 2002 with the goal of completing all 12 focus groups in time for CDIHP to report preliminary findings at a forum sponsored by the Medi-Cal Policy Institute on February 27, 2003. This short turnaround time placed some extreme conditions on the design of this qualitative research project and on the recruitment of focus group participants. As a result, the groups were smaller and less ethnically diverse than desired.

Due to both limited time and the geographic dispersion of the focus groups, three different professional facilitators were used to lead the groups. Meetings were held with the facilitators prior to the focus groups to discuss strategies and to ensure continuity of the interview questions within each group. However, differences in facilitation style, content expertise, and disability knowledge lead to some inconsistency in the facilitation of each focus group.

In the groups intended to target parents of adult children with developmental and other cognitive disabilities, recruitment was difficult due to persistent medical needs of potential participants’ disabled children. In some cases, family members were unable or unwilling to leave their adult children at home without care. Caregivers from group homes were added to the

target list to increase the number of participants in these focus groups. And, because the groups were held during the day, some working parents—and potential participants—were excluded from participation.

Finally, the qualitative nature and small size of the focus groups means that the findings cannot be projected to the entire population of Medi-Cal beneficiaries with disabilities with any statistical significance. Nonetheless, the study provides important insight into the experiences of people with disabilities in the Medi-Cal program.

II. Findings

Overall Findings

Based on the direct consumer input gathered through the 12 focus groups, there appear to be significant problems in both the Medi-Cal fee-for-service and managed care delivery systems in providing services to beneficiaries with disabilities. Focus group participants in both systems displayed an almost universal lack of understanding, and sometimes outright confusion, about Medi-Cal benefits, services, and grievance procedures. Across the board, participants reported difficulty finding physicians and adequately accessing services, programs, and facilities. Nearly all participants reported difficulty in locating a primary care physician, but it appears to be slightly easier for those in managed care plans to find a primary care physician. All focus group participants, regardless of service model, expressed difficulty with locating specialists.

One of the most striking findings of the study was the lack of consistency in quality that was reported by participants in different counties and different health plans. Participants with similar conditions in similar delivery systems (such as fee-for-service or managed care) reported vastly different experiences, depending on where they lived and where they received care. There was also a great deal of variation reported by members of different health plans within a single county. Clearly, some health plans are better developed and more successful in addressing the health care needs of people with disabilities than others.

Awareness and Perceptions of Managed Care

Focus group participants demonstrated a distinct lack of awareness of and understanding about Medi-Cal managed care. Typically, they knew they had Medi-Cal coverage, but often beneficiaries were not very aware of the different kinds of Medi-Cal service delivery models

available to them. Most consumers in voluntary managed care counties were not aware that they had a choice about their Medi-Cal coverage.

“I didn’t actually get any packets or anything or I wasn’t prompted for a choice,” reported a consumer in a Two-Plan Model county. “I just took straight Medi-Cal as it was given to me.” Another Two-Plan Model consumer stated, “When I was laid off from my job, they offered me Medi-Cal and I did not understand what they were doing. They just said, ‘You get Medi-Cal.’ I said, ‘Okay. I got the point.’ No one explained to me that I needed [an HMO] or [that] I could get [another HMO]. They just say, ‘Here you go.’ They did not take the time to explain.”

Among consumers who were aware that they had a choice between Medi-Cal managed care and FFS, enrollment decisions were typically influenced by a desire to keep a current primary care or specialist physician. “I chose [my managed care plan] because all our family always had and I knew this doctor all through my childhood,” a Sacramento participant told the group. “Then when they sent me this enrollment [information and said] that I had to make a choice, I chose [my plan] because this particular doctor that I had always seen accepted [it].”

In a few instances, focus group participants indicated that they had made a choice based on differences in services offered between fee-for-service and managed care or between participating managed care health plans. Deaf focus group participants indicated a preference for managed care over fee-for-service because of the availability of interpreters. “I am a member of [an HMO]. I used to belong to [a different HMO] and I chose [the new one] because they provide sign language interpreters,” a deaf participant in Riverside recalled. “So, I decided to go with [the new HMO] because of that.” Deaf participants in Sacramento County also reported choosing between health plans based on the availability of interpreter services.

Focus group participants from voluntary managed care counties who elected fee-for-service did so for a variety of reasons, including flexibility. “[With] straight Medi-Cal, you have your choice of choosing your own doctor, whereas in the managed care you have to see their doctors [and] you have to go to their hospitals. If you are injured severely, you have to make a call and you have to get approval before you can even go to a hospital for a broken arm or whatever it is,” one fee-for-service participant in a Two-Plan Model county stated. “I wouldn’t have the managed care for myself.”

Most focus group participants with mental illnesses in voluntary managed care counties reported choosing fee-for-service primarily because they were quite satisfied with the county services they received. As one participant explained, “I had an HMO for a very short period of time and, having to go to those certain doctors, I found out that they don’t really care about you, about your concerns, [or] about your health. They just care about money. So, I like what I got—[fee-for-service Medi-Cal].”

Perceptions about managed care were mixed throughout the focus groups. Some participants were passionate about their disdain for managed care. One participant said, “I am very unhappy and I am furious that I have to be in this managed care program.” Another in the

same group added, “I would love to get off of . . . [managed care]. . . . This is the first I heard of it—that I had a choice.”

Other consumers expressed frustrations with fee-for-service Medi-Cal or touted the services available under managed care. “I just got straight [fee-for-service] Medi-Cal and I will say being on straight Medi-Cal has been nothing but hell for me,” reported one person. “It has just been nothing but call[ing] up doctors. They say we can choose our doctor, but practically everybody I call says, ‘No, no, no. We don’t take it. We don’t take it.’ So, I have just—although I am grateful to have it—have had nothing but negative experiences being on it.” Another consumer commented, “I prefer [my HMO] because of their services. They give you all the information there; the quality of services is much better than going to a straight Medi-Cal doctor.”

One participant from a Two-Plan county group who had recently switched health plans summed it up by saying, “[My HMO] is better because I feel that they care about us as patients as well as people. They don’t just look at us like we are animals and herd us this way and herd us that way.”

“The whole system is confusing to me and it seems like everyone else is a little confused, even if they know what coverage they have.”

—*Fee-for-service beneficiary
in Los Angeles County*

For the most part, however, focus group participants expressed a lack of understanding or outright confusion about Medi-Cal, rather than a preference for one delivery model over another. As one person put it, “The whole system is confusing to me and it seems like everyone else is a little confused, even if they know what coverage they have.”

Finding A Physician

Across the board, focus group participants reported that locating a physician who is willing to accept Medi-Cal can be very difficult; however, finding a primary care physician was reported as being somewhat easier by groups in managed care counties. Some consumers reported traveling to neighboring counties to find a doctor who was both willing to take Medi-Cal and knowledgeable of the issues related to their disability. In some cases, when transportation was a problem, participants who were unable to find nearby physicians reported going without needed care.

Participants in fee-for-service Medi-Cal, in which beneficiaries are responsible for finding their own doctors, described the search process as especially difficult. “No doctors accept Medi-Cal,” one participant stated bluntly, capturing the feelings of many fee-for-service consumers in the focus groups throughout the state. “It is hard to find a doctor that accepts Medi-Cal.”

A common response from exacerbated participants was, “I just looked in the phone book. I just called doctors until I found somebody who accepted Medi-Cal.” Another fee-for-service participant said, “It did take me awhile [to find a doctor]—call after call. And, I called the

“It did take me awhile [to find a doctor]—call after call. And, I called the Medi-Cal referral [number], and they told me the best thing to do would be to make phone calls because they do not have a list of doctors.”

—*Fee-for-service beneficiary
in Ventura County*

Medi-Cal referral [number], and they told me the best thing to do would be to make phone calls because they do not have a list of doctors.”

Finding a specialist was reported as being difficult as well, and the issue surfaced equally among fee-for-service and managed care respondents. “When it comes to some kinds of specialt[ies], they are practically nil,” one Los

Angeles participant reported. One caregiver said, “In terms of psychiatric care, certainly no one who we can consider a quality provider will take . . . [Medi-Cal].” Focus group participants from rural areas expressed particular concerns about the availability of specialists.

Because finding physicians is so difficult, consumers reported frequent use of hospital emergency rooms and urgent care clinics. “When I go [to see a doctor], I go to the emergency room. It only takes an hour,” reported one deaf participant. Another consumer said, “My regular doctor passed away about six years ago, and, since then, I just go to an emergency room whenever I get sick.”

Getting a timely appointment for routine or specialty care was often reported as being problematic. Although some reported only having to wait a couple of days for a medical appointment, most reported waiting weeks to see both primary and specialist physicians even when the medical need was urgent. “I have to wait at least three weeks, and [then], while I am there, it is up to a four-hour wait.” In two counties (Santa Barbara and Alameda), roughly half of the participants reported waiting several months for appointments to see their physicians.

Provider Knowledge and Sensitivity

Many focus group participants felt that their health care providers did not adequately understand their disabilities. Participants also stated that medical technicians and office support staff lacked knowledge of and sensitivity about people with disabilities. This sentiment was reported by fee-for-service and managed care groups and was a prevalent concern for deaf and mentally ill beneficiaries.

“They think that I am a nitwit,” commented one deaf participant in a managed care plan. “They think that I don’t understand certain terminology [because of my deafness], but they are wrong.” Deaf participants reported frustration about physicians who refused to acknowledge or accommodate their disability. “[My physician] will often try to talk to me,” said one consumer. “I say, ‘No, write back and forth,’ and he will [continue to] try and talk to me. Then it becomes extremely frustrating. I try to write back to him about something I want to know about and then he talks to me again. Oftentimes, I ask for an interpreter and people are avoiding it and it becomes frustrating.” Another participant in the same group recalled that

her doctor “has this attitude and he gets real snotty almost. He will say, ‘You should know how to write and you should be able to communicate through written communication.’”

Beneficiaries with mental illnesses reported feeling discriminated against due to their disabilities. One fee-for-service beneficiary with a psychiatric disability expressed frustration with the way he is treated: “Why do they have to talk to me in this loud tone of voice and embarrass me at the counter?” Another focus group participant reported, “It seems that I am getting partially discriminated against or being talked to slightly different or treated differently because of [my disability]. So, if I say anything about my face breaking out, it is [attributed to] stress; it is not [considered] a physical problem, which it has been. [The discrimination] . . . is very subtle.” A woman from another group said, “I feel like I have been treated a little differently from the get go. . . . The feeling that I got was that [my primary care physician] thought that I was delusional about my brain lesion.”

“It seems that I am getting partially discriminated against or being talked to slightly different or treated differently because of [my disability].”

—*Fee-for-service beneficiary
in Los Angeles County*

Throughout the focus groups, participants expressed dissatisfaction with providers’ explanations about care. “I need to know what [the doctor] is going to do to my body,” one consumer stated. “They don’t explain. [They say], ‘It is an antibiotic, so just take it so many days. Just go to the pharmacy and they will know.’ That is the extent of the conversation, but I would like to know what I am putting in my body. I am curious about what kind of medication it is—will it have side effects.” Another consumer said, “If I don’t ask questions, then I get no answers. I ask a lot of questions because I like to know about my condition.”

Not surprisingly, consumers and caregivers reported providing a lot of disability awareness education to their health care providers. Many focus group participants said that they felt responsible for educating their doctors and the medical staff they interacted with about the needs associated with their disability. In most cases, participants reported that providers were receptive to this education. “I think we have really helped train our doctor, and I mean it in the kindest way. Because she was absolutely open, but . . . [the disability we are dealing with] was not her area of expertise,” one caregiver in the developmental disabilities arena reported. “So, we work with them and we try to do absolutely everything we can to make their jobs easier, but they do listen to us and consider the whole person.”

Access to Health Facilities and Medical Equipment

Difficulty accessing facilities and medical equipment was a resounding issue across all focus groups. This issue was particularly problematic for beneficiaries with physical disabilities, regardless of whether they were fee-for-service or managed care consumers. One individual reported that he had to change doctors because, when he showed up to his appointment, there

were no wheelchair ramps. “My first doctor’s office had no ramps at all,” one person said. “I couldn’t get in easily.”

Consumers who were able to get inside a medical facility often encountered inaccessible medical equipment. Wheelchair accessible scales were not widely available. Examining tables were reportedly too high to easily transfer onto and were difficult to stay on for people with spasticity. As a result, some focus group participants reported that their examinations were incomplete and the quality of their care was compromised.

“We have a number of people that have mobility problems and they are expected to just step up on that little stool,” said one caregiver. “They are having to balance on one foot and turn around and be facing the right direction or lay over facing the wall and then flip around,” she continued. “If they had bars or something on either side of the scale, that would be a big help. That is such an easy solution.” Some consumers reported bringing their own assistants to help them transfer onto an exam table, while others reported less than thorough exams because they

“My doctors examine me right here—in my wheelchair. They try to avoid putting me on . . . [the exam table].”

—*Managed care beneficiary
in Santa Cruz County*

were not on a table where the physician could examine their entire body. One beneficiary with a physical disability explained, “My doctors examine me right here—in my wheelchair. They try to avoid putting me on . . . [the exam table].” Such treatment can lead to undiagnosed secondary conditions.

Access to Information

In every focus group, participants indicated that the information they received was difficult to understand. The format was often not appropriate for someone with a cognitive disability or with a visual impairment—usually because the print was extremely small or alternate formats were unavailable. Information provided by both Medi-Cal fee-for-service and Medi-Cal health plans, including letters, booklets, and forms, was not always provided in accessible formats, such as Braille, large print, audiotape, or electronic formats. “I asked a long time ago, and at the time I asked, they did not have [the benefits information] in Braille,” one visually impaired consumer commented.

Among consumers who were physically able to read the materials, many reported that the language in the materials was convoluted and difficult to understand. “I am not able to understand [the information provided],” one participant stated. “I’ll read it a little bit and get lost in it. Then I just deal without it. If I have any questions, I either ask my doctor or I call up my [health care] workers.” Some par-

“I am not able to understand [the information provided]. I’ll read it a little bit and get lost in it. Then I just deal without it. If I have any questions, I either ask my doctor or I call up my [health care] workers.”

—*Managed care beneficiary
in San Bernardino County*

ticipants stated that verbal communication might be more effective. “If I had somebody sit down with me and go through it with me, it would probably be easier because I understand things more when they are verbally explained than me sitting down and trying to read it myself.” A deaf managed care participant suggested the health plans “could have a class that would explain what they can do with the medical card” and “put it on video tape with a person signing it.”

By far, the biggest challenges related to accessing information were experienced by deaf consumers. Focus group participants, particularly those in Medi-Cal fee-for-service, cited the lack of sign language interpreters to be their biggest barrier. Often interpreters were not provided and consumers were forced to resort to writing notes or to bringing their own interpreters. On some occasions, consumers reported delays in care while interpreters were located and scheduled.

“Medi-Cal has not accepted interpreters from me. They refused to pay. Insurance seems not to want to cover [interpreters],” said one deaf fee-for-service Medi-Cal beneficiary in Riverside County. “My doctor refuses to get an interpreter—even after I ask,” echoed another fee-for-service consumer. “He absolutely refuses.” A third consumer recalled entering a hospital where she noticed that there was a sign referencing interpreters: “I asked them and said, ‘I want an interpreter.’ Two, three, four hours went by, and it ended up [that] the interpreter never did show up. But, I [had] noticed that a sign said if you need interpreting service that you could get it.”

When interpreters were available, participants stated that they did not always have the proper skills necessary to communicate medical complexities. “Sometimes the interpreters themselves are unclear and I don’t understand them,” reported one beneficiary. “Sometimes there are not qualified interpreters [available].”

On the other hand, several managed care enrollees reported satisfaction with their plan’s coverage of interpreters. One deaf consumer reported that her plan provided her with an interpreter for her Lamaze class. “They had an interpreter and it was pretty good,” she said. “I went to the classes and they taught everything, and we had the interpreter, so it was fine.” In fact, several participants in both deaf focus groups reported changing health plans based on interpreter services.

Benefits

Understanding of the Medi-Cal Benefits Package

There was a significant lack of consumer understanding about the scope of covered benefits and services in both fee-for-service and managed care groups. Many focus group participants were unaware that they were entitled to certain benefits and services, such as coordinated care or preventive services, under managed care plans.

Nearly all fee-for-service participants said that they did not receive any written materials describing their benefits. The only written materials that most fee-for-service beneficiaries recalled receiving were payment denial or appeals letters. In contrast, nearly all managed care group participants stated that they had received books and other materials about their health plans. However, many managed care participants reported that the materials contained medical and legal jargon that they did not understand. Further, many participants expressed confusion about how to get questions regarding covered benefits answered.

“I did get a lot of paperwork and it was overwhelming,” said one fee-for-service consumer in a Two-Plan Model county. “I did look for an 800 number to call somebody and ask them what is going on because the paperwork was too hard for me to read.” A managed care participant in a different county recalled his experience when he signed up for his health plan: “The lady said, ‘If you have any problems, you have a card and there is an 800 number on the back.’”

Durable Medical Equipment

Durable medical equipment refers to equipment (such as wheelchairs, canes, portable oxygen tanks, and augmentative communication devices) that helps people with physical disabilities to live more independent lifestyles in their own homes and communities. The timeliness of

“The time in between something breaking and the people coming out, doing the assessment, submitting their request, and getting the approval could be a couple of months.”

—*Fee-for-service beneficiary
in Ventura County*

DME maintenance, repair, and replacement was repeatedly raised in the physical disability focus groups as areas of significant concern. One caregiver described the time lag between the identification of the need and the actual repair: “The time in between something breaking and the people coming out, doing the assessment, submitting their request, and getting the approval could be a couple of months.”

A second caregiver expressed frustration with the lack of coverage for routine maintenance and backup equipment. “I have one woman who is in a motorized chair and repairs to that often take a long time to get approved. She is a big woman and she is hard on her chair and it needs practically a tune-up like a car does. Just routine maintenance would be really great, but that is not in the lexicon.” According to the caregiver, the woman has an alternate wheelchair that Medi-Cal would not purchase. “We wanted to get her a nonmotorized chair for emergency use, such as for emergency exits from the home and for backup in the event that her motorized chair was not available to her,” the caregiver continued. “Medi-Cal would not fund it because they funded the primary chair.”

Participants reported that, as a result of delays, they sometimes had to significantly restrict their daily activities. One participant explained: “If they are fixing my chair, then I have to depend on my manual chair and that means I have to stay at home because I can’t go down hill in a manual chair.”

Prescription Drugs

The issue of prescription drugs raised the most emotion, frustration, and discussion in all the focus groups. Prescription drugs that are covered by Medi-Cal fee-for-service are listed on the program's drug formulary. Typically, a fee-for-service beneficiary is eligible for up to six prescriptions listed on the formulary in a given month, and anything over that amount requires prior Medi-Cal approval. Medi-Cal managed care health plans maintain their own individual formularies and limits.

Many focus group participants expressed confusion about which drugs are covered by Medi-Cal. Further, they reported that their providers seem to have a limited knowledge of the Medi-Cal formulary and that they often prescribed medications that were no longer covered by Medi-Cal. This resulted in a long process of shuttling back and forth between the physician and the pharmacist to get an appropriate, covered medication. "The doctor prescribed a medication and I went to the pharmacy and the pharmacist said I am not covered," one fee-for-service participant told the group. "So I walked away with no medication. In the end, I ended up using herbs instead of buying the prescription."

"The doctor prescribed a medication and I went to the pharmacy and the pharmacist said I am not covered. So I walked away with no medication. In the end, I ended up using herbs instead of buying the prescription."

—*Fee-for-service beneficiary
in Riverside County*

Focus group participants expressed dissatisfaction in many cases regarding drugs that were not covered and the practice of substituting a generic for a brand-name drug. For example, a caregiver in Ventura County stated, "We get situations where Medi-Cal will not pay for the prescribed medication—even when it is the absolute indicated medication and a generic is not satisfactory." A San Diego consumer admitted, "The potency of the prescription is not as good as it is supposed to be, so you end up taking more of that prescription—overdoing the dosages—just to get the same effect of one brand-name prescription."

Another consumer expressed frustration with the length of time needed to get authorization for a nonformulary drug. "I needed a drug, but it was a thousand dollars a month. It took a month for the doctor to work with Medi-Cal in order for me to get the drug. Sometimes it becomes a life and death situation, and they don't have choices anymore to refuse you."

Beneficiaries also expressed concerns about not being given sufficient notice when changes were made to the drug formulary. "I have just recently been cut off [from a specific drug]," said a fee-for-service participant in the Los Angeles focus group. "My complaint was [that] I wasn't even told that it was going to be cut off. No warning! I just went down to my drugstore to get my prescription refilled and bam! 'No, Medi-Cal doesn't cover it anymore.' I have to call my doctor and get an appointment with her and try to find out if I can get an alternate prescription. In the meantime, I am in pain. I don't feel great." Another participant in the same group added, "It is really weird . . . how they will cover certain types of medications, and then they

are not covering it and then they are covering it again. It is just like a whirlwind of—you just never know.”

Another major concern was time required for refilling prescriptions. Focus group participants indicated that if they knew that it would take a long time to receive authorization to refill, they would seek alternative methods to secure the medications they needed. Sometimes, people would purposefully skip pills or cut the dosage in half in order to extend the prescriptions for the uncovered time. A few consumers reported that their pharmacist would refill their prescriptions that were not covered while they were waiting for the appeal process, and often these pharmacists would not be reimbursed for these medications.

Focus group participants cited some creative approaches to dealing with these challenges. As one participant from Los Angeles explained, “When I had a gap in coverage—when I didn’t have prescription coverage—I would either get free samples sometimes, pay for it, or go to Tijuana,” He added, “There were sort of ways to get around it—if you really, really needed it. You can get the Canadian [drugs] . . . over the Internet now, but if you are close to the border . . . (it is only a two-hour drive from here), you can go with a bunch of people down there to Tijuana.”

Other Services

Several other benefits issues were raised by focus group participants:

- According to Medi-Cal fee-for-service focus group participants, care coordination and case management services appeared to be nonexistent. Among managed care enrollees, care coordination services seemed to vary dramatically by health plan. In the areas where these services were not available, beneficiaries had the added burden of coordinating the complexities of their medical care and the communication across all of their providers. Many beneficiaries reported that they sought the assistance of community agencies to advocate for needed services when physicians were unable or unwilling to help.
- Although unprompted, the issue of access to nonemergency medical transportation arose so frequently in the first two-thirds of the focus groups that a question about it was added to the last four groups. In rural areas and in counties with disparate public transportation systems, transportation was particularly problematic. In contrast, transportation issues were not cited as a significant barrier in the San Francisco Bay Area groups.
- The inability to secure dental services was also a significant frustration for many focus group participants. “Dentists don’t accept Medi-Cal,” said one deaf managed care beneficiary. Another frustrated consumer stated that to get “just an initial deep cleaning by a dentist . . . I have been waiting a month to get an approval [from Medi-Cal].”

Grievance and Appeals Processes

Focus group participants demonstrated a lack of understanding about where to turn if they had problems with the Medi-Cal system. Most participants said that they were not aware they had the right to file an appeal when a benefit or service was denied. There was confusion in all counties as to where to go to file a complaint, who to talk with, and the process by which they could file a complaint. A deaf participant reported, “I was talking to a friend of mine and they . . . told me I could file a complaint about these different issues. I didn’t know that—I wasn’t aware. [Medi-Cal] . . . didn’t tell me about what their policies and procedures were.”

“I was talking to a friend of mine and they . . . told me I could file a complaint about these different issues. I didn’t know that—I wasn’t aware.”

—Beneficiary in Riverside County
(delivery system unknown)

Among those who said they did know where to file complaints, most cited their physicians or health plans as sources of information. “I have been finding out what I can and cannot do by being told directly—one-on-one—by a doctor or a pharmacist,” a Los Angeles beneficiary explained.

For those who attempted the process of filing an appeal or grievance, it was noted that significant persistence and self-advocacy skills were essential. “You have to be very assertive,” one Los Angeles participant said, noting that a lot of people are unable to be as assertive as necessary. “They feel intimidated by the pharmacist or the doctor, and if you don’t [act assertively], you are not going to get . . . the services that you need. You have to be very persistent in your health care.” However, the majority of focus group participants indicated that the process of an appeal or complaint was daunting and pointless. “It is not worth it,” one participant said, “because it is difficult for me to fight through the polic[ies] and procedures. So, I usually end up quitting and not following through. I guess I am kind of weak. I just don’t have the assertiveness to follow through the . . . [process].”

III. Conclusions

The findings from this project indicate that the current Medi-Cal delivery system does not adequately meet the needs of people with disabilities. Focus group participants reported difficulties finding physicians, understanding their benefits and services, and accessing services, programs, and facilities. Many participants said that they must turn to nonprofit community organizations for assistance with advocacy and support programs. They also reported using services offered through the county health programs to supplement their unmet needs.

These findings were pervasive in both fee-for-service and managed care groups. However, although consumers and disability advocacy organizations have expressed concerns about the impact that managed care might have on provider choice and access to a comprehensive range of services, the focus groups revealed a number of potential benefits to managed care, including:

- Improved ability to find a primary care physician;
- Increased availability of services that are not always available through the fee-for-service delivery system (such as interpreter services for deaf beneficiaries); and
- Improvements in the provision of information about health care benefits and services.

Despite these differences, however, it is clear that there are significant problems with both delivery systems that should be addressed. Until the entire Medi-Cal system has been evaluated for its ability to more appropriately serve people with disabilities, questions regarding the benefits and shortcomings of managed care, as compared to fee-for-service, cannot be resolved.

Some of the barriers identified through this study may be unique to the Medi-Cal program, while others are likely to be indicative of problems that all people with disabilities experience, regardless of the type of health insurance they have. For example, it may be more difficult for Medi-Cal beneficiaries with disabilities to find a provider knowledgeable about their condition than it is for those who have employer-sponsored coverage because only about one-half of physicians participate in Medi-Cal. Other issues, such as finding accessible medical offices and equipment, are problematic throughout the health care industry. Nonetheless, each of these barriers must be addressed to improve the delivery of care for Medi-Cal beneficiaries with disabilities.

Based on the findings from the focus groups, the following recommendations are offered as steps toward improving the current Medi-Cal delivery system for people with disabilities:

1. Qualified people with disabilities, their family members, and representatives from disability advocacy organizations need to be involved in a meaningful way in every step of the Medi-Cal policy process.
2. Gaps in Medi-Cal benefit design and delivery that adversely impact people with disabilities should be addressed.
 - The myriad of prescription drug issues raised in the focus groups need immediate attention. DHS should provide an outlet, such as a Web site or a toll-free number, where consumers and providers can get accurate, up-to-date information about the drug formulary. Policies and procedures that lead to consumers stretching and skipping needed medications should be reviewed and modified. The drug formulary needs to be more flexible to allow for specific drug types when warranted and prescribed by physicians.
 - Medi-Cal should provide reimbursement for sign language interpreter services. Managed care plans that do cover interpreter services should educate providers about the availability of these services, and their provision of the services should be enforced.
 - Durable medical equipment maintenance, repair, and replacement policies should be revised to recognize the essential function of the equipment in a person's ability to live independently in the community. Specifically, preventive maintenance should be covered, the timeliness of repair approvals should be improved, and loaner equipment during repair should be provided. In addition, backup DME should be authorized, especially for emergency health and safety purposes.
 - Care coordination services need to be improved. For the most part, these services are not covered by fee-for-service Medi-Cal. While many Medi-Cal managed care plans do provide care coordination services, most Medi-Cal managed care focus group participants were unaware of their availability.

- Preventive care and integrated long-term care services that are designed to prevent secondary conditions and promote healthy lifestyles and community living should be provided.
3. Best practices should be defined, identified, shared, and adopted. New approaches to health care service delivery for people with disabilities should be developed, pilot tested, and evaluated. There is much to be learned from the experiences of the health plans that are currently participating in Medi-Cal and from the experiences of other state Medicaid programs about improving information and outreach, benefit design, and service delivery for beneficiaries with disabilities.
 4. Department of Health Services and Medi-Cal health plan administrators must work to improve outreach efforts to Medi-Cal consumers to increase awareness about managed care options, covered benefits and services, and the grievance and appeals processes.
 - DHS, Medi-Cal health plans, and individual health providers should provide understandable materials in a range of formats, such as large print, audio cassettes, Braille, diskettes, and electronic formats, to assure access for people with disabilities.
 - DHS should create and advertise a statewide information resource hotline similar to member services phone lines available through managed care health plans for Medi-Cal fee-for-service consumers to get their questions answered.
 5. Quality of care outcomes measures and access standards and guidelines should be developed and adopted to address the specific needs of people with disabilities in Medi-Cal's fee-for-service and managed care programs. Quality-of-care indicators should include physical, program, communication, and technology accessibility standards. The testimonials from the focus groups support a growing body of evidence that such standards and guidelines are needed to address discrepancies in quality of care and access issues with regard to facilities and medical equipment. To this end, DHS should convene a technical panel to develop a set of quality and access standards for people with disabilities, and disability-specific consumer satisfaction surveys should be used in both Medi-Cal fee-for-service and managed care.
 6. Cross-disability awareness and sensitivity training needs to be incorporated into academic-based health care provider education and training. Likewise, trade associations, professional networks, and accrediting bodies should require ongoing cross-disability awareness and sensitivity training. A technical panel should be established to develop licensure and certification standards that incorporate disability knowledge and sensitivity.

7. Existing public and private health care research surveys and projects should incorporate disability-related issues. Research projects need to be developed in consultation with and, when possible, conducted by qualified people with disabilities.

In conclusion, policymakers and health care providers need to keep in mind that using language like “the disabled” is merely a way to reference a large subpopulation of Californians. People with disabilities come in many different sizes and shapes, and with many interests, abilities, and conditions. “The disabled” are not a discreet population that can be squeezed into a “cookie cutter” health care box.

As health care policies, programs, and services are being developed and reshaped, the following comment from a frustrated focus group participant should be kept in mind: “The [Medi-Cal] rules do not seem to make sense and don’t have any application to an individual. If people could just look at what all these hoops mean to a single individual, it would really be helpful.”

Appendix A: Project Advisory Committee Members

Farra Bracht, Legislative Analyst's Office

Mary Lou Breslin, Disability Rights Education and Defense Fund (DREDF)

Gretchen Brown, CalOptima

Richard Bruno, Inland Empire Health Plan (IEHP)

Nancy Hammons, Deaf Counseling Advocacy and Referral Agency (DCARA)

David Pieribone, AIDS Project Los Angeles

Laura Remson Mitchell, Advocate and Disability Policy Consultant

Tiffany Reyes, Legislative Analyst's Office

Cheri Rice, California Department of Health Services

Shelley Rouillard, Health Rights Hotline

Bud Sayles, San Diego IHSS Public Authority

Appendix B: Consolidated Focus Group Topic Guide

Notes:

- We use the term “provider” throughout the protocol to reflect a broad group of people who provide health-related services. Providers include, but are not limited to, physicians, specialists, technicians, and therapists.
- The protocol includes a list of questions followed by smaller, more specific questions marked “probe” or “expand if needed.” These are questions that will be used by the moderator as a tool to tease out more thorough answers. If they are not needed, do not ask them.

Introduction

The Medi-Cal Policy Institute is working with the Center on Disability Issues for the Health Professions at Western University of Health Sciences in Pomona California to gain a better understanding of the experiences of Californians with disabilities who are enrolled in Medi-Cal. They would like to use this information to improve the Medi-Cal program. You have been asked here today to discuss with us your experiences as a Medi-Cal consumer. Thank you for joining us. For the next two hours we are going to ask you a series of questions regarding your experience with Medi-Cal. All information and answers will be kept confidential and only your general responses will be used to inform our study. Sponsors of the study will be observing the group through a two-way mirror. We'd like to start with introductions. Let's go around the room. Please tell us your name and how long you've been on Medi-Cal.

Ground Rules for Discussion

1. Cell phones and/or pagers need to be turned off.
2. Participants should feel free to excuse themselves for any reason, and then re-join the group as soon as possible. [Point out where bathrooms, drinking fountains, and other facilities are.]
3. We would like to hear from each participant throughout the discussion. However, each person does not have to answer every question.
4. There are several topic areas that we need to cover today. Thus, we must keep the discussion moving and may need to interrupt someone who is talking. Please do not be offended by this gesture; we want to be sure that we get a chance to have an adequate time for discussion about each topic.
5. Remember that there are no right or wrong answers. We are interested in hearing real life experiences, and it is okay that your experiences may be different from others in the group.
6. If you could please identify yourself by saying your name before you speak, for recording purposes.
7. If a question is unclear, please feel free to ask any question of clarification.
8. I would like to take a few minutes to answer any questions you might have.
9. If that is all, let's get started.

Topic 1: Understanding and/or Choosing Medi-Cal Managed Care

1. [This question asked only of respondents in voluntary managed care counties.]
In your county, you have a choice between using straight Medi-Cal or enrolling in a managed care health plan such as Blue Cross or Alameda Alliance for Health.

For respondents in straight Medi-Cal: How and/or why did you decide to stay in regular (straight) Medi-Cal rather than enroll in a managed care plan?

For respondents in managed care: How and/or why did you decide to enroll in a managed care plan rather than staying in straight Medi-Cal?

Expand if needed:

- a: Your current primary care physician suggested it?
- b: Differences between straight Medi-Cal and your managed care plan?
- c: Extra services provided under managed care, such as preventive health services, transportation, and case management?
- d: Access to a different network of specialists?

2. [This question asked only of managed care respondents in voluntary managed care counties.] If you decided to enroll in a health plan, how did you decide which plan to enroll in (Blue Cross versus Alameda Alliance for Health)?

Expand if needed:

- a: Your current primary care physician suggested it?
- b: You attended a health fair put on by the health plan?
- c: Your doctor was a member of this plan?
- d: Did you receive help from an advocacy organization or legal services in order to choose?

Topic 2: Finding a Physician

Choosing a Primary Care Provider

1. What process did you use to find a primary care physician or regular medical doctor?
Probe a: Assigned by the plan, referred by a friend or family member, or chose from a phone book or provider list?
2. Was it difficult to find a primary care physician or a regular medical doctor (for example, someone you can see for a routine check-up and/or exam to check things like blood pressure, blood, breathing, and so on) who was willing to take Medi-Cal?
3. How often do you see a regular medical doctor?
4. How long does it take you to get an appointment (1 week, 2 weeks, 3 weeks, 4 or more)?

Access to Specialists

1. If you have experience with requesting to see a specialist (such as a neurologist, cardiologist, immunologist, occupational therapist, physical therapist, or speech therapist), was it difficult to find a specialist who was willing to take Medi-Cal?
Probe a: Do you have a choice of providers?
Probe b: Were you able to see the specialist quickly or did you have to wait a long time? How long?

Topic 3: Provider Knowledge and Sensitivity

1. What has been your experience regarding primary care doctor's knowledge and experience about your disability?

Expand if needed:

- a: Is your provider aware of the important health and disability-related issues specific to your condition?
2. Do you believe your primary care doctor has skipped treatments or only provided partial treatments due to your disability?
 3. If you have had experience with mammograms, colonoscopies, or other x-rays, radiology, or testing procedures (such as MRI scans), were the providers knowledgeable about and experienced in conducting tests and procedures with people with disabilities?

Topic 4: Accessibility of Services

Communication

1. Does [Medi-Cal / your Medi-Cal health plan] provide information in a format you can use about your health care coverage, such as the complaint process, satisfaction surveys, medical history forms, or consent to treat forms?

Expand if necessary:

a: Examples of accessible formats: Braille, large print, diskettes, audio cassettes, video with captions or audio descriptions.

b: Do you have an opportunity to review forms prior to arriving for an appointment?

Physical Access

1. Do you find your health care facility to be physically accessible? Explain.
Probe a: Can you get to the facility? Can you get inside the facility? Can you use the facility?
Probe b: Is a height-adjustable exam table available?
Probe c: Are the office staff and providers trained in transfer techniques?
Probe d: Are accessible scales available?

Topic 5: Benefits and Services

1. How well do you understand the benefits / services that are covered by [Medi-Cal / your Medi-Cal health plan]?

Probe a: How were the benefits explained to you? Were you given written information? Did your provider or the office staff of your provider tell you?

Care Coordination

1. If you have a complex, complicated disability, health issue, or condition, is there someone to help you to coordinate your care? (Examples: a primary care provider, a social worker, a service coordinator, a case manager, no one, or other.) How do you access this person?

Prescription Drugs

1. Does [Medi-Cal / your Medi-Cal health plan] cover the prescription medications that you need?

Probe a: If not, how do you get the medications you need that [Medi-Cal / your Medi-Cal health plan] does not cover?

Equipment [These questions asked only in physical disability and chronic illness groups.]

1. What has been your experience with obtaining Durable Medical Equipment (DME), such as wheelchairs, adjustable beds, oxygen, batteries, or communication devices?

Probe a: Does [Medi-Cal / your Medi-Cal health plan] cover the equipment that you need?

Probe b: Are you able to get the equipment that you need in a timely way?

Probe c: Have you ever been denied coverage that you felt was necessary? Please explain.

2. What is the quality and timeliness of repair or replacement of your DME?

Probe a: Can you choose the person who does the repairs or is someone assigned?

Probe b: Does [Medi-Cal / your Medi-Cal health plan] provide backup (emergency need) DME?

Probe c: How often will [Medi-Cal / your Medi-Cal health plan] replace your equipment?

3. Have you had experience obtaining consumable supplies such as catheters, colostomy bags, and on? If yes, please describe your experience in terms of ease, coverage, timeliness, and so on.

Preventive Services

1. Have you ever been offered services such as nutrition counseling or programs for quitting smoking or weight loss?

Topic 6: The Complaint and Appeals Processes

1. Does [Medi-Cal / your Medi-Cal health plan] give clear explanations for all denials of care?

Expand if needed:

If you are denied coverage for access to specialists, prescriptions, or equipment, do you receive an explanation?

2. Are you familiar with the processes for filing a complaint or grievance with [Medi-Cal / your Medi-Cal health plan]?

Probe a: If yes, how were you made aware of these processes? Did [Medi-Cal / your Medi-Cal health plan] provide you with any written materials explaining the processes?

3. Have you filed a formal complaint with [Medi-Cal / your Medi-Cal health plan]? What was your experience?

Probe a: What was the timeliness of process and the outcome of your experience with this process?

Probe b: Did anyone help you file your complaint? If so, who?

Thank you for being a part of this focus group today. You have helped us to learn more about your experiences with Medi-Cal.

Appendix C: Community-Based Organizations Assisting in Focus Group Participant Recruitment

Alameda

Community Resources for Independent Living
439 A Street
Hayward, CA 94541
Telephone: (510) 881-5743
Fax: (510) 881-1593
TDD: (510) 881-0218

Los Angeles

Verdugo Mental Health Clinic
1540 E. Colorado Boulevard
Glendale, CA 91205
Telephone: (818) 241-6780
Fax: (818) 244-7257

Orange

CalOptima
1120 West La Veta Avenue
Orange, CA 92868
Telephone: (714) 246-8400 or (888) 587-8088

Riverside

Deaf Counseling, Advocacy, and Referral Agency
14895 East 14th Street, Suite 200
San Leandro, CA 94578

Greater Los Angeles Council on Deafness, Inc.
2222 Laverna Avenue
Los Angeles, CA 90041
Voice / TDD: (323) 478-8000
Fax: (323) 550-4205
E-mail: info@gladinc.org

Sacramento

NORCAL
Starfleet Headquarters: Sacramento (serving Sacramento, Yolo, El Dorado, and
Placer Counties)
4708 Roseville Road, Suite 112
North Highlands, CA 95660
Voice / TTY: (916) 349-7500
Fax: (916) 349-7580

San Bernardino

Rolling Start, Inc.
570 West 4th Street, Suite 103
San Bernardino, CA 92401
Telephone: (909) 884-2129
Fax: (909) 386-7446
TDD: (909) 884-7396

Inland Empire Health Plan
303 E. Vanderbilt Way, Suite 400
San Bernardino, CA 92408
Telephone: (909) 890-2000
Fax: (909) 890-2003
Web site: www.iehp.org

Molina Health Care Inc.
One Golden Shore
Long Beach, CA 90802
Telephone: (800) 986-4649
Web site: www.molinahealthcare.com

San Diego

Access Center of San Diego
1295 University Avenue
San Diego, CA 92103
Telephone: (619) 293-3500
Fax: (619) 293-3500
TDD: (619) 293-7757

Visions Mental Health
499 H Street
Chula Vista, CA 91910
Telephone: (619) 420-8603
Fax: (619) 420-0385

San Diego Alliance for the Mentally Ill
Albright Information and Referral Center
5384 Linda Vista Road #301
San Diego, CA 92110
Telephone: (800) 523-5933

United Behavioral Health
Public Sector Division
3111 Camino Del Rio North
San Diego, CA 92108
Telephone: (800) 479-3339
Fax: (619) 641-6729

Blue Cross of California
Individual, Small Group and Medicare
2000 Corporate Center Drive
Newbury Park, CA 91320

Blue Cross of California
Large Group
21555 Oxnard Street
Woodland Hills, CA 91365

San Francisco

AIDS Project San Francisco
995 Market Street, Suite 200
San Francisco, CA 94103
Telephone: (800) 367-AIDS

Center for Independent Living
2539 Telegraph Avenue
Berkeley, CA 94704
Telephone: (510) 841-4776
Fax: (510) 841-6168
TDD: (510) 848-3101

Positive Resource Center
973 Market Street, 6th Floor
San Francisco, CA 94103
Telephone: (415) 777-0333

Kaiser Permanente San Francisco
2238 Geary Boulevard
San Francisco, CA 94115
Telephone: (800) 464-4000
Spanish line: (800) 788-0616
Web site: www.kaiserpermanente.org

San Luis Obispo

Independent Living Resource Center Santa Maria Office
327 East Plaza Drive, Suite 3A
Santa Maria, CA 93454
Telephone: (805) 925-0015
Fax: (805) 349-2416
TDD: (805) 925-0015

Santa Barbara

Independent Living Resource Center
423 West Victoria Street
Santa Barbara, CA 93101
Telephone: (805) 963-0595
Fax: (805) 963-1350
TDD: (805) 963-0595

Santa Cruz

Central Coast Center for Independent Living Santa Cruz Office
1395 41st Avenue, Suite B
Capitola, CA 95010
Telephone: (831) 462-8720
Fax: (831) 462-8727

Ventura

The ARC
5103 Walker Street
Ventura, CA 93003
Telephone: (805) 650-8611
Fax: (805) 501-4444

Appendix D: Focus Group Screening Questions

You have been selected to participate in a focus group to help state policymakers better understand the impact of the decisions they make about the state's health care systems serving people with disabilities.

Your comments will be held strictly confidential. Any use of information will not include any of your identifying information and would be used for illustrative purposes only. Information you provide us will not jeopardize your health benefits or any other disability-related benefits you may receive. This is strictly a research project.

Thank you for your assistance.

1. Is Medi-Cal [your / your adult child's] primary form of health care coverage?

- a. Yes
- b. No

[Continue with screening only if respondent, or person being represented, has Medi-Cal.]

2. [Do you / does your adult child] also receive coverage through Medicare?

- a. Yes
- b. No

[Continue with screening only if respondent, or person being represented, does not have Medicare.]

3. How old are you?

[Continue with screening only if respondent, or person being represented, is 18 or older.]

4. Do you consider [yourself / your adult child] to have a disability or chronic illness?
- Yes
 - No

[Continue with screening only if respondent, or person being represented, has a disability or chronic illness.]

5. Which of the following would you consider to be [your / your adult child's / the person for whom you are a caregiver] primary condition or disability?
- Physical disability in which you use equipment such as a wheelchair, scooter, cane, crutches, or augmentative communication device (Easy Talk, Dynovox, or DynaMyte) [If yes, please name your physical disability];
 - Developmental or intellectual disability, including but not limited to autism, Down Syndrome, brain injury, or dementia [If yes, please name your developmental or intellectual disability];
 - Chronic or long-term condition or illness, including but not limited to multiple sclerosis, cerebral palsy, muscular dystrophy, sickle cell, chronic obstructive pulmonary disorder (COPD), chronic pain, lupus, or AIDS/HIV [If yes, please name your chronic illness];
 - Psychological disability or mental illness, including but not limited to bipolar disorder, depression, anxiety, panic disorder, obsessive compulsive disorder (OCD), and schizophrenia [If yes, please name your specific disability]; or
 - Deaf or hard of hearing.

[Continue with screening only if respondent has identified having, or being responsible for someone who has, one of the above disabilities.]

6. How long [have you / has your adult child] been on Medi-Cal?
7. Which county [do you / does your adult child] live in?
8. [Are you / is your adult child]:
- Enrolled in a Medi-Cal managed care plan, or
 - In straight Medi-Cal, which is sometimes called fee-for-service Medi-Cal?
9. If [you are / your adult child is] in a Medi-Cal managed care plan, what is the name of this plan?
10. What is your gender?
- Male
 - Female

11. Which of the following groups best describes you?

- a. American Indian or Alaska Native
- b. Asian
- c. Black or African American
- d. Native Hawaiian or Other Pacific Islander
- e. Latino
- f. Non-Latino Caucasian
- 6. Multi-ethnic

Notes

1. Medi-Cal Policy Institute (MCPI). *Medi-Cal for Non-elderly People with Disabilities: Fact Sheet #13*. Oakland, CA: February 2003.
2. Legislative Analyst's Office (LAO). *Enrolling the Aged, Blind, and Disabled in Medi-Cal Managed Care*. Sacramento, CA: February 27, 2003.
3. MCPI (2003).
4. LAO (2003).
5. MCPI (2003).
6. MCPI (2003).
7. California Department of Health Services. *Serving the Disabled in Medi-Cal Managed Care*. February 27, 2003.
8. Convenience sampling is the selection of the most readily available persons (or units) as participants in a study; also referred to as accidental sampling. Snowball sampling is the selection of participants by means of nominations or referrals from earlier participants; also referred to as network sampling.



CALIFORNIA
HEALTHCARE
FOUNDATION

Medi-Cal *Policy Institute*

476 Ninth Street
Oakland, CA 94607
tel: 510/286-8976
fax: 510/238-1382
www.medi-cal.org

A project of the
CALIFORNIA HEALTHCARE FOUNDATION