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Making Tough Choices: Adults with Disabilities Prioritize Their Medi-Cal Options

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CALIFORNIA HEALTHCARE FOUNDATION

by

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CHAT (Choosing Healthplans All Together) is copyrighted by the University of Michigan and the National Institutes of Health and is licensed to Sacramento Healthcare Decisions. For more information about CHAT, contact chat-info@umich.edu.

Medi-Cal CHAT could not have been implemented without the contributions of the Advisory Committee members (listed in appendix A), whose knowledge, wisdom and enthusiasm were instrumental in the design of the project. The authors are also grateful to the many organizations that assisted in recruiting participants and hosting Medi-Cal CHAT sessions in their communities

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Sacramento Healthcare Decisions (SHD) is a nonprofit, nonpartisan organization whose purpose is to educate and involve the public in health care policy and practice issues. For more information, contact Marge Ginsburg at 916.851.2828, marge.shd@quiknet.com, or visit the SHD Web site at www.sachealthdecisions.org.

About the Foundation

The **California HealthCare Foundation**, based in Oakland, is an independent philanthropy committed to improving California's healthcare delivery and financing systems. Formed in 1996, our goal is to ensure that all Californians have access to affordable, quality health care.

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I. Executive Summary

Medi-Cal beneficiaries—like most Americans—place a high value on choice.

The Project

In the face of a growing state budget crisis and possible reductions in Medi-Cal services, Sacramento Healthcare Decisions (SHD) involved Medi-Cal beneficiaries in a project to identify their individual and collective health care priorities. With support from the California HealthCare Foundation and Sutter Medical Center, Sacramento, SHD used CHAT (Choosing Healthplans All Together), a computer-based group process developed by physician-ethicists at the National Institutes of Health and the University of Michigan.

An Advisory Committee of local and state experts on Medi-Cal and the disabled community assisted SHD in designing CHAT for non-institutionalized, disabled adult Medi-Cal beneficiaries. This group was the focus of the project because they use a variety of health care services, represent a significant share of the Medi-Cal budget, and often have Medi-Cal coverage for many years.

The CHAT Board

For this project, CHAT participants designed their Medi-Cal benefits by making choices on the CHAT board, a pie chart with 14 categories of services, each with two or three tiers of benefits. While each category included a benefit tier that reflected current services, other tiers offered lower or higher benefits. There was one additional category (Enrollment) in which participants could tighten eligibility by adding premium cost-sharing for some beneficiaries.

Each category tier cost a specific number of markers based on the proportional cost of that service in the Medi-Cal budget. The higher the tier, the better the benefit, and the more markers it cost. The markers attributed to each category were derived from fee-for-service medical claims data provided by the California Department of Health Services and analyzed by The Lewin Group, a national health care and human services consulting firm. There were a total of 123 marker spaces on the CHAT board. Choosing all current services required 114 markers, and participants were given only 100 markers to use in designing the benefits. Thus, the structure of the exercise required participants to prioritize the services they regarded as most vital.

Participants and Structure of Sessions

Medi-Cal CHAT was conducted in spring 2004 with 131 participants in 12 separate groups convened in urban, suburban, and rural locations throughout the state. Most participants were recruited from local Independent Living Centers and represented different age groups, ethnicities, years with Medi-Cal coverage, and types of disabilities.

Each three-hour session was led by two facilitators and included 9 to 12 participants. Each participant used a laptop computer for pre- and post-CHAT survey questions and four rounds of CHAT:

Round 1. After instructions, participants worked individually on their laptops, designing a five-year Medi-Cal coverage plan just for themselves.

Round 2. Participants worked in groups of three, creating a Medi-Cal coverage plan for all disabled Medi-Cal beneficiaries in their county. The three had to come to agreement on the coverage plan.

Round 3. The entire group designed a benefits package for all disabled Medi-Cal beneficiaries in California. The facilitator led the discussion using a wall-projected CHAT board. This round was audio-recorded and was the basis for much of the qualitative findings.

Round 4. Participants once again created a coverage plan for themselves, as in Round 1. This indicated whether and how participants changed their benefits package after hearing the views and experiences of others.

Summary of Findings

The following statements reflect the dominant views and values conveyed during the group discussions, as well as the CHAT choices made by participants.

1. Given the nature of their health status, adult disabled Medi-Cal beneficiaries are often highly dependent on medical and supportive services. The CHAT decisions they make are heavily influenced by this basic fact.
2. Maintaining a full range of Medi-Cal services is the most important consideration when CHAT participants design coverage that affects all disabled Medi-Cal beneficiaries.
3. Having sufficient choice and availability of providers is essential for beneficiaries to feel secure about their health care services and confident that quality care is attainable. Choice of physicians is especially important.
4. Even though the CHAT process required participants to design a benefits package with reduced resources, there were nevertheless three categories in which many felt the need to increase services, not reduce them. These categories were Doctor Care, Dental Care, and Equipment.
5. To maintain a full range of services, participants most often opted to limit the scope of Medi-Cal coverage for three categories: Drugs (brand), Enrollment (eligibility), and Personal Care.
6. Participants were pleased by the chance to voice their individual and group opinions, an opportunity few have had before. Seventy-eight percent thought that CHAT was “definitely” a good way for others to understand the views and priorities of those on Medi-Cal.

Recommendations

As state legislators and agency personnel consider redesigning Medi-Cal in ways that are both fiscally and ethically responsible, the central issues and concerns of disabled Medi-Cal beneficiaries should be taken into account:

- Maintain the full range of Medi-Cal services, even if this means having to institute greater restrictions in how services are used.
- Avoid actions that will reduce the availability of physicians serving Medi-Cal beneficiaries, especially those whose disability requires an extensive use of health care services.
- Consider strengthening pharmacy benefit management practices that can help reduce costs without adversely affecting beneficiaries' health status.
- Pursue cautiously the option of premium cost-sharing for some beneficiaries. While many CHAT participants regard that option as preferable to other service changes, participants might have been influenced by the perception that they personally will not be affected by this change.
- Keep in mind that Medi-Cal beneficiaries—like most Americans—highly value the attribute of choice. This population is often dependent on others for assistance with many daily activities, and individual choice provides a vital sense of control and self-determination.
- Consider ways that managed care programs can be responsive to the issues raised in this project. If these programs are going to be promoted for the adult disabled population, Medi-Cal beneficiaries need a better understanding of what managed care is, how it is used, and what it can offer disabled individuals. Beneficiaries would be particularly interested in what impact managed care has on choice and availability of providers.

The CHAT process is based on the principle that the only way to truly gauge how people value services is to have those services compete within a finite budget. However, agreeing to make trade-offs during the CHAT process is not the same as accepting those cutbacks in real life. Some participants were well aware of the danger that the CHAT results could pose: that policymakers would mistakenly interpret their decisions as acceptance of cutbacks. Others saw this exercise as a way to openly and honestly tell policymakers what services are important to them and why. Both groups—the suspicious and the eager—participated in the CHAT process because they wanted their stories and concerns to be heard.

II. Introduction

One purpose of Medi-Cal CHAT was to allow beneficiaries to have a voice in decisions that could have a profound impact on their health and well-being.

CALIFORNIA'S CURRENT FISCAL PREDICAMENT, escalating state expenditures for Medi-Cal, and the growing number of uninsured people in the state present a challenge for state leaders. In January 2004, Governor Arnold Schwarzenegger proposed a major overhaul of Medi-Cal to contain costs while avoiding deep cuts in eligibility or benefits. As part of an effort to seek stakeholder input on the proposed changes and suggestions for new ideas, the state requested assistance from the California HealthCare Foundation and The California Endowment to support a process to solicit, receive, and organize public input and technical expertise through a series of work groups.

Anticipating these challenges facing state leaders, Sacramento Healthcare Decisions (SHD), a nonprofit, nonpartisan organization, developed a simulation project to ask adult disabled Medi-Cal beneficiaries to design their own health benefits package when there were more options than dollars. The Medi-Cal CHAT project had two unique aspects:

- Participants had to prioritize their health care needs and make explicit trade-offs in health care coverage.
- The project participants were Medi-Cal beneficiaries, rather than representatives of interest groups or lobbyists.

This project used CHAT (Choosing Healthplans All Together), a computer-based program developed by the University of Michigan and the National Institutes of Health. CHAT is a tool that engages individuals in the challenges of choosing health care benefits when choices exceed available resources. Different versions of CHAT have been used in several states with a variety of participants, including employees, the uninsured, medical students, and health policy leaders. Medi-Cal CHAT was the first time this process was used with Medicaid beneficiaries.

The purpose of Medi-Cal CHAT was to:

- Identify the perspectives of Medi-Cal beneficiaries, as individuals and groups, regarding how they value and prioritize Medi-Cal services.
- Provide input to state legislative and regulatory personnel as they consider options for redesigning Medi-Cal.

- Allow Medi-Cal beneficiaries themselves to have a voice in decisions that could have a profound impact on their health and well-being.
- Test a model of consumer participation with a population that historically has had a minimal role in policy input.

Designing CHAT for Medi-Cal

The basic CHAT board is a pie chart consisting of up to 16 categories. In developing a CHAT project, the categories must represent services that the target audience uses and that translate to budgetary relevance. Because the Medi-Cal program includes medically diverse beneficiaries (e.g., young mothers and children, institutionalized seniors, and disabled adults), it is not possible to create a realistic CHAT board that will be relevant to all those groups simultaneously. For example, the main health care services used by young mothers will be very different from those used by institutionalized seniors. Therefore, to make CHAT a valuable exercise, project leaders had to identify a subset of Medi-Cal beneficiaries that had a similar pattern of service usage.

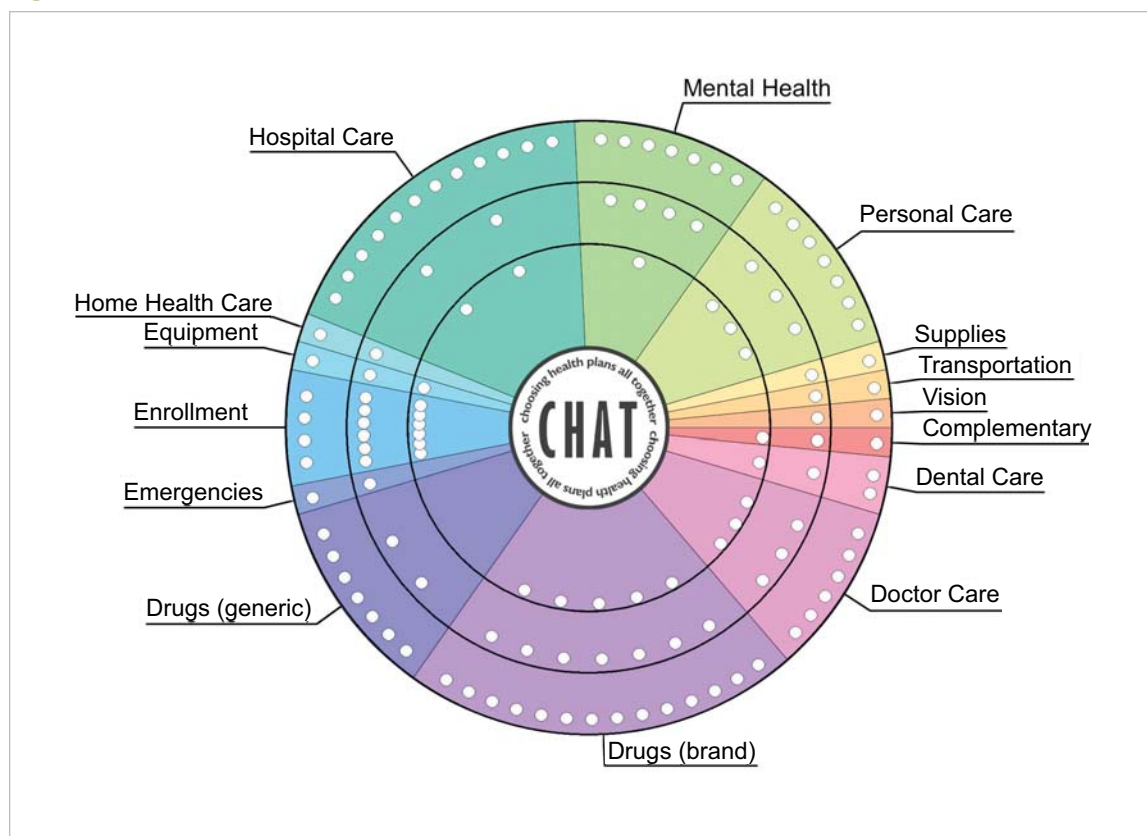
During the early planning stage, SHD concluded that the most appropriate subset of beneficiaries would be disabled, non-institutionalized adults. This group was chosen for several reasons: They constitute 14 percent of all Medi-Cal beneficiaries, but their service usage accounts for 37 percent of the total Medi-Cal budget.¹ With the long-term nature of their disabilities, beneficiaries are typically enrolled in Medi-Cal for many years and are often familiar with the range of services and nuances of the delivery system. Because they use services disproportionate to their numbers, this group might also be at greatest risk of service or enrollment cutbacks from the state's redesign efforts.

SHD convened an Advisory Committee (see Appendix A) of government personnel, health plan representatives, consumer advocates, and disability and Medi-Cal experts to help select the CHAT categories used most often by adult disabled beneficiaries and in developing alternative tiers. One of the tiers in each category described the current Medi-Cal benefit; other tiers offered lower or higher benefits. In addition to 14 service categories like Hospital Care and Equipment, there was an Enrollment category in which participants considered tightening eligibility with premium cost-sharing (see Figure 1). Appendix C gives the definitions of all categories and tiers and the number of markers required for each.

Each category tier costs a specific number of markers based on the proportional cost of that service in the Medi-Cal budget. The higher the tier, the better the benefit, and the more markers it costs. Costs associated with each category tier were derived from fee-for-service medical claims data provided by the California Department of Health Services and analyzed by The Lewin Group.

Altogether there were a total of 123 marker spaces on the CHAT Board. Choosing all services at the current level required 114 markers, but participants had only 100 markers to use in picking their benefits.

Figure 1. CHAT Board for Disabled Adult Medi-Cal Beneficiaries



Using the CHAT Board to Prioritize Benefits

The Medi-Cal CHAT board has 15 categories, depicted on the board as the wedges of a pie chart. Each category has up to three tiers to choose from, representing levels of benefits. The tiers closest to the center have more generous benefits, meaning that players must use more markers as they add coverage. For example: selecting Tier 2 of Mental Health requires a total of eleven markers: seven in Tier 1 plus four in Tier 2.

There are 123 total marker spaces on the CHAT board. If participants wanted all the benefits and services that Medi-Cal currently provides, they would need 114 markers. Since they were given only 100 markers, they had to make decisions about which categories and tiers they regard as the most important.

When doing CHAT on the computer, the descriptions of the categories and tiers are displayed on the screen while participants consider their options (see Appendix C for the descriptions). Participants can move markers around the CHAT board as often as they want until they have the configuration they feel works best.

Challenges in the Design Process

Using the CHAT exercise for the disabled Medi-Cal population presented some interesting challenges that distinguished it from CHAT sessions with the privately insured:

The theory of insurance seemed irrelevant.

With private employer-based insurance, CHAT participants can make their choices and trade-offs based on an assumption that either they won't need the service or that they can afford to pay out-of-pocket if they do. With the adult disabled population, many of the services are ones that they already use frequently (sometimes on a daily basis), so gambling that they won't need a service is not a dominant feature of their thinking. Additionally, most feel they have little discretionary income, so the option of self-pay is even less realistic. While insurance is based on the concept that one is being protected from the unanticipated cost of health care services, Medi-Cal beneficiaries are already making use of most services and trying to protect that which they value. The Advisory Committee was faced with the awkward task of asking participants to make "no-win" decisions.

A managed care CHAT version was not feasible. There was considerable discussion among Advisory Committee members on ways that managed care concepts or systems could be part of the CHAT board. Although the committee wanted to incorporate the pros and cons of managed care as part of the CHAT exercise, they concluded this would not be feasible. One challenge was how to reflect the impact that managed care would have on access and quality, given the lack of conclusive data. Another challenge was that the characteristics of the managed care program would not be known or understood by participants in counties not currently served by managed care. Consequently, the CHAT format was restricted to the fee-for-service environment.

The disproportionate size of the pharmacy budget required a creative approach.

In the state budget, pharmacy costs represent about 36 percent of total cost of services for the disabled population. If presented on the CHAT board with that proportion dominated by one category, it would create havoc with the other 14 categories being squeezed into a limited space. The visual dominance of pharmacy might also promote a preoccupation with that category that would diminish attention to other services. After various options were discussed, the group suggested separating brand-name drugs from generic drugs to create two categories. This worked well and stimulated much discussion about the virtues of generic versus brand-name drugs.

Components of a Medi-Cal CHAT Session

Each session was led by two facilitators and included 9 to 12 participants (each with a laptop computer) seated around a large table. There were five parts to the three-hour CHAT session.

Introduction. After introductions, the facilitator briefly explained the background of CHAT, the purpose of the project and confidentiality issues. On their laptops, participants completed a pre-CHAT survey, and the facilitator explained and demonstrated the CHAT board. The Enrollment category was the only one that was not optional; participants had to choose one of the tiers.

Round 1. After instructions, participants worked individually on their laptops, using their 100 markers to design a Medi-Cal coverage plan for themselves that would be in effect for five years.

Round 2. Participants worked in groups of three, using one of the laptops. They now created a Medi-Cal coverage plan for all disabled Medi-Cal beneficiaries in their county, not just for themselves. The three people working together had to come to agreement.

Round 3. Participants closed their computers, and the facilitator projected a new CHAT board on a screen. Together participants designed a benefits package for all disabled Medi-Cal beneficiaries in California. The facilitator led the discussion, calling on participants to nominate categories and benefit levels. Anyone could veto the choices of others and all participants had an equal voice. Participants discussed, debated, and negotiated which categories were most important and why. Usually groups voted if they could not agree on certain categories. This round was recorded on audiotape and the discussion transcribed for later review.

Round 4. Participants used their own computers for the last round. Again they created a coverage plan for themselves, just as in Round 1. But now they had learned more about the benefit categories, heard the views and experiences of others, and negotiated to develop a statewide plan. Thus, their choices were often different than in Round 1. When finished with their coverage plan, they each completed a post-CHAT survey.

Testing and Recruitment

Before conducting this project statewide, SHD arranged a pilot test with four sessions in the greater Sacramento region in early 2004. The purpose of the testing phase was to determine whether CHAT could be sufficiently modified for ease of use by this population; whether the process produced worthwhile information; and whether the Medi-Cal categories and tiers needed to be reworded. The Advisory Committee reviewed the results of the pilot and concluded that this process would contribute valuable information at a time when the state was considering profound changes in the Medi-Cal program. Several modifications were made to the CHAT descriptions, and statewide sessions were conducted in April and May 2004.

To recruit participants, SHD contacted independent living centers in various parts of the state (see Appendix B). Centers were paid \$50 for each person they recruited for a CHAT session; participants were paid \$75 for their time. Each participant had to meet certain criteria: be a non-institutionalized disabled adult under age 65; receive primary health care coverage from Medi-Cal; be literate in spoken and written English; have sufficient cognitive ability; and have basic computer experience.

For participants who needed specific computer support, help was provided by readers, computer assistants, and translators for the hearing-impaired. Despite the often-profound disabilities of some participants, the vast majority could manage the computers and communicate their priorities independently.

Limitations of the Project

The following should be taken into account when considering the findings and conclusions:

- These data and conclusions applied only to adult disabled Medi-Cal beneficiaries, not to other categories of Medi-Cal beneficiaries.
- These results were based on 131 participants.
- The criteria for participation noted above precluded the involvement of other disabled Medi-Cal beneficiaries who might bring different perspectives than those described here, such as those confined to their home or an institution because of the nature and severity of their disability.
- Given the complexity of the Medi-Cal program, the CHAT categories and tiers could not capture all the details, exceptions, and nuances that exist.
- The number of markers assigned to each category tier was an approximation based on historical costs and estimated projections.

III. Results and Findings

The services of greatest concern included Doctor Care, Dental Care, and Personal Care, while Emergencies, Vision, and Drugs elicited the most debate.

THESE RESULTS AND FINDINGS WERE BASED ON quantitative data (choices of categories and tiers; responses to pre- and post-surveys) and qualitative data (the reasons and comments offered during the Round 3 group discussion).

CHAT’s structure required participants to select *less* coverage overall than what they currently receive. This strategy identified the categories and service levels that participants regarded as critical, but it was not intended to convince individuals that they could manage with less coverage.

Given the limited number of markers, it was particularly meaningful when participants choose a higher-than-current tier because this meant that significant compromise would have to be made in other areas. Therefore, the focus of most discussion was on which category characteristics needed to be *better* than their current Medi-Cal level, which were *adequate* at their current level, and which could be reduced or eliminated in order to use the markers for another priority.

Table 1. Decisions Made by the 12 CHAT Groups in Round 3
Designing a benefits package for all disabled Medi-Cal beneficiaries

CATEGORIES	No Coverage	Tier 1	Tier 2	Tier 3
Complementary	0	4	6	2
Dental Care	0	1	7	4
Doctor Care	0	0	7	5
Drugs (brand)	0	6	6	0
Drugs (generic)	0	1	11	
Emergencies	0	10	2	
Enrollment		1	8	3
Equipment	0	1	5	6
Home Health Care	0	2	10	
Hospital Care	0	0	11	1
Mental Health	0	0	4	8
Personal Care	0	1	5	6
Supplies	0	2	10	
Transportation	0	3	9	
Vision	0	9	3	

Legend: Current level of service
 Benefit level was not an option

Table 1 shows how the 12 groups voted on their statewide benefit plan. Example: For Dental Care, one of the 12 groups (8 percent) picked Tier 1; seven groups (58 percent) picked Tier 2; and four groups (33 percent) picked Tier 3. It is worth noting that:

- None of the 15 categories was left out of any groups' statewide plan.
- There were three categories that none of the groups felt was adequate at Tier 1: Doctor Care, Hospital Care, Mental Health.
- Drugs (brand), Emergencies, and Enrollment were the categories that most often were chosen at lower benefit levels.
- Equipment was the category that most often was chosen at a higher level of benefits.

Services of Greatest Concern

There were six categories that elicited the most discussion when participants wanted better benefits than were currently available or feared loss of the benefits they currently had.

Doctor Care

Almost every group started by wanting to increase the number of doctors available for Medi-Cal patients. Recurrent themes were: There are too few doctors now accepting Medi-Cal; it takes a long time to find a doctor; and insufficient choice often means poor quality of care. Five of the 12 group decisions included the higher benefit (Tier 3) for Doctor Care in order to improve physician availability.

This concern was reinforced in a post-CHAT survey question (see Appendix D) in which the largest percentage of responders (47 percent) indicated that the least acceptable way to reduce Medi-Cal spending was “there will be fewer doctors available for Medi-Cal patients.”

If a doctor simply cannot perform or give you quality of care because they're too busy or they just don't want to deal with you, you need to have an option.

— San Bernardino participant

I literally went through 50 doctors in the phone book before someone said, “OK, we'll take Medi-Cal.”

— Auburn participant

Dental Care

Like Doctor Care, Dental Care was a category with many stories of inadequate services and insufficient providers. Tier 3 offered more dentists and greater coverage than the current; one-third of the groups decided to include that highest coverage.

It'd be kind of difficult to go down on the current levels because a lot of people have [dental problems]. You know, when your mouth is in trouble, your whole body is in trouble.

— Pomona participant

I was in a car accident and got most of my teeth knocked out. I have 11 healthy teeth left. I want Level 3 so I can have [a] partial instead of just pulling out all my healthy teeth to give me full dentures.

— Garden Grove participant

Equipment

Unlike Doctor Care or Dental Care, not all participants use this category, and many were not inclined to prioritize it. Yet most of the CHAT sessions composed of people with mixed disabilities and those with profound physical limitations provided compelling arguments, often assisted by the visual impact of working independently with the help of technologically advanced equipment. Half the groups picked an improved benefit level for Equipment, a support not matched by any other category.

Too bad there's not a [Tier] 2 1/2 [option for equipment]. I'd say give them a loaner, but make the replacements every five years.

— Pomona participant

You're gonna end up using beaucoup hours of Personal Care when a loaner chair would have done as well. You know that's the weird part about some of these regulations.

— Sonora participant

Personal Care

Like Equipment, Personal Care is a category that is critically important to some and not at all to others. Users of Personal Care (California In-Home Supportive Services) were persuasive with their colleagues about the need to maintain the current level of services; half of all groups chose Personal Care at its highest tier (current services) rather than accept the copayments with the lower tiers. Unlike Equipment, however, Personal Care required many markers to reach the current benefit level, so the commitment that half the groups made to maintain that level underscores participants' recognition of this vital service among the disabled community.

It's a very well-run program; it's a low-cost program. And very few people get [the maximum] 283 hours. And 283 hours, even if it is a family care person, it's a 24-hour-a-day job, so 283 hours doesn't even cover the amount of time these people actually do [work].

— Bakersfield participant

Mental Health

Many of the CHAT participants have mental health diagnoses as their qualifying disability so it is not surprising that this category elicited considerable discussion. Two-thirds of the groups kept Mental Health at its highest tier (current services), and none of the groups picked the Tier 1 level. Some comments indicated that many were not satisfied with the services now available and certainly didn't want to settle for a lesser benefit.

I suffer from depression; I have yet to be able to get anybody for counseling. Hardly anybody takes Medi-Cal for it, and the one place that does, they have a waiting list years long before they'll take anybody.

— Central Los Angeles participant

Enrollment

This category was problematic because many participants felt that the lack of specificity in the tiers descriptions made it difficult to make a good decision. The theoretical basis for the different tiers—that some people would have to pay more to enroll in Medi-Cal—was too abstract if participants didn't know exactly where the line would be drawn. And while they thought that some people might be abusing the system, having a sliding-scale premium for enrolling didn't seem reasonable because the current income requirement to qualify for Medi-Cal was, in the view of many, “so low.”

They agree that people with adequate means should have to pay something but were skeptical of what that meant in real dollar terms. While

their instinct was to keep Enrollment at its current level, compromising to a lower tier freed up many markers; consequently, 75 percent of the groups opted to require some people to pay a premium.

Services that Elicit the Most Debate

There were three categories that generated the most disagreement among the participants. These debates occurred either at the initial placing of the markers in the group discussions or at the conclusion when participants were moving their markers around to get more categories covered.

Emergencies

This was often the first category to be compromised when another marker was needed. Some participants argued that it was better that unnecessary ER visits cost a patient \$35 (Tier 1) instead of \$5 (Tier 2) to discourage inappropriate ER use. Others countered that their access to primary care is limited and they have no choice but to use the ER. While 83 percent of the groups ultimately voted to reduce Emergencies to Tier 1, there was not universal agreement:

And if you're sick enough to call the ambulance or go into emergency, it has to take a lot. If you're thinking, I'll just lay here because I ain't got \$35, a lot of people would end up dead.

— San Rafael participant

Vision

This category was unique in that Tier 1 was the current level and Tier 2 was better benefits; there was no lower benefit level than the current. Like Emergencies, the tiers were differentiated by

relatively small out-of-pocket costs. Nevertheless, participants debated this as wholeheartedly as they debated the larger life-altering categories.

The primary issue at stake was getting one pair of glasses every two years versus two pairs of glasses every year. For a variety of reasons many people had a difficult time making do with one pair. Other participants usually overruled them, and 75 percent of the groups stayed with the current benefit at Tier 1.

[I say] Tier 1, because when it comes down to the wire, we will find out that every dot is precious. Losing your glasses is just not a good enough reason to spend the money.

— San Rafael participant

Drugs (brand)

This was the most expensive category on the CHAT board. It required 28 of the 100 markers to keep the benefit at its current level. This category elicited much discussion about brand-name and generic drugs. In meetings with participants who could argue convincingly, groups often started at Tier 3 (current). But every meeting ultimately ended at Tier 2 or Tier 1. Participants saved so many markers by lowering the tier that the pressure to cover other services was greater than the persuasive abilities of those participants with extensive medication needs.

If you need a \$900 drug and you only have to pay \$3, that's a gift.

— San Rafael participant

I take a lot of medications, and about half of them are name-brand; they're not generics. And if I had to pay for my own medication, I wouldn't be able to. And due to my mental illness, I can't function without my medication.

— Auburn participant

You guys are missing the point. Brand-name drugs are taking up all the markers... you're paying for the name, that's all you paying for... I mean, what's happening here?

— Central Los Angeles participant

Individual Decisions

As individuals, participants have far greater leverage with their 100 markers than they do when making group decisions. This is because several of the large categories — Drugs (brand), Personal Care, and Mental Health — are not used by everyone. Therefore, if an individual participant sees no reason to include Personal Care in her plan (or includes it at Tier 1), she has far more markers at her disposal than someone who is highly reliant on Personal Care. While the varied needs of disabled participants in Round 3 resulted in all categories being included in the group plan, individual participants in Rounds 1 and 4 didn't have to be concerned about a fair distribution of the markers.

Table 2. Medi-Cal Participants' Individual Decisions at the Beginning and End of the CHAT Session
Benefits for yourself (by portion of responses)

CATEGORIES	ROUND 1 (131 participants)				ROUND 4 (130 participants)			
	No Coverage	Tier 1	Tier 2	Tier 3	No Coverage	Tier 1	Tier 2	Tier 3
Complementary	11%	21%	34%	34%	8%	22%	42%	28%
Dental Care	2	7	37	54	2	5	48	45
Doctor Care	0	2	29	69	0	2	43	55
Drugs (brand)	4	31	33	31	2	28	54	16
Drugs (generic)	9	13	77		2	18	79	
Emergencies	5	24	70		3	36	61	
Enrollment		12	32	55		11	54	35
Equipment	10	8	34	47	8	15	38	38
Home Health Care	11	17	71		7	22	71	
Hospital Care	0	6	53	41	0	7	64	29
Mental Health	15	21	21	43	5	18	32	44
Personal Care	11	27	24	37	4	19	38	38
Supplies	15	24	61		12	28	61	
Transportation	17	20	63		12	35	53	
Vision	4	40	56		5	41	55	

Legend: ■ Current level of service ■ Benefit level was not an option

Although there were few major changes in how participants designed their own health coverage from Round 1 to Round 4, several differences were evident:

- Participants chose a greater number of categories for themselves in Round 4 than in Round 1. At the beginning, people often chose not to cover categories they are not now using; by Round 4, many added in categories they originally rejected.
- Opting for more categories in Round 4 required that participants reduce the tier levels. Even with these reductions, participants often chose better-than-current benefits for Vision, Doctor Care, Dental Care, and Equipment.
- While choosing Emergencies at the higher Tier 2 was the choice of only 17 percent of

the groups in Round 3, as individuals they thought otherwise: 61 percent choose Tier 2 coverage for themselves in Round 4.

Weighing the Priorities

Participants' decisions center on the competing priorities of the four core features of health care services that are illustrated in CHAT:

Range of Services. Comprehensiveness was the dominant issue for group decisions in Round 3. All the groups decided it was better to offer some coverage for every category than to risk leaving off one that some people might use. Although individuals dropped services they didn't use from their individual plans, when making decisions for everyone, groups did not want to exclude any services.

Responses to the CHAT survey questions reinforced this concern. “Having Medi-Cal pay for as many different services as possible” was the highest ranking (21 percent) of eight factors (see Appendix D).

But we're talking about the masses. Believe me, there are areas up there that I would like to make better for myself. But we're talking about the whole of California.

— San Rafael participant

Choice. The issue of choice was most visible in three categories: Doctor Care, Drugs (brand), and Hospital Care. Doctor Care pertained to the need for high-quality doctors; participants felt that adequate choice was their only way to ensure they would find a doctor who met their needs. The debate about brand-name drugs was mainly over the issue of formulary limitations and participants’ ability to get the drug that worked best for them. For those highly dependent on certain medications, a greatly restricted formulary was difficult to accept.

Choice was the issue that defined the tiers with Hospital Care, and this generated considerable debate. Because 31 percent of participants had been in the hospital within the past 12 months (see Appendix D), perhaps their concerns about choice of hospital should not be surprising. In Round 4, 29 percent of participants wanted a higher level of Hospital Care than the current level to allow greater choice of hospitals.

But you need choices. It's all about choices. It's all about getting as many choices as you can with all the money that we have.

— Chico participant

I don't think [that as a person using] government money, you should be able to go to one of those expensive millionaire hospitals for a broken arm.

— Bakersfield participant

Cost Sharing. Many of the categories used copayments to differentiate the tiers. For some people, an increased copayment was the factor that most troubled them in considering a lower tier; for others, choice was a more important issue. High users of certain categories — e.g., Drugs (brand) or Supplies — were very vocal about their inability to afford copayments because of the amount of services they use.

All of that kind of stuff [supplies] is extremely expensive, and if you're on [SSI], you'll never be able to pay for it all. A lot of the supplies you cannot reuse. You cannot [reuse] syringes; you cannot reuse incontinence supplies. You can't reuse cotton. I mean, just, you can't. So if you don't have the money what are you going to do?

— Central Los Angeles participant

Availability. This issue addressed concerns about the ability to access services and providers in a timely way.² While “getting a doctor’s appointment quickly” ranked fairly high, “having doctors available who are close to where I live” ranked low (see Appendix D). However, there is a thin line between what is considered available and the features of choice and range of services. Participants with unusual needs—such as the hearing-impaired—have particular problems accessing services that can help them, such as having interpreters with their mental health providers.

A year for a wheelchair, a year and a half for teeth; that is unreal and unnecessary cruelty.

— Chico participant

It's hard enough to find a doctor anyway right now. You gotta go through the whole phone book just to find like two doctors that take Medi-Cal. Or you have to go to the emergency room. It would stop a lot of ER traffic if you were able to get in to [see] a doctor.

— Chico participant

IV. Discussion

The CHAT sessions demonstrated how central health services are to the lives of adult disabled Medi-Cal beneficiaries.

CHANGES IN MEDI-CAL SERVICES COULD AFFECT the lives of adult disabled Medi-Cal beneficiaries in profound ways. As noted previously, these individuals use a relatively high percentage of the Medi-Cal budget. The CHAT sessions demonstrated clearly how dependent many are on health care services in their everyday lives.

This was particularly evident during Round 3 of CHAT. Medi-Cal participants spoke of the CHAT categories with knowledge and personal experience. Making and accepting trade-offs was not a theoretical premise; it meant genuine sacrifice of valued services that could affect their functional status and well-being.

Range of Services

Maintaining the full range of Medi-Cal services is a more important consideration than maintaining the current “depth” of those services. When participants engage in group decision-making, they recognize that all Medi-Cal services have value to those beneficiaries who use them. Even relatively inexpensive services (e.g., vision, chiropractic) seem outside the reach of an SSI recipient. Thus, they believe that the fairest approach is to ensure that everyone has some access to those services they deem important to their health and functioning.

For example:

- All 12 Medi-Cal CHAT groups voted to include every service category, even though that meant several had to be reduced in scope.
- Only 13 percent thought that “Medi-Cal will no longer pay for certain types of services” was an acceptable way to reduce the Medi-Cal budget.
- “Having Medi-Cal pay for as many different services as possible” was the highest ranking of eight factors related to Medi-Cal services.

Choice of Providers

Sufficient choice of providers—whether doctors, dentists, hospitals, or mental-health professionals—is a powerful theme for Medi-Cal beneficiaries. Although choice and availability are often closely connected, availability does not always guarantee choice, or vice versa. For people with chronic health problems and little discretionary income to be spent going “outside the system,” being able to change providers if needed is essential. Individuals need a health care provider who understands their medical conditions and recognizes their abilities and challenges.

For example:

- In their individual plans, 55 percent of participants choose to increase the availability of Medi-Cal doctors.
- The highest proportion of participants chose Doctor Care as the category they would have increased if more markers were available.
- Only 15 percent thought that “fewer doctors available for Medi-Cal patients” was an acceptable way to reduce the Medi-Cal budget.

Categories for Compromise

When participants had to compromise, they most often reduced the current benefit level for Drugs (brand), Personal Care, and Enrollment (eligibility). These reductions were evident in both group and individual decisions. Because these were expensive categories, shifting the markers allowed other categories to be included more easily. Yet none of these categories was reduced without debate with participants who would be most affected. It is also likely that most participants thought (or hoped) that the Enrollment restrictions would not apply to them.

For example:

- All 12 groups and 82 percent of individuals included Drugs (brand) at a level lower than the current level.
- Only 50 percent of groups and 38 percent of individuals included Personal Care at its current level.
- Only 25 percent of groups and 35 percent of individuals included Enrollment at its current level.
- 69 percent of participants thought that “those with higher income will pay a monthly fee to join Medi-Cal” was the most acceptable option if Medi-Cal spending must be reduced. This scored twice as high as the next-highest option.

V. Medi-Cal Beneficiaries and the Privately Insured: a Comparison

Noteworthy differences and similarities were apparent in the themes and priorities of privately insured individuals and Medi-Cal beneficiaries.

POLICYMAKERS HAVE INDICATED INTEREST IN MAKING Medi-Cal more like private insurance: using incentives for strengthening service efficiency and quality, reducing waste, and increasing consumer responsibility and accountability. To help inform considerations of Medi-Cal changes, it might be useful to examine how these population groups — those using Medi-Cal and those with private insurance — respond to coverage issues and limitations.

Before the Medi-Cal CHAT project, SHD conducted a CHAT project with 41 private and public sector companies in the Sacramento region.³ Noteworthy differences and similarities were apparent in the themes and priorities of mostly healthy, privately insured individuals and chronically ill or disabled Medi-Cal beneficiaries.

Reliance on Health Care

While health care plays a major role in the lives of disabled Medi-Cal beneficiaries, it is usually not central to the lives of most privately insured employees. Disabled Medi-Cal beneficiaries need and use far more health care services than do the privately insured. Survey questions from both CHAT projects reveal some interesting comparisons:

- Only 19 percent of Medi-Cal CHAT participants considered their health to be “Excellent/Very Good,” compared with 79 percent of people with private insurance.
- 53 percent of Medi-Cal participants visited a doctor more than 12 times in the previous 12 months, compared to 5 percent of people with private insurance.
- 31 percent of Medi-Cal participants were in the hospital overnight in the past year, compared with fewer than 11 percent of people with private insurance.
- 48 percent have been dependent on Medi-Cal for 11 or more years, 18 percent for more than 20 years.

Compromise and Consensus

Compromising on a benefits package was easier for privately-insured employees than it was for those on Medi-Cal. When employed individuals discussed their health care coverage, most had little knowledge of services outside of hospitals, physicians, and pharmaceuticals. With minimal health care experience, healthy individuals had less struggle coming to agreement with their colleagues on a compromise package than did those on Medi-Cal who use services extensively. For example, only half of the employed groups had to vote to come to agreement on statewide benefits, and this usually involved just one vote. All of the Medi-Cal groups required multiple voting to reach consensus. This struggle suggests that disabled individuals have much more to lose than healthy folks in compromising on a package that would affect them so directly.

Despite this concern about losing benefits, both Medi-Cal beneficiaries and privately insured employees responded similarly when asked the post-survey question “Were you satisfied with the choices made by the whole group together?” Thirty-three percent of Medi-Cal beneficiaries were “very satisfied,” and 52 percent were “somewhat satisfied.” This compares to the privately insured employees, who responded 39 percent “very satisfied” and 51 percent “somewhat satisfied.”

Cost Sharing

Moderate cost-sharing was more acceptable to privately insured employees than it was to those on Medi-Cal. Although the increasing cost of health care is becoming more of a burden for everyone, most privately insured employees have discretionary income and might be able to assume a share of their routine health care costs. As low-income individuals with higher-than-average health care needs, disabled Medi-Cal beneficiaries have a difficult time imagining how

they can absorb greater out-of-pocket expenses if copayments are increased.

Spectrum of Services

Both groups felt that having a full range of health care services was the most important criterion for their coverage. This theme dominated all the groups in both projects. For Medi-Cal beneficiaries, having the full range of services was seen as essential for meeting the diverse needs of disabled individuals. They felt that giving priority to those with high needs in one area (e.g., Personal Care) while ignoring those who are dependent on other categories (e.g., Equipment) was unfair and inappropriate. For the privately insured, comprehensive coverage was also viewed as the fairest way to provide insurance, but this was seen mainly as a hedge against an unknown catastrophe.

Importance of Choice

Both groups consider choice to be the cornerstone of a quality health care system. It has been well-established that Americans of all stripes consider choice to be the key guarantor of quality. For many, knowing that they can seek a new doctor if their care is inadequate may be the only real control they feel they have in health care. While true of all CHAT participants, choice is particularly vital for those with chronic conditions. When participants cite examples of inadequate care from health care systems or professionals, they feel their only recourse is seeking another source of care.

Opportunity for Feedback

Both groups highly value their role of providing input to policy decisions. Post-CHAT survey questions indicated participants’ appreciation for the opportunity to give their views. (See Figures 2 and 3 on the following page.)

Figure 2. Post-CHAT Sentiment of Participants

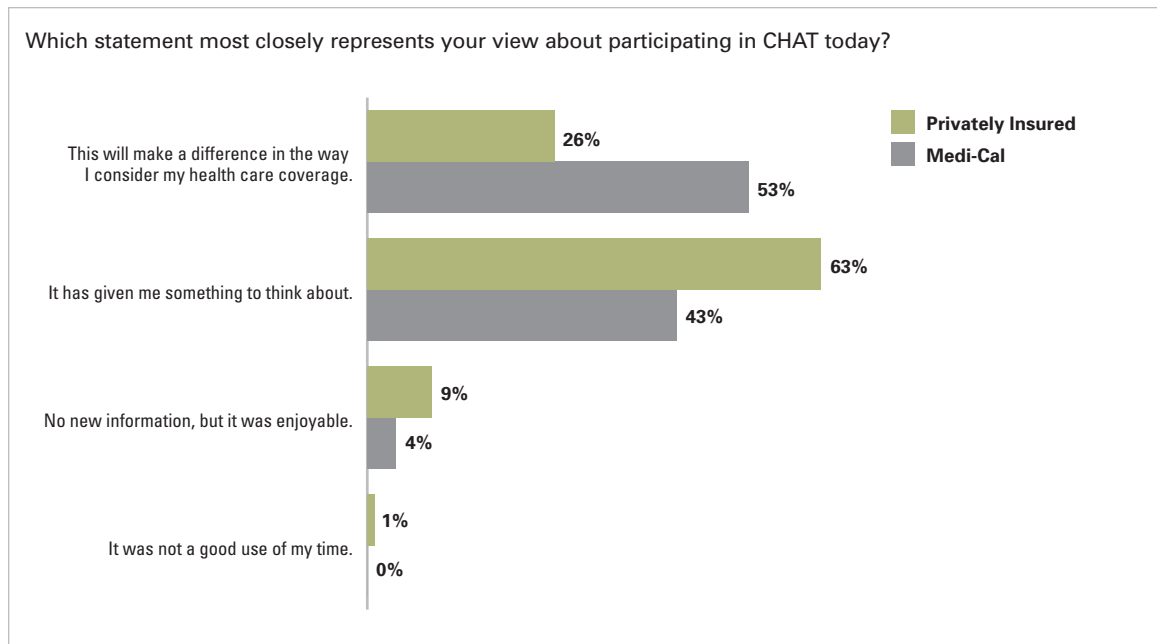
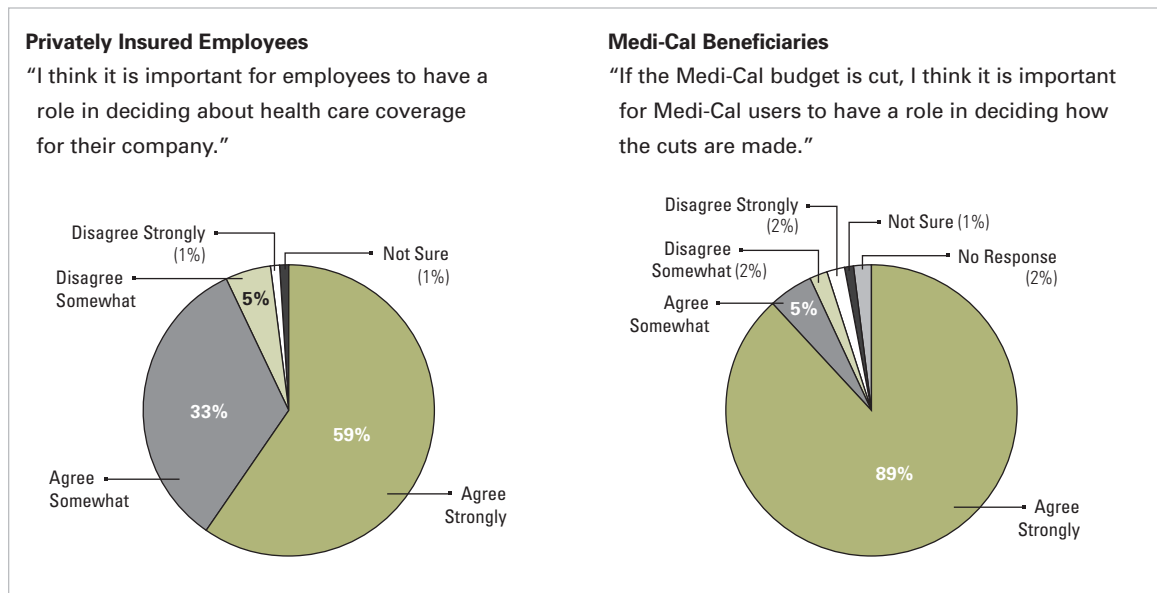


Figure 3. Post-CHAT Responses on the Role on the Insured in Deciding Coverage



VI. Recommendations for Policymakers

From the perspective of the CHAT participants, there is no low-hanging fruit in Medi-Cal.

Lessons from CHAT Participants

California's budget problems have motivated state policymakers to re-examine how Medi-Cal is provided and to propose strategies that reduce the state's financial burden.

The medical needs of adult disabled Medi-Cal beneficiaries require a proportionally higher cost commitment than other Medi-Cal enrollees; thus, developing more efficient use of funds presents a greater opportunity for cost savings. However, service reductions can also pose an increased risk to the health of this population.

The results of Medi-Cal CHAT reflect the experiences, concerns, and values of 131 disabled individuals. As policymakers consider changes to the Medi-Cal program, the messages of the CHAT project suggest the following:

- Maintain the full range of Medi-Cal covered services, even if it means having to institute greater restrictions in how services are used. Medi-Cal beneficiaries put high priority on having a variety of services available. Although all disabled individuals do not use each of the covered services, the range of disabilities and the needs of individuals vary greatly. Eliminating certain categories while keeping others seems harsh, unfair, and ultimately counterproductive if cutting services puts individuals at greater health risk. If restrictions must be imposed, it might be better to establish stricter guidelines for their use than to eliminate the service altogether.
- Avoid reducing provider reimbursement or other actions that might diminish the availability of Medi-Cal physicians. Expanding physician availability might even be an acceptable trade-off to other service restrictions. The need for compassionate, skilled, and available health care professionals is a high priority, second only to maintaining coverage for a full range of services. Loss of provider access means more trips to the emergency room, poorer health status, and greater cost to the state.
- If instituting service changes in any form, maintain the opportunity for Medi-Cal beneficiaries to make individual choices in how they obtain their health care services. Like virtually all Americans, Medi-Cal beneficiaries highly value

the attribute of choice. But unlike others, many disabled individuals on Medi-Cal face limited options in their lives and are dependent on the services and assistance of others for daily activities. For those most vulnerable, having choices provides a vital sense of control, dignity, and self-determination.

- Of all the service components, pharmaceuticals are the area that most participants thought could be changed to reduce costs. Because Drugs (brand) is the category that most CHAT participants were willing to compromise on, the state might consider strengthening practices to manage the pharmacy benefit that can help reduce costs without adversely affecting beneficiaries' health status.
- If enrollment is an issue that must be targeted, it is more acceptable to expect eligible beneficiaries in the higher ranges of income to contribute toward the cost of their Medi-Cal enrollment than to implement service reductions. This option was not met with enthusiasm but was viewed as the least objectionable of the alternatives. Because participants did not think their own situations were ones that could accommodate cost-sharing, few participants imagined that they personally would need to make additional financial sacrifices.
- Any decision to promote greater use of managed care plans should: 1) include reliable, accurate information about its advantages and disadvantages, and 2) consider how the priority of physician choice and availability can be fully developed and communicated within a managed care environment. Most participants were unfamiliar with the term “managed care” or attributed negative qualities to it.

Conclusion

The CHAT process is based on the principle that the only way to truly gauge how people value services is to have those services compete within a finite budget. CHAT provides a window into the thought processes of individuals and groups as they struggle to balance their own needs and those of the larger population.

Agreeing to make trade-offs during the CHAT process is not the same as accepting those cutbacks in real life. Some participants were well aware of the danger that the CHAT results could pose: that policymakers would mistakenly interpret their decisions as acceptance of cutbacks. Others saw this exercise as a way to openly and honestly tell policymakers what services are important to them and why. Both groups — the suspicious and the eager — wanted to convey their stories and concerns.

From the perspective of the participants, there is no low-hanging fruit in Medi-Cal. Every service category has its advocate; every higher level tier has its promoter. While many acknowledged that Medi-Cal may have to change in response to California's budget problems, participants were concerned that the state will make life considerably harder for them that it is now. Their hope is that policymakers will start by reducing misuse and inefficiency, rather than needed services.

*Well you know most of the
Medi-Cal people are poor to begin
with, so it seems to balance the
budget on the backs of the poorest
of people who are on Medi-Cal
doesn't make any sense to me.*

—Bakersfield participant

Appendix A: Medi-Cal CHAT Advisory Committee

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Consultant
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Brenda Premo

Director, Center of Disability Issues
Western University of Health Sciences

Miko Sawamura

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Patricia Yeager

Executive Director
California Foundation for Independent
Living Centers

STAFF

Marjorie Ginsburg

Executive Director
Sacramento Healthcare Decisions

Kathy Glasmire

Associate Director
Sacramento Healthcare Decisions

Appendix B: Locations of Medi-Cal CHAT Sessions

Californians for Disability Rights,
Sacramento Chapter
Sacramento, California

Center for Disability Issues,
Western University of Health Sciences
Pomona, California

**Communities Actively Living Independent & Free
(CALIF)**
Central Los Angeles, California

Community Resources for Independence
Santa Rosa, California

Dayle McIntosh Center (DMC)
Garden Grove, California

**Disability Resource Agency for Independent Living
(DRAIL)**
Sonora, California

FREED Center for Independent Living
Grass Valley, California (pilot session only)

Independent Living Center of Kern County
Bakersfield, California

Independent Living Resource Center
Ventura, California

Independent Living Services of Northern California
Chico, California

Inland Empire Health Programs
San Bernardino, California

Marin Center for Independent Living
San Rafael, California

Placer Independent Resource Services (PIRS)
Auburn, California

Appendix C: Medi-Cal CHAT Categories, Benefit Levels, and Number of Markers*

Complementary: Out-patient services such as speech, physical and occupational therapy, podiatry (foot care), acupuncture, and chiropractic.

Tier 1: (1) No more than one visit each month to any of the services listed. You pay \$3 for each visit. For most services, your doctor or Medi-Cal must approve in advance.

Tier 2: (1+1) No more than two visits each month to any of the services listed. You pay \$1 for each visit. For most services, your doctor or Medi-Cal must approve in advance. (Current)

Tier 3: (1+1+1) Same visits as Tier 2, but they do not need to be “medically necessary” as long as they help you function better. Approval by doctor or Medi-Cal is not necessary.

Dental Care: Pays for the care of your teeth.

Tier 1: (2) Provides the same services now available with Medi-Cal, but it takes longer to find a dentist and get appointments. You pay \$5 for each visit and have a maximum coverage of \$1,000 each year.

Tier 2: (2+1) Provides the same services now available with Medi-Cal. You have no copayment for visits, and the maximum coverage is \$3,000 each year. (Current)

Tier 3: (2+1+1) Provides the same services, but many more dentists are available so appointments are easier to get. You have no copayment for visits, and there is no maximum coverage each year.

Doctor Care: Primary care and specialists for treating routine and complex medical problems. Includes tests, X-rays, and scans for evaluating problems, as well as procedures and surgery.

Tier 1: (6) Medi-Cal decides to reduce payments to doctors. Though you may go to any doctor who accepts Medi-Cal, many will no longer take Medi-Cal patients. It may take you six to eight months to find a doctor.

Tier 2: (6+3) You may go to any doctor who accepts Medi-Cal, but finding a primary doctor is often difficult, and specialists are sometimes not available. It may take you three to six months to get a doctor’s appointment. (Current)

Tier 3: (6+3+3) With better payment, many doctors will accept Medi-Cal, so you have many more to choose from and can change doctors easily. It may take only a few weeks to get a routine appointment.

Drugs (brand): Pays for brand-name drugs on the Medi-Cal formulary (approved list). These brand-name drugs are newer medications that are copyrighted. They are often much more expensive than generic medicines.

Tier 1: (14) The formulary will be very limited, and many brand-name drugs will no longer be covered (especially new, expensive drugs). You have a \$5 copayment for each. If there is a less costly generic drug available, your doctor cannot order the brand-name version.

Tier 2: (14+7) The formulary will be somewhat limited, and some brand-name drugs will no longer be covered. You have a \$3 copayment for each. But your doctor may order brand-name drugs even if the generic drug is available.

Tier 3: (14+7+5) Your doctor does not have to order generic drugs to substitute for brand-name drugs. You have a \$1 copayment for each. Your doctor must get approval to prescribe a non-formulary drug. (Current)

Drugs (generic): Pays for generic drugs on the Medi-Cal formulary (approved list). These medicines are made the same way as brand-name drugs when their copyright expires. Generics are usually much less expensive than brand-name drugs.

Tier 1: (7) The formulary for generic drugs will be quite limited, so some drugs will not be covered. Your copayment is \$3 for each generic drug you use each month.

Tier 2: (7+2) The formulary for generic drugs is not limited. Also, if Medi-Cal approves, your doctor may prescribe a generic drug not on the formulary. Your copayment is \$1 for each generic drug you use each month. (Current)

Emergencies: The use of hospital emergency rooms.

Tier 1: (1) Pays for emergency room services at the nearest hospital. If the visit is not an emergency, you pay \$35.

*The number of markers are noted in parentheses after each tier level.

Tier 2: (1+1) Pays for emergency room services at the nearest hospital. If the visit is not an emergency, you pay \$5. (Current)

Enrollment: (required category) This sets the rules for Medi-Cal enrollment based on income and property. There are currently about 750,000 disabled California residents receiving Medi-Cal services.

Tier 1: (4) Medi-Cal changes the rules for income and property. With this change, one out of five disabled people (those above the minimum income) will have to pay for some of their medical visits or must pay a monthly fee to enroll.

Tier 2: (4+6) Medi-Cal changes the rules for income and property. With this change, one out of ten disabled people (those well above the minimum income) will have to pay for some of their medical visits or must pay a monthly fee to enroll.

Tier 3: (4+6+6) Medi-Cal rules stay the same, so this does not affect those who enroll in the program. (Current)

Equipment: Includes items such as wheelchairs, breathing equipment, and assistive devices that prevent or improve a functional limitation. Must be ordered by a doctor.

Tier 1: (1) Equipment must be approved by Medi-Cal, and models are limited. Repair time is slow, and you pay half the cost of repairs. “Loaners” are not covered. Replacements every seven years.

Tier 2: (1+1) Medi-Cal approval is required for some of the equipment. When repairs are needed, “loaners” are not covered. Replacements every five years. (Current)

Tier 3: (1+1+1) All equipment must be approved, but specialists will advise you and equipment can be customized to your needs. “Loaners” are available when needed. Replacements every three years.

Home Health Care: Part-time skilled care in the home on a short-term basis by nurses, aides, and others, usually after hospital care. Used to prevent decline in health status and maintain highest level of function.

Tier 1: (1) All services must be approved in advance. Aide services are limited to a few hours each day. Total number of hours cannot exceed five per week for no more than a couple of weeks.

Tier 2: (1+1) All services must be approved in advance. There is no stated limit on the number of visits each week or number of weeks of service. (Current)

Hospital Care: Pays for in-patient hospital stays (including mental illness), out-patient services, and short-term physical rehabilitation in a skilled nursing home.

Tier 1: (12) You have no choice of which hospital or skilled facility you go to.

Tier 2: (12+2) You have some choice of private or public hospitals or skilled facilities. (Current)

Tier 3: (12+2+2) You can go to any hospital or skilled facility you choose.

Mental Health: Out-patient mental health therapy; may include drug or alcohol treatment programs.

Tier 1: (7) Pays only for the most severe mental health illnesses such as bipolar disorder, severe depression, and anorexia. You have a \$3 copayment each visit. Does not cover drug or alcohol treatment.

Tier 2: (7+4) Besides the severe illnesses, also covers many other mental health problems. For less severe problems, limit is two visits per month with a \$2 copayment. Also covers drug and alcohol treatment.

Tier 3: (7+4+1) Besides the severe illnesses, also covers many other mental health problems. Amount of service depends on client needs, but no limit. Average copayment is \$1 per visit. Also covers drug and alcohol treatment. (Current)

Personal Care: In-home personal care services (California In-Home Supportive Services, or IHSS) for those with a disability lasting more than 12 months. Medi-Cal approves an average of 110 hours each month (maximum is 283 hours).

Tier 1: (7) If you need more than 110 hours each month, you pay 30 percent of the cost of all approved hours above 110. This will affect about one-third of the users of Personal Care.

Tier 2: (7+3) If you need more than 110 hours each month, you pay 10 percent of the cost of all approved hours above 110. This will affect about one-third of the users of Personal Care.

Tier 3: (7+3+2) Provides personal care services for up to 283 hours each month, with approval. There are no copayments. (Current)

Supplies: Disposable medical equipment and supplies for in-home use (such as syringes, catheters, urinary incontinence protection, etc.).

Tier 1: (1) Pays for supplies that are prescribed by a doctor. If not on the supply formulary, approval is needed. Only pays for \$100 of supplies each month.

Tier 2: (1+1) Same as Tier 1, except that there is no limit to the amount that can be purchased (but there is a \$165 monthly limit for incontinence supplies). (Current)

Transportation: For those whose condition prevents the use of private vehicle or public transportation, this provides rides for approved medical appointments. Also provides an ambulance in an emergency.

Tier 1: (1) For rides to medical appointments, the copayment is \$2 for each ride. Pays for four one-way trips each month. Pays for an ambulance in an emergency. If the doctor says it was not a real emergency, you pay \$35.

Tier 2: (1+1) For rides to medical appointments, there is no copayment and no limit on the number of rides each month. Also pays for an ambulance for emergencies, without a copayment. (Current)

Vision: Eye exams and glasses from an optometrist.

Tier 1: (1) You get an eye exam and glasses every two years, if needed. This entitles you to basic lenses and frames. Contact lenses are provided only if medically necessary. (Current)

Tier 2: (1+1) You get an eye exam and two pairs of glasses or contact lenses every year, if needed.

Appendix D: Medi-Cal CHAT Pre- and Post-Session Surveys

12 Groups: Auburn, Bakersfield, Central Los Angeles, Chico, Garden Grove, Pomona, Sacramento, San Bernadino, San Rafael, Santa Rosa, Sonora, and Ventura.

Session Dates: April 1 through May 26, 2004

Number of Participants: 131

NOTE: While recruitment was conducted with the intention of maximizing the diversity of participants, those who volunteered may not be fully representative of the population at large. Participants also completed the pre- and post-CHAT survey questions on their own and this information was not verified in any way.

Pre-CHAT Questions

Gender		
Male:	40	31%
Female:	91	69%
Ages		
18–29	9	7%
30–39	31	24%
40–49	41	31%
50–59	33	25%
60 and up	17	13%
Family Status		
Single	79	60%
Single with dependents	23	18%
Couple	21	16%
Couple with dependents	8	6%
1. What type of community do you live in?		
City	82	63%
Suburban	21	16%
Rural	27	21%
No response	1	1%
2. Your race or ethnic group (choose all that apply).		
Asian	7	5%
Black or African American	14	11%
Hispanic or Latino	17	13%
Native American	4	3%
White	88	67%
Other	4	3%

3. What is the highest grade or level of school that you have completed?

8th grade or less	2	2%
Some high school but did not graduate	15	11%
High school graduate or GED	33	25%
Some college or two-year degree	56	43%
Four-year college graduate	12	9%
Post-graduate degree	10	8%
No response	3	2%

4. On average, how frequently do you use a computer?

Nearly constantly	17	13%
Several times a day	32	24%
About once a day	20	15%
About once a week	22	17%
About once a month	11	8%
Less than once a month	11	8%
I do not use a computer	16	12%
No response	2	2%

5. Generally, would you say your health is:

Excellent	5	4%
Very Good	19	15%
Good	34	26%
Fair	45	34%
Poor	25	19%
No response	3	2%

6. How many years have you been on Medi-Cal? (Total time as an adult, not just current enrollment.)

Less than one year	4	3%
1 to 5 years	32	24%
6 to 10 years	26	20%
11 to 20 years	39	30%
More than 20 years	24	18%
No response	6	5%

7. In the past 12 months, how many times have you been to a doctor (including dentist and optometrist)?

0 to 5 times	30	23%
6 to 10 times	31	24%
11 to 20 times	33	25%
More than 20	36	27%
No response	1	1%

8. In the past 12 months, have you been in the hospital overnight?

Yes	40	31%
No	89	68%
Not sure	1	1%
No response	1	1%

9. In the past 12 months, about how much did you spend personally on medical, dental, vision and personal care services for yourself?

\$0	27	21%
Less than \$100	30	23%
Between \$100 and \$250	17	13%
Between \$250 and \$500	15	11%
Between \$500 and \$1,000	9	7%
Between \$1,000 and \$2,500	5	4%
More than \$2,500	5	4%
I do not know	20	15%
No response	3	2%

10. Are you currently in a Medi-Cal “managed care” plan?

Yes	36	27%
No	64	49%
Not sure	29	22%
No response	2	2%

11. If you answered YES on the last question, skip this question. If you answered that you are NOT in Medi-Cal managed care, indicate the reason below (check all that apply).

I’ve never heard of Medi-Cal managed care.	37	12%
No one has offered me this option.	16	12%
I’m satisfied with my current type of healthcare.	22	17%
I don’t think that “managed care” provides good care.	16	12%
Other	16	12%

12. The state’s budget problems will have an impact on Medi-Cal. If this were your decision, what would you do to prevent Medi-Cal cut-backs? (Choose all that you think are good ideas.)

Cut back other state services	34	26%
Have the state borrow more money	17	13%
Raise state income taxes	32	24%
Reduce waste in State government	98	75%
Increase the sales tax	24	18%
Not sure	16	12%
Other	61	47%

Post-CHAT Questions

13. Of the factors listed below, select the 3 that are MOST important to you in considering your Medi-Cal coverage:

	Pre-game	Post-game	Single Most Important
Having Medi-Cal pay for as many different services as possible	56%	44%	21%
Having very small (or no) co-payments for doctor visits and medicines	31%	42%	15%
Being able to get a doctor appointment quickly	38%	38%	15%
Having a good selection of primary care doctors to choose from	50%	37%	15%
Being treated with respect by my healthcare providers	34%	33%	13%
Having a good selection of specialists to choose from	45%	37%	9%
Having a choice of which hospital I go to	22%	38%	8%
Having doctors available who are close to where I live	34%	19%	4%

14. If you had more money (“markers”) to spend on the last round, what ONE thing (e.g. another category or higher level) would you have spent them on?

Doctor Care	22	17%
Drugs, Brand-name	12	9%
Personal Care	12	9%
Dental Care	10	8%
Drugs, Generic	8	6%
Enrollment	8	6%
Hospital Care	8	6%
Mental Health	8	6%
Durable Equipment	6	5%
Supplies	5	4%
Vision	5	4%
Complementary	4	3%
Home Health Care	4	3%
Emergencies	3	2%
Transportation	3	2%
Drugs Generic	1	1%

15. The health care information presented in this CHAT computer game was:

Very easy to understand	74	56%
Somewhat easy to understand	42	32%
Somewhat difficult to understand	8	6%
Very difficult to understand	2	2%
No response	5	4%

16. Using the computer to participate in this CHAT session was:

Very easy	93	71%
Somewhat easy	29	22%
Somewhat difficult	7	5%
Very difficult	1	1%
No response	1	1%

17. Was it easy or difficult for you to decide where to put your CHAT markers?

Very easy	27	21%
Somewhat easy	43	33%
Somewhat difficult	41	31%
Very difficult	18	14%
No response	2	2%

18. To what extent were you satisfied with the Medi-Cal coverage choices made by the whole group together?

Very satisfied	43	33%
Somewhat satisfied	68	52%
Somewhat dissatisfied	17	13%
Very dissatisfied	2	2%
No response	1	1%

19. Do you think that CHAT is a good way for others to understand the views and priorities of those on Medi-Cal?

Yes, definitely	102	78%
Yes, probably	24	18%
Probably not	4	3%
Definitely not	0	0%
Not sure	0	0%
No response	1	1%

20. Agree or Disagree: If the Medi-Cal budget is cut, I think it is important for Medi-Cal users to have a role in deciding how the cuts are made.

Agree strongly	117	89%
Agree somewhat	6	5%
Disagree somewhat	2	2%
Disagree strongly	3	2%
Not sure	1	1%
No response	2	2%

21. The state is considering many ways to reduce how much it spends on Medi-Cal, which will affect the services YOU receive. Of the changes listed here, which TWO do you like the LEAST?

There will be fewer doctors available for Medi-Cal patients.	62	47%
Medi-Cal will no longer pay for certain types of services.	48	37%
Medi-Cal patients must get all medical care from one local health plan.	45	34%
There will be stricter limits on the services a patient can use each month.	38	29%
Medi-Cal patients will have higher co-payments for some services.	35	27%
Those with higher income will pay a monthly fee to join Medi-Cal.	21	16%

22. Of the changes listed on the last question, which TWO are MOST ACCEPTABLE to you?

Those with higher income will pay a monthly fee to join Medi-Cal.	91	69%
Medi-Cal patients must get all medical care from one local health plan.	44	34%
Medi-Cal patients will have higher co-payments for some services.	42	32%
There will be stricter limits on the services a patient can use each month.	28	21%
There will be fewer doctors available for Medi-Cal patients.	19	15%
Medi-Cal will no longer pay for certain types of services.	17	13%

23. Which statement is closest to your view about participating in this CHAT session:

This will make a difference in the way I consider my Medi-Cal coverage.	70	53%
This has given me something to think about.	56	43%
No new information, but it was enjoyable.	5	4%
This was not a good use of my time.	0	0%
No response	0	0%

Endnotes

1. California HealthCare Foundation. *Medi-Cal Facts and Figures: A Look at California's Medicaid Program*. Oakland, CA: January 2004.
www.chcf.org/documents/policy/MediCalFactsAndFigures.pdf
2. Disabled people often face structural and communication barriers that greatly impede their use of medical services. This issue was not a topic within CHAT, and readers should not infer that its absence here means that these accessibility problems do not exist.
3. Sacramento Healthcare Decisions. *When Options Exceed Resources: Making Trade-Offs in Healthcare Benefits*. Results of the Capitol Region CHAT Project. October 2003.



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