THE COMMUNITY SPEAKS

Qualitative Report
from 16 Community Focus Groups
The Community Speaks

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ADVISORY COMMITTEE

In order to gain a broader community base and to have a reciprocal role with non-medical based stakeholders the OCHNA Steering committee decided that a community based advisory committee would be of great importance to the process. The OCHNA Steering committee identified a list of 450 community stakeholders, and from that list 20 representatives from 10 different segments of the community were selected. These sectors, included organization from health, education, business/media, advocacy/social services, public safety, government/political, the religious community, as well as representation for seniors, youth and children. The identified community leaders were then contacted and asked to serve on the project in an advisory capacity.

The OCHNA Advisory Committee first met on April 23, 1998, in which their opinions were solicited and recommendations established, for the development of the 16 community focus groups. A 64 question, electronic survey (OptionFinder) was administered to the group that polled their views on health and human services issues. Five main areas of concern were discussed, prioritized and selected for presentation to the Steering Committee. Advisory members offered to act as community contacts and liaisons for the Steering Committee and the subsequent task teams that were developed.

The Advisory Committee met again in early March 1999 to review the results of the primary, secondary and focus group data. Another OptionFinder activity was conducted to help the Advisory Committee validate and prioritize the needs identified. This information was taken back to the Steering Committee for their consideration as they worked through a second round of prioritization and selected the focus for the Executive Summary.

The Advisory Committee has provided the project with tremendous support and invaluable input, and has further indicated that they are willing to evolve into a stronger and more active role for the coming year.
THE COMMUNITY SPEAKS

BEHAVIORAL HEALTH SERIES: QUALITATIVE REPORT

This report presents the results of 3 focus group discussions concentrating on behavioral health care issues. The first group, which met on Tuesday, September 22, discussed workplace issues related to behavioral health from the perspective of employers. Participants included a physician, a variety of employee assistance professionals, compensation and benefits administrators, and a wellness program manager from a major Orange County corporation. The second group was conducted Wednesday, September 23, and it focused on the provider point of view. This group consisted of psychologists, psychiatrists, and health and wellness administrators. The third group in the series, conducted Thursday, September 24, consisted of physicians, psychiatrists, and others providing behavioral health care to ethnic communities in Orange County. This group focused on cultural issues relevant to behavioral health.

Behavioral Health Defined

How do you define behavioral health? This question stimulated an extensive conversation about the components of behavioral health. The relationship between mental health and physical health, the sources of behavioral health problems, various treatments, the stigma attached to mental health, and cultural differences as they pertain to behavioral health were also discussed.

It’s got to do with psychosocial and mental issues, adjustment disorders. Things of that nature that may be affecting employee performance. I think it could be expanded a bit to include all other life-type situations that may affect performance in the workplace, interactions between employee and supervisor and coworkers. (1:3-4)

...Working in the school system, it means the entire range. The full compendium, from kids who are acting out behaviorally, who maybe don’t have a serious disorder, but could benefit from counseling or interventions early on, to kids who are really seriously disturbed or staff who are seriously disturbed because of certain things happening in their life span which causes them to respond in a manner that’s different behaviorally for them. (2:4)

...And helping the people basically with economic needs and physical, mental, stress in dealing with being here, you know. We deal with a lot of...sometimes a lot of illegals coping with finding jobs and things like that. (3:4)

While mental health was explicitly discussed in all 3 groups, only participants in the employers focus group mentioned substance abuse without being prompted by the moderator. Substance abuse was not mentioned during a discussion of the definition of behavioral health. There appears to be some disagreement about the role of substance abuse within behavioral health care. Some see it merely as a symptom of underlying conflict while others regard it as a primary diagnosis.

Historically, the employee assistance field began with chemical dependency. There was a union movement and it was healthy people with chemical dependency. It was very specific and it, over the years, expanded to include all the other aspects. (1:11)

I think that’s in it when you look at the whole gamut of things. Those are symptoms. (2:8)

This participant (see quote above) in the providers group blends substance abuse into the “whole gamut of things” referring to it as a symptom.

The discussion of varying cultural perspectives regarding behavioral health is relevant to its definition within and across client subgroups.

For us as Vietnamese, I think when we talk about health, usually people are thinking about physical health, but they never think about...a full well-being of health that includes mental health and social well-being. It’s just...their physical health that they were thinking [to] include in their [concept of] health. (3:7)
So, with Latin Americans and people of Hispanic descent, it is, first of all, you don’t share your business with people on the outside...you handle your own problems...In Asian cultures, you know, talk about behavioral health, they say, “what?” So they’re really not familiar. What we’re finding is they’re not familiar with the resources. In addition, with Asian cultures—even though it’s probably a stereotype, but where Asian people are reputed to take care of their own within their own community. Studies I’ve read said that it’s not true. That is just not possible for a community to address all these problems. But...but if you look at the individuals...the culture individually, you will see a variety of responses to behavioral problems. (1:12)

The distinction between physical and mental health, the stigma associated with acknowledging adjustment problems, and seeking treatment are concepts central to these comments:

In my experience, there’s still tremendous stigma associated with behavioral health issues and there’s a tendency to run for cover when a person appears at work in some sort of impaired capacity from a mental issue and the reactions tend to be a lot more misunderstood in the psychosocial behavioral area than it would be if it were a pure physical thing. It’s okay if Joe had a heart attack, but if Joe is having an adjustment disorder...they don’t know how to cope with that. (1:5)

Culturally, I think certain groups are less likely to access behavioral health services because of the stigma and they’re...it’s just a foreign concept to them. And then [with regard to] gender, study after study shows that women are more likely to access behavioral health care than men, although we can assume that the rate of incidents is the same in both genders. (1:6)

The appropriate approach to treatment is not always clear until the separation of “inward issues” from “outward behavior” is resolved:

...[My concern as a psychiatrist, and in seeing children, is that there is sort of outward behavior and then there’s inward issues. And I think in many ways society wants to treat the behavior problems or...but we don’t. If someone is functioning quite well, but they’re miserably unhappy, do they have a behavioral problem? I don’t know. That’s an interesting question.

That’s a good issue, I think, because you don’t want to just treat the symptoms, you want to really look and help people be the best they can be. (2:4)

Particularly in the employer and provider groups, the concept of prevention is as important a component of the definition of behavioral health as treatment.

...[It seems like what we’re talking about might be construed as more reactive to symptoms. Are there proactive or preventive approaches that you can describe.? (2:9)

You’ve been reading my mind, I think. Because I was sitting over here thinking, well, this is basically treatment-focused and not prevention-focused. In the school systems, ...it’s not consistent enough, but for those schools and those teachers who are consistent about utilizing conflict management, good communication skills, learning how to problem-solve early, and how to set goals. When those things can be taught early and consistently reinforced throughout the career of the child, adult, adolescent, whatever, ...my guess is, because we don’t have any firm studies on these, but we do know is while they’re in school, they have less problems at the school site. There are less referrals. They are less involved with the juvenile systems. (2:9)
Behavioral Health Issues in the Workplace and Community

The incidence of panic or anxiety disorders is also related to alcohol abuse because people who suffer from severe anxiety have a tendency to self-medicate in order to cope. The problem with a “substance abuse” diagnosis is that many clients fear treatment will focus on the substance abuse rather than those conflicts that motivate this behavior.

The doctor said something that’s really important... there’s a lot of substance abuse in the workplace, but it’s not necessarily the primary diagnosis, although we treat it as such. I think a lot of people are fearful of coming forward to discuss drinking problems because they believe that they’ll be stuck there and the underlying problem will never be identified... another thing that I’m seeing a lot of in the 90s are panic attack disorders that people are self-medicating with alcohol. (1:9)

About the time the clients get to an in-patient setting, it’s probably 1 out of 4 who does not have a chemical problem. It’s extremely high. It would be very unusual to find someone who has not utilized chemicals, other than the prescribed ones to try to cope. (2:13)

In the cultural issues group, discussion of behavioral health concerns in the community included domestic violence and alcohol abuse. These dysfunctional behaviors are seen as a result of the strain associated with the process of assimilation and economic pressures. The role of the family and how it is affected is clearly emphasized to a greater extent by participants in this discussion.

I would say many of the people that are indulged in alcohol to significant levels don’t come to our clinics. What we’re seeing is the devastation of the alcohol in regards to how it affects families, family relationships, resources within families, and how it essentially compromises already very difficult living-type situations due to the socioeconomic dynamics within families, where it compromises all kinds of things that, you know, to a great degree, you have a major impact on the individuals and families. (3:8)

Extent to Which Behavioral Health Issues Affect the Workplace

A “multiplier effect” created by employees suffering from adjustment difficulties in the workplace is noted below. A participant in the employers group emphasized the magnitude of the disruption that the affected individual has upon his coworkers and the problems that result. The scope of these problems is significant in both fiscal and human terms.

I just read a statistic where 20% of any workforce is impaired at... any point in time in any corporation. And of that 20%, 25 to 30% of those individuals are affected by substance abuse, so statistically about 20% of any workplace [is involved] in the myriad of problems that we see... I think that 20% is on the rise. (1:9)

And if you say it’s 20%, then that 20% affects another 20 or 30 or 40% in the workplace by their behavior. (1:9)

It’s synergistic. Absolutely. (1:9)

Behavioral health should not be considered solely in terms of deficits or employer costs. By addressing behavioral health issues promptly, there may be a bottom-line impact on profitability.

...[F]rom what I’ve been reading in the financial press, there’s beginning to be actual data showing in some large companies... I think one of the companies they mentioned was Sears or Penney’s... are beginning to demonstrate statistically that they can show a relationship between happy employees and a profit line, which before... people didn’t realize. And so you could say that if there were early interventions, prevention and early intervention, and the employees became happier, that the company would have more profit. (2:29)
Gaps and Deficiencies in the System of Behavioral Health Care

Access and Coverage
The first gap in the system of behavioral health care that came to mind among participants in the employers group addressed access and coverage:

Some policies, some coverage is very good, and I have no difficulties getting referrals for clients that come in. Others are very restricted. I think the ones that are the most frustrating for me are the ones that just basically don’t have the benefit to cover… the type of problem we’re dealing with. And I see that most frequently with chemical dependency. That’s an issue. And there is no benefit for that type of coverage. It’s very difficult because I think the community it’s pretty limited in what we can offer, and it’s a very unstructured type of resource that’s out there. So chemical dependency needs a lot of structure, at least initially, for successful [treatment], I think. So that’s a real tough one for me to deal with. (1:13)

The irony for me is that…is that the federal government has many, many state legislatures that mandated parity for mental health coverage, but totally obviated chemical dependency treatment. (1:13)

I would say at least 30% of people that I see [have a substance abuse issue]. Now…some of those people have good coverage. To add to the frustration, I think that people that typically don’t have that coverage in their policy also have the least amount of financial resources. And so we’re talking about the lower part of the economic scale, and then you’re trying to come up with something to give them some resources is really a tough one. (1:14)

Another obstacle to behavioral health care access is the employer who does not support the employee affected by a behavioral health concern and does not help the employee to connect with nor allow him or her to use a treatment benefit.

Often times, employees may be sent to use the EAP counselor because they’re exhibiting behavior in the workplace that is problematic…in one way or another. I can connect them with their benefit, but then the workplace, even though they want them fixed or to be better, or straighten up, doesn’t want to allow freedom. If the employee, say, needs to make a doctor’s appointment during work hours, and they ask far in advance, they may not be told until the last minute that they can’t go… (1:14)

An additional complication is the reticence on the part of the employee to disclose problems that may be perceived to threaten his or her job. Consequently, this lack of security compromises the extent to which an employer receives feedback from the employee about a particular benefit, including any difficulties such as access that may have arisen.

...Are there gaps from our perspective. You know, we don’t…we don’t see that there are gaps. We’re not hearing it.

You’d have no way [to know if gaps existed] because people would rather drop off...

...the face of the map. Exactly.

...before they’d let you know that they have a problem.

Exactly. So, from a provider prospective, we’re not getting information we need to make sure it’s adequate for employees.” (1:16)

The decision to access care is by no means the end of the struggle:

Well…even the coverage…employers offer…in terms of the behavioral health area, a lot of the smaller employers don’t cover it. Although it may even be mandatory now, but I’m not sure if it. Even still,…in terms of reimbursement, they only cover 50% of the cost or they limit the amount of visits. (1:8)
Participants in the providers group noted because coverage varies from employer to employer, if an employee changes jobs the type of coverage may differ and, therefore, continuity of the treatment is broken:

*I do think part of the fragmentation that people have is if their insurance and healthcare coverage is always tied to your job and then they move, lose their job, quit, take another job, their health care changes. They can’t stay with the same provider. There’s no continuity; it’s a real problem. There is no continuity for people.* (2:30)

Access to care is a critical issue for providers in the cultural issues group also. Ethnic and immigrant populations must overcome very basic constraints before they can even begin to engage with the behavioral health care system:

*I find this population is in great need of knowing how to access the health...you know, the services that they need...for, maybe a lack of language or transportation.* (3:4)

*With the Cambodian...[population] they need to provide translation and transportation...especially for woman clients.* (3:5)

In the cultural issues group, neighborhood-based services and outreach activities are critically important to identify those in need and to deliver services:

*We do reach into the communities because we believe that people usually don’t go out of their houses looking for help as much as...you have to...come to them and find out what their needs are... especially within the Hispanic [community].* (3:10)

**Confidentiality and Stigma**

The client’s desire to remain anonymous, to protect an image, and to preserve privacy cannot be regarded as a gap in service or a deficiency of the system. This desire, although understandable, obstructs access to behavioral health services. This point was noted in all three discussions. Quotations from the cultural issues group are presented first:

*I’m glad that they now changed the name of mental health to behavioral, but it’s still the same...and they don’t want to say that they go there because back to the country, people look, you know, for people to go to meet the psychiatrist...he lost something. You know, he’s not 100%... So that they didn’t want to be saying that they have problem.*

The issue of confidentiality stops many people from accessing necessary treatment and services. There is a fear that records associated with behavioral health care will outlive the period of treatment. This point is illustrated in the quote below, which is taken from a discussion of federally supported treatment made available to residents of Laguna Beach after the firestorm. The provider describing the situation revealed, to his surprise, he and his colleagues had been instructed not to keep any treatment records. When the clients learned records were not being maintained, they were more likely to use the services offered.

*...That there were people who were thinking...maybe one day they were going to run for president or a school board, or what have you, and when they found that you weren’t even going to identify that they had the care, they were very appreciative and all sorts of treatment was done. You know, I was thinking, I didn’t realize that people were that paranoid. Well, evidently, they are. It was very instructive. So, evidently...maybe lesser functioning people are not that concerned, although, they should be, too, I would think. In essence, we were able to provide treatment to all sorts of people who said...sort of like, thank God for the firestorm because otherwise I could not have gotten this type of counseling.*
Yeah. Just as an anecdote, a colleague I know who has a psychoanalytic practice. He says that’s exactly why people come and pay cash. They don’t want any records. They don’t want any paper trail. They pay for insurance, I’m sure. But they are very happy to see you. Here’s your money. (2:11)

Pharmacy Costs and Consistent Formulary

Participants in the employers and providers groups cited pharmacy costs as a significant issue in behavioral health. When pharmacy costs are controlled by nonclinical considerations, a deficiency in the system of care occurs:

...[W]e ran into a situation with an HMO changing their formulary in the middle of the year, and the whole situation of getting your employees [switched to new medications before this]. They’re finally on a medication. It’s really working for them. And now you have to switch them to another one. And they start screaming. I’m not going back to that drug. And I think employers need to fight back more with HMOs somehow and saying, ‘No. You’re not changing our formulary.’ (1:17)

...[A] big problem that I hear about, especially from people in private practices,[is] the restrictive formularies that exist for medications...there is so much research going on...medications that would affect behaviors...central nervous system, that there’s going to be a lot of medications continuing to come out.

That’s a good point. I think it’s unconscionable for a formulary not to include new generation antidepressants and, for example, to insist on a failed and outdated class of antidepressants. (2:16)

Other Barriers to Behavioral Health Care

Several issues identified in this section relate to behavioral health care clients rather than the health care system. However, these issues may escalate and become deficiencies in the behavioral health care system if they are not addressed by care providers. For example, in the Vietnamese, Latino/Hispanic, and mainstream cultures, substance use tends to be downplayed or regarded as a legitimate coping mechanism rather than identified as a concern.

You raised the issue of substance abuse. I would like to mention beer. Part of the [problem among] Vietnamese [is that] the beer isn’t alcohol.

In the way they think about it?

Beer is not alcohol, not for them. And also they take pride showing their male dominance and their male character. How many cans of beer that they can drink. So that [pattern] affects the young people...

...Within the Hispanic community, often times, you have to clarify when you say, “Do you drink alcohol?” You have to clarify, “Do you drink beer; do you drink wine; do you drink spirits?” Because beer by itself is not necessarily...doesn’t come to the mind of individuals. It’s like asking someone, “Do you take medicines?” And they say, “No.” But they may be taking over-the-counter medications which they don’t count or both. (3:9)

The cultural issues group emphasized the way a potential client is treated by a provider from the first moment of contact is extremely important. If a client is treated without respect and dignity, he or she will either stop treatment altogether or seek treatment elsewhere. In turn, the client may tell others about the experience and the negative impact of word of mouth on the provider is tremendous:

[T]o have a friendly reception when they get to a place. If anyone in any way bats an eye wrong, it’s misinterpreted. You know, they don’t want to see me. I don’t belong here. This isn’t a resource for me, and so on. And they may just... wander away. So that’s one thing...the resources have to be user friendly. (3:12)
The informal support network [and] communication within the communities are faster than AT&T. You provide bad service, and, in an instant, everyone knows. And that’s what, I think, the administrators need to know. You know, you have to treat everyone with respect. You have to provide them with services you offer and, ultimately, you have to do it, to some degree, in a way that you’re going to accommodate to the needs of the patient time-wise, or whatever. It’s a big challenge, you know. (3:19-20)

The manner in which phone calls are handled is just as important to the client as the first impression. Increasingly, computer-automated telephone answering systems (“phone trees”) are being used by large and small institutions. Even though these systems may be convenient for the institution, more often they are seen as frustrating and a barrier to communication on the part of the client.

Yeah. Under-utilization in…for many, many reasons of which we’ve touched on. But one of the other things I think that’s more of a newer development that tends to serve as an increasing barrier is phone trees.

Yeah. People have difficulty with the concept of appointments and then they get…they call and then they wind up on the phone tree and they don’t know. You know, they just don’t know, and they hang up. (3:17)

Transportation is a significant problem in many subpopulations, especially for the elderly, disabled, and those who do not have cars. Many people do not live near major bus routes or must travel to agencies located far from public transportation routes.

…[I]n the disabled community, we have found transportation to be such a problem for the disabled community. (3:17)

The Relationship Between Primary Care Physicians and Behavioral Health Care Providers

The relationship can be difficult between primary care physicians and behavioral health care providers and can cause obstacles for the client. Each provider is approaching the client from a different direction.

How well do the primary care and behavioral health care practitioners work together today?

In some settings, beautifully. In most settings, terribly. You know, I think your organization (Kaiser) is a good example of how it can work. …you’ve got other examples…where it works quite well. But I think in most of American medicine today, it works terribly. Behavioral health practitioners don’t talk to primary care practitioners, and vice versa. I think it’s fair to say that many, if not most, primary care practitioners don’t value behavioral health care services. We’ve been carved out for so long that we’ve become alien to the rest of the health care systems. (2:21)

What do you see as the pros and cons of integrating primary care into behavioral healthcare?

…I think the major con in any system, and I think it is in our system, too, is the issue of confidentiality. If you go to your primary care practitioner and say, I’m depressed…and I have had that issue because some people have moved from the HMO where I work, and they’ve moved to other settings, and they have not been provided with a psychiatrist. They are told to go to their primary care practitioner. And these are people with serious problems. They are not like just some people with garden variety depression. These are people that have psychotic episodes and [have been] hospitalized, and you’re going, there’s no way. And then their primary care practitioner would ask for their records, and we would say, well, no. We can’t release these records. We have to do this summary letter about the treatment. We’re not going to send all their records that’s going to go into their medical chart wherever at…the place they are. And there is this whole issue about confidentiality which I think helps preserve the relationship, the therapeutic relationship that is necessary to do the kind of work that needs to be done to provide this safety and security for people to come and talk about things. …when it goes into their regular record…It’s all going to be there. And a lot of it is information that will potentially negatively impact people. And I don’t think that most of the primary
care practitioners are aware of it to the same degree, because they haven’t experienced people who have been discriminated against and have had bad things happen to them, because they were too honest about their treatment...

You’re kind of touching on a double bind issue, too. And that is that the behavioral healthcare provider has to tell it like it is in such a way as to justify the care, and then it can backfire if it’s too bad. (2:22-23)

Successful and Innovative Behavioral Health Care Programs: What’s Working Now

Successful treatments can motivate clients to continue their care and inspire others to seek help.

I would say the treatment for depression. You know, in terms of medications available and how effective they are. They’re wonderful. I mean...there are plenty of studies that show that treatment of depression is much more effective than treatment of high blood pressure and some other things, that it works really well, and it’s safe and effective. I think it’s recognized. I think more people are coming in and asking for help than ever have before...realizing...they see other people doing well. They’re saying, go get help. Don’t wait around. (2:7)

Participants considered education and prevention to be successful approaches. These approaches are well received by clients also.

I know with our workplace, we do a lot of stress management classes...probably one a month, varying from parenting to dealing with elder care, to drug abuse, to almost anything. And we always educate the employees that this is a service by EAP. You get 3 free visits. And really educating the population right there. And we do a lot of advertisements in our benefits newsletters that goes out...and they do have the 1-800 number that they can call also. So...you can tell when that stuff goes out because our increase of calls is dramatic at that point.

And my company does the same thing. We hold [meetings] once a month on different topics – parenting, stress-related issues, and they’re very, very well attended. (1:19)

We also do economic seminars. I mean, that’s a huge burden for a lot of people right now. And those are very well attended, too.

We have massage stations set up twice a week down in our nurse’s office, and employees pay for it. It’s on their own time. But it’s a 10-minute shoulder massage to help relax them the rest of the day. (1:20)

Employee Health Benefits Within the Workplace

Participants discussed employee health benefits and how they are determined.

How should employers determine what benefits will be made available to address employee behavioral health issues?

Well, a starting point for us is, again, to consider competition. Skilled patient care workers are...hotly pursued down in Orange County, so we have to make sure that we offer a competitive menu of benefits, which would include behavioral health, chemical dependency, mental health benefits, EAP counseling. So that’s a first place for us, how competitive are we in what we offer, and then do we share cost with the employers so that we consider the financial parameters of that benefit as well.

On the other side, though, the company has to stay competitive within their industry and not press themselves out of the market because of the care that they’ve selected. I mean, in the long run, we all know that it’s going to save them money, but they don’t always think that way. (1:22)
How can the determination of employee benefits best be influenced?

[Conducting a] needs assessment and ...I personally have gone to benefits people and said this is a less than adequate benefit and is there anything that can be done when it comes time to renegotiate. So I let them be aware as much as I can of problems that I’m experiencing with what’s already in place. So I think education if nothing else. (1:27)

[The PPOs and HMOs could assist companies also. They’re always tracking, giving everything in code. If they could get a code that this was denied because it’s not a covered benefit, and it’s for drug abuse or something. If they could then come back...I mean, I don’t know if a company would really listen to them, but come back and say we denied about 100 claims this year in regard to drug abuse assistance, and offer that information to a company. Because we don’t know how many people are really trying to access that. They’re not going to come to tell us. (1:27)

Directions for Improving the Delivery of Behavioral Health Care

Training and educating people within the behavioral health care system to meet the future needs of Orange County’s ethnic and immigrant populations is viewed as a positive place to start:

We really need to advocate and to find people that are skilled in the language of our customers, of our people, and that are very, very sensitive to the culture. And I think that has to be present in all the different agencies, in all the different resources, somehow. It would be nice if we could offer scholarships within our own communities to make sure that we could boost the representation of all our communities so that they become educated and, ultimately, be providers as our, you know, cultures evolve. (3:26)

Participants in all 3 groups agreed that prevention education delivered through the schools is important. However, because there is a lack of trained nurses in the schools, there needs to be a significant increase in school nurses before this goal can be realized. Collaboration across sectors is viewed as necessary to effectively deliver prevention services. Parenting classes and resources are also viewed as necessary additions to the current health care system:

We have 460,000 kindergarten through twelfth grade students here in Orange County. And the nurses gather statistics for me every single year. This year we were 8-1 social morbidities versus physical things...8-1. ...I’m talking social morbidities everything from violence, homicide, intentional injury, child abuse, acute depressions, all of those versus, you know, asthma, onset of diabetes, seizures, that kind of thing. ...I think prevention needs to be a really important piece, but I think it needs to be done collectively. Schools can’t do it alone. (2:25)

I think anything that would help with the parenting issues in the workplace. That’s such a key factor. And I think just our society, in general, we don’t give much support to parents on how to be parents, and, certainly in today’s environment with both parties working or both parents working and the stress involved with children raising children. You know, I really think that’s a key. It’s just...it’s vital that companies do more. (1:20)

Providers believe that the ultimate goal is for comprehensive services to be delivered to clients in an accessible manner. The constant review of the effectiveness of behavioral health services is seen as a large piece in the ideal health care system puzzle:

I think the ideal system ought to be one where services are easily accessed and appropriately accessed. ...a system where there are comprehensive offerings ...across mental health, chemical dependency, various settings that are community-based, that gets to the access issue. [Services] that are either integrated or coordinated and that are evidence-based. (2:26)
Group therapy is viewed as a successful method of treatment that is not used often enough:

And I’m thinking of some really good group therapy, particularly in the long-term patients who need a support system. So that perhaps if there was more training and education in how to provide a therapy…we give you a good group therapist, but you need a certain type of patient. You can’t have a group if it’s too heterogeneous. …there should be a way to come up with a system for being able to figure out which patients can benefit from group therapy. And it can be very, very, very effective, particularly…not just the simple patient support groups, but it can extremely effective, maybe even more so than individual therapy.

That’s a good point. I mean, group therapy is wildly un-utilized. If you just look at the efficacy studies, estimates range anywhere from 12 to 25% of the general psychiatric population are best served with group therapy, and yet in most systems less than 2% of services are delivering group therapeutic formats. (2:18)

Effective Information Distribution

Participants in the cultural issues group were asked about the most effective means of distributing behavioral health care information:

Most of the time the Vietnamese will rely heavily upon the radio. (3:16)

Within the Spanish-speaking community, I would say television is probably the most powerful and actually probably the best resource…one is the talk shows and the other is the novelas, the tele-novelas. (3:19)

Flyers are not viewed as an effective means of disseminating information unless they are simple, translated very carefully, and distributed by a respected member of the community.
Community Health: Working the Puzzle
Children’s Focus Groups

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CHILD AND TEEN HEALTH SERIES: QUALITATIVE REPORT

This report presents the results of the 2 focus group discussions concentrating upon child and teen health. This group, consisting of 12- to 18-year-old boys and girls was conducted Wednesday, October 7, at the Buena Park Boys and Girls Club.

Children’s and Teen’s Views of the Meaning of Good Health

The brief discussion in the child and teen group regarding the meaning of good health introduced physical considerations first but blended this idea almost immediately with mental health and attitudinal considerations:

To me good health means...knowing what your limitations are. Knowing what’s right from wrong. (2:4)

Taking care of yourself, like not doing drugs. (2:4)

Good health is...like good nutrition. If you eat well, if you exercise. You just don’t...lay around and do nothing...you get out and play a sport, it’ll keep you in shape. (2:5)

...It’s a mental health thing, too...you could be in perfect health. I mean...you could...not have any sicknesses, have perfect vision, everything could be fine, but you could be a mental case... If you don’t love yourself, then you could be considered not healthy. (2:4)

The mental component of self-esteem is important to these teens who anguish over their appearances. They recognize that a poor self-image (e.g., ‘I’m fat!’) can lead to unhealthy behavior.

Children’s and Teens’ Views of the Meaning of Health Care

Health care is clearly perceived in terms of access to professional service providers and having the insurance coverage to obtain health care at an affordable rate:

...Having a doctor.

...And like a health plan where you don’t have to pay every visit, or if you have some kind of emergency and you have to go to the emergency room, then you don’t have to pay right up front... (2:5)

Health care is viewed in terms of multiple disciplines by these young people who also recognize self-care and their own role in seeking preventive care:

And healthcare isn’t just a doctor, it could be a dentist, a psychiatrist, a therapist, an optometrist...

Yourself. (2:5-6)

I think you have to care about knowing where you can be taken care of... Wherever you go, you have to depend on the doctors... to check you out, but not just go around [saying] well, I can’t afford this, so I can’t go to the dentist. (2:6)

Children’s and Teen’s Views of the Health Care System in Orange County

Just like the day laborers focus group, children and teens see that profit is the motive, and that money matters more than patient health. It is interesting to note that this view is expressed in 2 groups of disenfranchised county residents: children and teens, and undocumented immigrants.
[B]ecause some people can't afford like a health plan...so not everybody gets the same treatment.

...Because like what if you have a disease and they have a cure, but the cost and you can't afford to buy it.

...Like I don't really know what an HMO is really, but I have an idea. And everybody says like they don't care about your health, they just care about your money. (2:17)

This cynicism was also expressed when discussing HIV:

I remember a couple of days ago, me and my friend...we were thinking about... the cure for AIDS and all that, and how they're getting closer...And we were saying...just imagine the guy who finds a cure for it, how rich he's going to be... you know, he's not going to care, as long as he gets paid.

...If you don't have the money, you don't have anything. (2:18)

Several of the participants speculated that a cure for AIDS has been discovered. These youth believe the cure has not been released to the public “because then they'll say, oh, well, you know, you should provide it to people who can't afford it, and they don't want to do that.” (2:19)

These young persons expressed a great deal of interest in and sympathy for the homeless. Four or 5 of the children and teens indicated they see homeless persons daily. They discussed with interest a project one of them had heard about in New York City, in which outreach was conducted to provide medical care to homeless persons there. The prevailing view among these youth was that people in Orange County do not care about the homeless, and consequently they lack adequate medical care. Interestingly, the homeless were not mentioned in the providers focus group.

One teen responded to the current effort to move individuals and families off the welfare roles with the following comment:

[It's okay for them to cut welfare, you know, because they want them to work. They weren't going to go out there and get jobs and everything...I can see them saying, okay, we're not going to cover you because you're an adult. You should go out and get a job, but I think they should have full coverage for the kids. (2:17)

When asked about access to care and the quality of care they and their peers received, the responses were “pretty good” and “average.”

It’s not like anybody is walking around with all their teeth falling out. (2:22)

Children’s and Teens’ Perceived Health Risks

Children and teens participating in the focus group were asked to describe the health risks to which they felt vulnerable. Earlier in the discussion, they had mentioned their exposure to “that meningitis thing” and had described the awkward steps (such as declining to drink from another’s soda can) that were required to reduce the risk of contracting meningitis. The next comment had to do with AIDS and sexually transmitted diseases.

[Y]ou’re having sexual intercourse with your partner, and, you know...I would ask them...You know, you don’t have any disease, do you, because you don’t want to end up, you know, having sex and then after, they’re like, whoops, you know, ‘It slipped my mind. Sorry. Not my problem anymore. It’s your problem.’

I just want to know that, you know, can I trust this person? Can I...can I have sexual intercourse without having anything happen to me? (2:26)

The second concern expressed by these children was violence. They indicated weapons are not uncommon in their environments, and that they worry about being at the wrong place at the wrong time.
...people having all kinds of weapons and how they get you for no reason just because you’re there. just because you give them a dirty look. (2:26)

Mostly it’s being scared of being killed or beat up... because [where] I live... it’s not like the upper class at all. (2:27)

Fights break out frequently. Sometimes these involve multiple participants with a presence on school campuses, gangs, or racial/ethnic cliques.

Because one girl last year, she was like in the hospital because they beat her up so bad. I’m scared that they’re going to do that to me because they just... they think me and my friends are weird, so they don’t like us very much.

And last week, 2 guys went at it and they were not from the same race... And one of them had his head open back here, and [there have been] hate crimes at that school, so I don’t feel safe anymore. (1:24)

Stress, worry, depression, and pressure inspired even more animated conversation than the topic of violence among these young people.

I think there’s a lot of mental pressure as a teenager... I mean, it’s real hard to find your place in school... and then like those people start rumors that goes on with the violent thing... pressure probably from your parents, I mean, to get good grades in school, not to have sex, not to do drugs, not to, you know, get in trouble with the police...

I think... like a lot of that has to do with peer pressure, but some girls go like... they’ll start feeling like they’re not valued anymore because they think that... because there’s like a standard of how to be pretty. ...I know guys, too, they all like... They have to be with like the crowd... I like to stand out, though. Because people at my school, everybody like... they have their groups... There’s like the Mexican group... And... if you’re like black you... you can’t go over there because that’s where they hang out, and you’re scared to go there because they might beat you up for coming in their territory or whatever. (2:28)

Participants also described pressures related to meeting their own goals and adult/parental expectations of them:

...if you’re like an honor student in school and there’s a class that’s too fast paced for you, then you get all stressed out... like a math class that’s too hard for you, and you think you have to meet like expectations of your teacher or your parents. (2:28)

...I was on the honor roll all last year. And now this year... I don’t understand a lot of it [math], but I don’t like to raise my hand because I’m afraid someone is going to laugh because I don’t understand it... I feel like I can’t go in and ask the teachers, they’ll think I’m stupid or something. (2:30)
Despite their self-assured exteriors, these children and teens revealed a great deal of apprehension about entering the adult world after high school:

…I’m so scared to grow up. I mean, once I turn 18, you know, it’s like you’re on your own. We’re an adult now. You’re in charge, so you have all the responsibilities. You don’t have somebody there telling you what to do, when to do it, how to do it, and it’s scary.

A lot of heads nodding for the tape.

…say if you have the good grades, but you want to go to college, but they’re not quite good enough to go to college. I mean, there’s a lot of pressure on you there. You’ve got to get a job and you’ve got to work...

…I’m a senior. I’m already graduating and I want to stay in high school. I don’t want to go off because I have all my friends there… (2:29)

As the quotation below illustrates, adolescents too may turn to alcohol or drug use to cope with stress and pressure:

[S]ome people…they’re like really stressed out, like I was. I was really stressed out, you know, because of my mom, myself, other people, things I had to go through. So I like actually…I kind of like really turned to that, you know. Actually get it from myself, from nobody else. Nobody told me to do it, nobody told me to take it, you know. Showed it to me or anything. (2:34)

The youthful participants in this discussion had a matter-of-fact response to the presence of drugs:

Almost like… I have to say about two thirds of the kids that pass by me are smoking a cigarette or smoking weed. And… like if I just go around campus sometimes you might pass by a group and… you can see they’ve got it on the table. (2:31)

It’s always going to be there.

…It’s just… your choice of taking them or just going… no, I’m not going to do that kind of stuff. (2:30)

The drugs mentioned as most prevalent are marijuana, cocaine; glue, “white-out,” and other inhalants; LSD; and methamphetamines. Peer pressure was discussed, and several children also related stories concerning the impact of drug use on their peers.

…I know about drugs and everything, but still you want to be like your friends… you want to try it and see how good it is. And they’re talking about how good it is and all this stuff, but then everybody else is… and all your parents are there telling you how bad it is, because they’ve already gone through it. They’ve tried it already. They had their time, but they don’t want you to do it, too. (2:36)

Yeah, I’ve seen drugs in action. My best friend from fifth grade… what is that… 11 years old?… she started smoking weed. Starting smoking crack. She got pregnant. She had a miscarriage. She got pregnant again. She had an abortion. She got pregnant again and had a baby. It just… I mean, it basically… what she knew, she just like proved the statistics that drugs can lead to so many things that can go wrong in your life. (2:33-34)

Youth of this generation are exposed to the news describing drug use among authority figures, and many are aware that their parents used drugs as young people, thus creating some conflicting feelings and perhaps some resentment.

…if you hear the news about this one City official, you know, he just had a drug test and they found out recently he did drugs, that’s like how can you have this kind of person, you know, running the City and
nobody is doing it makes no sense. It’s just …they’re not doing their job, and, you know, they’re getting elected and, you know, if you have this kind of people who are running the City, you can’t trust these people. They’re just going to make it worse for you.

And the law enforcement, too, the policemen, like the guy that sneaked out the cocaine out of the…[evidence locker]. (2:33)

These children apparently have been educated about drugs and are cognizant of the issues around drug use. Interestingly, the educational focus on drugs may not adequately emphasize the problems associated with alcohol and tobacco use. Consequently, teens may feel less concerned about these legal substances and may even receive the inadvertent message that alcohol and tobacco use is acceptable as long as drugs are avoided.

Alcohol [and] like smoking are the two main things that they skipped over, and everybody thinks like, oh, those are just major drugs. I won’t do those. I’ll just do like…I’ll smoke cigarettes and drink all the time, and it’s better doing that.

Yeah. Most of that common stuff is like… I think that affects more than the regular drugs. Do you know what I mean?

Do you guys tend to agree with that, that alcohol has more influence than drugs with people of your age?

Yeah. They’re not saying, you know, look how bad it is.

And cigarettes, too. Like I think they’re starting to crack down on cigarettes because they show the posters. But I don’t really see anything about alcohol… They don’t talk about like a lot of different kinds of drugs. They just mostly talk about cocaine and weed. (2:37-38)

Peers and parents were cited as the most positive influences with regard to avoiding drugs.

My mom always tells me…to always have at least one friend that’s better than me, that knows more than me about health and drugs and everything so he could teach me…what to do and what not to do.

Yeah, I can agree with that. I mean, I used to smoke when I was in middle school. And it took one of my friends to actually come up to me and literally slap me and say, are you crazy? Do you know what you’re doing? Do you know how it’s damaging your lungs?…it hit me, literally, in the face and I was just like, whoa, and I thought about it, and, you know, and I quit. (2:36)

My parents pretty much scared me out of taking drugs. (2:36)

As the barriers fell away near the end of the discussion, the children and teenagers in this group indicated that depression was a major issue among their peers, particularly stemming from romantic relationships. These difficulties are made more acute when the adults in their lives are dismissive about their experiences.

I think they should have more with depression.

…Because like…a lot of times where you just want to die because you’re…a lot of the things are stupid, but to us, they’re big. Our parents are, oh, that’s dumb, why would you want something like that…like especially at first when I started in junior high last year, I was…I hated it. …I thought everybody hated me and everything, because I didn’t have a lot of friends. …And they should have classes on support groups about people who want to kill themselves. Because, I mean, when you’re doing drugs, you’re killing yourself, and then they have the people that they want to kill themselves, and they do. They should have more. They should do more things in that, too.

…Depression?
A lot of people go through it. I mean...say, for instance, relationships. I mean...

And adults will say, oh, that’s a bunch of B.S. Oh, you know, what, you’ll get over it. It was just puppy love. And they make all these excuses, and say, you know, that’s stupid. Why would you want to kill yourself and everything.

Yeah...They say that, you know, you’re too young. You don’t know what love is. But, I mean, I think that, to a certain extent, you do. And...I think that’s one of the main reasons like...like, I guess I could say why boys and girls go into depression is over relationships.

...Because, I mean, your emotions are raging when you’re adolescent. (2:40-41)

Gaps in Care and Barriers to Health Care for Children and Teenagers

The previous section revealed some potential gaps in school-based interventions designed to equip children with coping skills and to discourage health risk behaviors. For example, maintaining an emphasis on alcohol and tobacco use prevention in the context of drug abuse prevention education is important. In addition, these children and teens indicate that frank talk about relationships, coping with romantic disappointment, and dealing with depression would be helpful. The stress resulting from exposure to violence is another factor emphasized by these young people, which apparently is not dealt with systematically in our educational system. The discussion with children and teens indicated that help developing coping mechanisms related to each of these issues would be a positive contribution to their care. They expressed an affinity for the guided group discussion format in which their peers also shared their experiences.

How Children and Teens Learn About Health

In addition to information acquired from their parents and from health classes, participants in the child and teen focus group mentioned alcohol, tobacco, and other drug prevention education, and particularly some of the “scare” commercials and public service announcements they had seen.

[What is] the best way to get messages about health out to people your age?

T.V.

Because commercials like that...that lady that when she puts a cigarette in her throat, everybody was like talking about that of how gross that was. (2:12)

Television stations and programming thought likely to reach a lot of young people are MTV, BET, and any “high rated show”. A debate about the value of repetition was not completely resolved. Some teens reported tiring of repeated messages, but others thought the repetition was good, indicating they learned the lines of the health-related advertisements and could recite them along with the actors.

Interestingly, the Internet was also thought to be a good medium for communicating health education messages:

How many of you are on the Web? One, 2, 3, 4, 5, 6 out of, what, 9. That’s pretty cool. So you surf the Web? How do you...

At our school, they have like a...they let us use the Web in the library we sign a permission slip or something.

Do you go to any particular Web sites that talk about health?

No. It’s just...you know, if you’re going through the Web, like our...the whole page might just come up as some kind of health or something like that. Like, you know, if you type it in, you look at the screen and it just has, you know, get checked up or something like that.

When you look at it [advertisements and messages] before you go into your topic. (2:12)
CHILD AND TEEN HEALTH:
PROVIDER QUALITATIVE REPORT

This report presents the results of 1 of 2 focus group discussions concentrating on child and teen health. The first focus group in this series was conducted Monday, October 5 at Children’s Hospital of Orange County. The 12 participants provide health care to children and teens in Orange County. These participants included nurses, a dietician, a physician, dental care providers, a pharmacist, teachers, representatives from a city department of social services, a school district department of health services, and the director of social services for the Children’s Bureau of Southern California.

Summary of the Results

This report is organized around the principal topics that stimulated the most interest and discussion in the child and teen focus group and the providers focus group.

Issues and Problems with Health Care for Children and Teenagers

Providers engaged in a wide-ranging and lengthy discussion of the social and health concerns of children and teenagers in Orange County.

Language and Literacy

Given the racial/ethnic and linguistic diversity of Orange County, surprisingly little was said about language and literacy issues.

I was thinking about the number of clients that...are adults who cannot read, even their own native language. And so you’ve got to think of ways to being able to reach them in such a way that the message is as much verbal as it is visual, so that they can internalize it and say that’s what I need to do... (1:19)

Knowledge of and Access to Services

Knowledge about and accessibility of available health services are 2 recurrent themes among providers.

...When we have parents come in, or families come in, ‘I never knew about these services’. ‘I never knew they were available’ and, you know, they’ve been there for years. And so it is really an education issue. It’s getting the word out. (1:6)

In response to a question about the best way to improve access to health care, one provider replied as follows:

I don’t know whether it needs to be school-based. It certainly is a natural place where parents, at least of school-aged kids, go. Either school-based or community-based...(1:10)

...It seems as though [we have families] from every spectrum of the socioeconomic status... I think families need to have services that are easily accessible in their communities. They need to know how to access them. (1:5)

Knowledge of service locations, nonrestrictive eligibility requirements, proximity to the target population, and service locations on public transportation routes as well as hours that can accommodate working parents are critical to promote access.

...You’ll see them come into the emergency room...only because they can’t get an appointment with their doctor, or they don’t have a clinic that they can go to... Or with parents’ working schedules, you know, they’re unable to take the time off of work to take their child in so they end up in the emergency room. (1:6)
...The parents need to know where to take their child during a reasonable hour, because using the emergency room is an absolutely uneconomical way in which to manage illness...(1:7)

Providers’ discussions of access to health care are tempered by realistic appraisals of resource constraints. The issue of whether resources should be expended to provide “wide and shallow” care, in which a large number of patients receive initial treatment; or “deep and narrow” care, in which a smaller number of patients receive more comprehensive care is introduced:

The problem is...accessibility. I have a 300-patient waiting list...you’re almost doing a disservice by seeing a patient sometimes once every six months, because he actually needs several appointments to be in stable condition. And so sometimes you look at it and say, well, the mentality is...okay, if I just do one little thing, that’s going to be...better than nothing at all...(1:14-15)

**Dental Care**
The tremendous need among Orange County’s children for low-cost dental care is being addressed to an extent, but providers agree they are not meeting the demand although some of the existing services are excellent:

...I know there’s a lot of kids out there that need...dental care that aren’t getting it...And also there’s a lot of kids that have...for instance, Medi-Cal coverage, but they just really don’t know a good place to go. There’s a lot...I think there’s a lot of fear, really... (1:4)

**Domestic Violence and Child Abuse and Neglect**
What other issues come to mind when you think about children?

I think about child abuse and the issues of domestic violence and substance abuse and how...that plays a role in children being abused and neglected. And neglect is [viewed holistically]...parents not going to school and attending the child’s Open House, or taking them to their medical appointments or just sitting down with them and spending a little quality time with them.(1:6)

In the discussion of domestic violence and child abuse, providers suggest that social denial remains an obstacle and that progress in this area is difficult to measure.

Well, [with regard to] domestic violence...there’s a big denial factor. You know the couple next door is arguing, but you know, that’s all they’re doing. You don’t know what else is going on and you don’t want to go over and find out.

...How do you define...progress?...but there is more awareness I think that it [abuse] isn’t okay. I mean, the message is certainly out there, you know. You beat your wife, or you hit your kid, it’s not okay. You shouldn’t do that...At least people are talking about...(1:18)

**Teen Pregnancy**
Teen pregnancy was another issue identified by providers that affects the children and teens of Orange County.

A lot of it is a role model. If you grow up in a situation where your mom had you when she was 15, and there are seven kids and everybody was happy, you don’t see it as a problem...When you grow up in that situation, there’s nothing wrong with it. We need to find some other way to educate people to see that there is some alternative lifestyle that you can have, but it doesn’t come easy...(1:7)

Providers commented that teen pregnancy must be addressed from the “top down” with legislation enabling prevention and education, as well as from the “bottom up” with local programs and grass roots efforts.

We have teen pregnancy programs...addressing the issue, you have a child...a girl say who comes through with her first baby and goes through all the classes, and we teach parenting. We teach them how to
balance their checkbook, how to access the system, all the things they need, and a year later; they’re back with their second child. You know what do you do?

...I think that solutions need to come top down and bottom up...we need legislation that assists with the education, with the pregnancy prevention, with all of that...but we also need the grassroots, you know, people who are...with programs and who are willing to help. I mean, it needs to come from both ends.

...These kids...think because you have a baby it’s going to be perfect and everything is going to be hunky-dory, and your boyfriend is going to love you forever. (1:20)

Parenting Education
The need for parent education is one of the most consistently emphasized issues among these health care providers. Modifying parental behavior has more potential to affect children and teenagers in Orange County than any other single intervention. There must be continuity in parental skill development from the prenatal stage through at least the first year of an infant’s life.

It seems like parenting is very important, and I think...a lot of young people are having babies and they don’t know how to be a parent...So [it] seems that there should be some kind of way we could get to the new mothers and fathers in the hospital and when they take the baby home, that they have some parenting instruction or skills, or something of that nature.

There are a few programs out there, but they’re very piecemeal.

...It [education] would come...before the baby is delivered...if we could teach the obstetricians that maybe they’re more responsible than they think...they could distribute [information] to the soon to mothers... (1:11)

Although models for parent education, as it is envisioned here, do exist in Orange County, too few new parents are reached by these programs.

I just think that [programs] should be more available, a broader scope, because there’s still probably 50 to 60 percent of the moms that are delivering in the county that are not getting that information.

...There are...little pockets here and there of organizations and groups. There isn’t a county-wide effort, in other words. (1:13)

The physician and other medical care practitioners participating in this discussion also expressed the need for parent education focusing on their child’s health.

As a physician, I get calls at nights and parents say, ‘my kid won’t eat’ or ‘he’s vomiting’, or ‘he has a fever’, and it takes me about 5 to 10 minutes to pull out any other symptoms that may be available...and it’s very frustrating that these people have not an idea in the world [about] what constitutes a major illness or how...to explain what’s going on with their child... (1:18-19)

The following is one provider’s opinion about family planning:

...You can imagine a family with limited income and they have four or five children...They need to know how many children they can raise and how they can afford it...limit the [number of] children...and the child would be healthy, and the child has enough education, enough care from the parents...(1:6-7)

Subsidized Day Care and After School Programs
The number of programs in Orange County offering subsidized day care does not begin to meet the demand. Likewise, the programs that exist to promote constructive after-school behavior and the facilities that house them are overcrowded.
There’s a few [day care] programs out there, but nearly enough. [One facility] has a …I think they said close to 2000 on their waiting list for childcare.

We have an after school program, and there must be like 30 kids in there…they get assistance with their homework and they are to leave…but…They have nowhere to go, and yet we feel that we can’t push them out because what are they going to do? They’re staying out of trouble there, but there’s only two people for these 30 kids. It’s overwhelming. (1:16-17)

The Issue of Personal Responsibility for Health Care

The lack of personal responsibility is not restricted to any racial/ethnic or income group and it affects everything from care-seeking behavior to compliance with medical regimens.

…Americans spend five times as much on their hair as they do on their teeth…[people will say] I can’t afford insurance. I go, well, every month just stick a $20 bill in a coffee can. When you break your tooth, get out your coffee can. I mean…if you just teach them some simple budgeting…you’re not necessarily going to have fun…but plan things out a little bit, you know…(1:20-21)

The lack of a required copayment or insurance premium does not promote responsibility in terms of keeping appointments or selecting a provider location appropriate to the severity of the health concern.

Cultural Issues

Providing health care and education that is linguistically and culturally appropriate for the target population are challenges that demographic data indicate will increase in the coming years. Specific efforts must continue with Latino/Hispanic and southeast Asian populations.

…In their culture, maybe health care isn’t a priority…when they come to us with needed care, it’s because they are in pain, and it might be so horrendous that they, in turn, end up having more fear to return for follow-up visits…

Oh, preventive care in a lot of societies is not even thought of. (1:4-5)

The belief that seeking assistance to obtain needed health care may lead to deportation is one of the specific fears of some groups:

We’ve got to figure out a way to reach…to reach the parent, who has a cultural barrier…if they ask for help, that means government is going to be involved, government is going to know something about me, and I might be deported, whether that’s a realistic or true fear, but that’s the perception they have. (1:9)

Providers consistently recognized the merit of school-based dental and health care. After one remark about the necessity of campus or district-level health care and mental health services to serve high school students in low income families, the following barrier emerging from the political and social culture of the Orange County electorate was described.

…And they don’t understand the issue that these kids are there [school health clinic] for basic care. You know, they’ve got an earache or they’ve got a cold, or they’re depressed, or whatever it is. It’s a sad situation I think…(1:8)

Gaps in Health Care: Preschool Children and High School Students

Prenatal and immediate postnatal care appear to be moderately successful in Orange County, and the neediest of our elementary aged children get some care in school-based clinics and van visitations. However, health care, particularly immunizations, between infancy and school age is identified as a gap:
I think it’s important to outreach to families who have young children that aren’t in school. That’s often a population that is the most neglected... (1:10)

The consensus among providers appears to be that immunizations are administered to newborns at a high rate of coverage but that follow-ups between infancy and the early school years are extremely problematic.

Adolescents represent another gap in health care. As these providers see it, their parents are frequently occupied with younger siblings, and older children are left to fend for themselves. Providers see such situations as compelling support for school-based health care for children and teens.

At the high school level, Most of them just come to school sick. And after a while they’re hacking and coughing around for three or four weeks and you just say, ‘you’ve got to go to the doctor’. Well, they don’t have insurance. They don’t have the money, and, obviously, the parents aren’t caring at home to listen to this because they couldn’t miss it. We’ve got a school nurse maybe two days a week, and you refer them...I’m not just talking about physical health, but mental health, and all the other problems that go with that age. (1:8)

Child Care and Transportation
Public transportation in Orange County is a major constraint. The location of a clinic at any distance from a major transportation route will diminish attendance significantly, especially among women who must travel with more than 1 child to seek medical care.

...We have families walking [eight miles] with their kids to get to the clinic...

Half a day.

Yeah. They were so beat. And some offices if you’re a little bit late, they won’t see you. You know can you imagine that? You ride on the bus for four hours. They say, hey man, you’re late. (1:11-12)

The notion of a multidisciplinary approach to treatment that did not require transportation to many different locations was promoted in this group.

I think one of the keys...for lack of a better word, a one-stop place where families can come in and access a variety of services so they don’t have to drive all over town...and if it can’t be in one center, then close in proximity so that transportation isn’t an issue... (1:26)

Budgetary Constraints
A measure of frustration is apparent among providers who see so much need and must address it within the constraints of their operating budgets.

...[The article] it talked about demographic and population and how they have projected the year 2020. I thought, boy, how am I going to treat all these kids? That was my first thing, but then...we’re doing the best that we can, given our budget, given our circumstances. You know, we just can’t treat everybody, unfortunately... (1:13-14)

As these providers suggest, fiscal resources are a major issue. The challenge we confront may be defined in 2 ways: working smarter with available resources and seeking additional resources.

Elements of the System of Care for Children and Teenagers That Are Working Well

Providers consistently use adjectives such as “piecemeal,” “patchy,” and “scattered” to describe the available health care resources for children and teens in low income households in Orange County. The tremendous resources represented by faith-based organizations and by businesses in this county are slowly beginning to address these gaps. Collaborative approaches are viewed positively.
...We’re seeing more volunteerism...churches and the faith community are kind of stepping up to the plate...it seems and trying to fill the gap...businesses are...allowing their employees to volunteer, or to participated doing tutoring and things. (1:17)

Two themes are evident in providers’ responses to the “what works?” question: accessible services (school or community-based) and services that approach health care from a noncategorical, holistic perspective. In many cases, the family -- not the individual -- is the basic unit of service. Many providers believe a focus on family involvement is essential to the treatment and maintenance of child health.

I think...some of the problems that we’re involved in are school-based, where there is actually a collaborative...if a child gets referred for services, then there’s a case manager that kind of picks up that case with that family and the child...[and] try to make sure that all the needs of the family and the children are being met as best as they can. And I think that that system works, because it not only addresses the needs of the child, but they look at the family as a whole and try to link them up to whatever services... (1:12-13)

Our challenge is to amplify and disseminate more widely the programs that are working, shifting funds away from inefficient and ineffective models of care.

Key Components of the Ideal System of Care for Children and Teenagers

Parent education and prevention emerge in the forefront as the ideal system of care for children and teens in Orange County. The ideal system of care emphasized prevention far more than current resources in the county permit.

I think it has to start back with educating parent...Or actually start educating the kids that we have in school now because, before too long, they’re going to be the parents. (1:18)

Isn’t prevention the key to all of this?

If we can start...preventing some of these issues from even coming up, then, eventually, we’ll get to the point where we won’t need [as many services]. (1:15)

If providers are correct about the fiscal wisdom of funding prevention and developing a countywide system of care for children and teens, the obstacles to the ideal are decidedly more political than financial.

What I see in our school district...you have the ‘us and them’ mentality, and the...‘but not in my backyard’, you know. It happens over [there] and...so it doesn’t affect me. And until we can get society to see it globally, you know, those other people that vote, and who are the ones who are running for the school board and who are...vocal and who are the ones that are in power and in control. (1:20).

Key Strategic Alliances to Improve the System of Care

Providers have suggested working closely with schools throughout this discussion. In addition, it is important to work with churches as mechanisms to reach particular populations and to efficiently integrate the tremendous resources for child and teen care that are represented by the faith-based community.

I would also say churches. That’s very important...to have a better relationship with the churches whether it’s a school district, a city government...that’s also another place where you’re going to get to the people. I think that’s an important aspect that a lot of people are missing out on. (1:23)

Providers advocate collaborating to develop a countywide effort to move forward based on this discussion. The state goal is to improve the system of health care for children and teens. As in the other provider groups, an interest in the activities and experiences of the other agencies across the county that serve
children is expressed. Other provider groups have advocated the idea of a mini-convention so providers can meet one another face to face and network to develop referrals they have confidence in. These discussants hope momentum developed by the meeting of the minds in this context is not allowed to diminish.
Immigrant Focus Groups

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IMMIGRANT HEALTH SERIES: QUALITATIVE REPORT

This report presents the results of 1 of 2 focus group discussions concentrating on immigrant health issues. The focus group was conducted in Spanish on Saturday, October 24 at Share Our Selves (SOS) in Costa Mesa. It consisted of 9 Latino/Hispanic day laborers recruited in Laguna Beach and Costa Mesa. The men were offered $20 for “no more than 2 hours of easy work.” At both sites, many rushed to the pickup vehicles, extremely anxious to be employed. After 5 men from the Laguna Canyon site and 4 men from the Costa Mesa site were chosen, they were informed of the nature of the discussion. After each individual consented to participate, the 2 groups were driven to SOS. The participants were young men ranging in age from late teens to early 30’s. All from Mexico, they had traveled to the United States from the Mexican states of Puebla, Sonora, Hidalgo, Oaxaca, and Guerrero. They had been in the United States between 1 month and 5 years. Several were married although just 2 reported their wives and children were also residing in the United States.

Health Care Defined

The immigrants viewed health as encompassing their immediate surroundings: a safe environment, adequate housing, and sufficient income to take care of the necessities. When these basic needs are not met, a greater and more immediate hardship is created. Consequently, the issues and topics promoted by public health providers hold little value or meaning. Some of the day laborers talked about poor living conditions. The issue of adequate and safe shelter can trigger intense stressors that might understandably take precedence over less conspicuous health concerns.

“We are five in a one-bedroom apartment... because speaking of healthcare... it’s true that it is very expensive here. Sometimes one needs to get vaccinations and there are many times that there is no work or it slows down. There are times when we just don’t have money for doctors...” (2:6)

Adequate housing in a safe neighborhood was repeatedly given as a response to questions related to health concerns. This basic concern, together with the demands of assimilating into a foreign culture, comprises the most immediate concerns of an immigrant population.

When day laborers discussed the meaning of good health, they emphasized self-care and health as a necessary precondition to work. The theme of self-sufficiency is evident along with the importance of preventive medical care.

“If we are not careful you know, no one is going to take care of us. We have to take care of ourselves. We have to take care of our families...”

“Even if one is poor, so long as there is good health. That is, walks right... touches, sees, hears...”

“To be in good health we have to eat right. Taking care of yourself. A regular check up. For instance, a lot of people could be ill with diabetes and not know that they are diabetic. But if they never get a check up maybe they won’t find out until it’s too late.”

“It’s... not getting involved with women from the street...”

“Good health is... knowing whether you can lift a heavy can or if you need to wear back support. If you don’t have one, then you should ask because you should be able to know before you lift anything if you might get injured. Also, trying to... because good health starts at work because if your mental health fails...” (2:8)

The emphasis upon injury prevention is very important. The day laborers commented that their employers are not concerned with injury prevention. However, being injury-free and healthy is critical in order to sustain economic viability.
Alternative Health Care

The day laborers acknowledged that many immigrants use traditional healing practices. Mostly these practices are used before seeking traditional medical treatment, although sometimes they are used instead of traditional medicine. This group appeared to be wary consumers, and many did not personally use these treatments.

I was watching a program on TV... and I heard that a lady who suffered a back injury went to a curandero for treatment and apparently he left her in worse shape... Why do you suppose this person did this? I think it was because she didn’t have any money and she knew this would be inexpensive... Sometimes what you think will be cheap ends up costing you more. (2:12-13)

Using herbs and masseurs are common traditional healing practices that are tried before resorting to other care. Medical care including chiropractic care is perceived to be extremely expensive and not always effective.

I sprained myself while working and the lady took me to a chiropractor... the guy charged her $500 and he didn’t even heal me... later [I went] to a guy who gave me a massage and he only charged me $5. The chiropractor charged $500... and the massage guy only charged me $5 and he healed me. (2:10-11)

A strong tendency toward self-care, driven by economic necessity, is evident among the young men who participated in the day laborers discussion group.

Yes, if you have a headache you take some Tylenol. If you have an infection you get a penicillin shot. We don’t go to doctors because we already know more or less how to cure ourselves. This is because of money... We just don’t have enough of it. (2:15)

[Oftentimes] we don’t go to the doctor because once you go... if you have something... when they are scheduling you regularly... we don’t have the money so we rather not go. We would rather wait until we can save enough money to go. Right now things are tough and it’s difficult to be earning money and then having to go to the doctor and hand it all to them. (2:11-12)

As the quote below illustrates, initiative and creativity may have to be used in order to obtain the “appropriate” treatment. Unfortunately, antibiotics may be viewed as a panacea, and therefore, used inappropriately.

I got sick... I came here to the clinic and they told me that they did not give [penicillin] shots, that they only gave pills for the infection... I had no choice but to go to the clinic where they deal with venereal diseases. I told them that I had a venereal disease because they treat venereal diseases with penicillin... sure enough they gave me a penicillin shot and I got well again... (2:19)

Disseminating Health Care Information

The day laborers agreed that word of mouth and self-reliance were the 2 most common ways they received health care information.

by observing other people we can determine what is good and what is bad.

I get informed through conversations... in clinics.

But you also have to, have to, use your own criteria of what you are hearing and what you are being informed of. Sometimes there are lies. For example, television tells you a lot of lies... (2:9)
Posters, flyers, and other forms of print media have some value. However, because of literacy issues, only a limited amount of this information penetrates the community. More important, poorly translated materials can cause more harm than good. Such mistakes detract from the credibility of the message. Approaches to disseminating health information must be linguistically as well as culturally appropriate. Word of mouth is powerful in the immigrant community, but the method of disseminating information still must be consistent with the needs and world view of the population being served.

**Barriers to Health Care**

A couple of participants in the day laborers group communicated extreme cynicism about the health care system in the United States. They regard hospitals to be motivated solely by profit and to operate in a manner that maximizes their earnings without regard to the health of their patients:

*But it’s difficult here in California hospitals. If one uses Cal-Optima, its because you don’t have any money...[therefore] the hospital wants to get rid of you as soon as possible...they make us feel like we don’t matter because we are poor... there are times that they don’t heal you so that you come back, so that you return...because every time you return it means more money for them... (2:6-7)*

It may be incorrect to say that Mexicans cross the border in just one direction to obtain health care.

*When diabetes struck him he lost a lot of weight. He then went to Guadalajara to get medicine and see the doctors and then he returned. (2:10)*

In addition to these concerns, the day laborers indicated having to wait long hours to be seen by the doctor at a community clinic discourages them from seeking treatment:

*...they have these humongous waiting times where they have to be seen...those people...can’t...miss a day’s work and not get paid... (2:24)*

*...We had been waiting in line for 3 hours so my daughter could get her shots. I had to walk in and tell the lady that I had been waiting for three hours and I asked her, ‘How hard is it to give a little girl a shot, so I can go back to work. I’m about to lose my job for waiting here so long.’ They had a lot of patients waiting around. I imagine the people that they have there...since they are Hispanics, they don’t complain and they [medical staff] know that they can push them around. (2:20)*

*I’d rather go to work than waste a whole day in the waiting room to be seen by a person who is going to spend five minutes, and he doesn’t even care that I have pain all over my body. (2:11)*

Language is another barrier to receiving health care:

*...When I used to go to doctor they were not able to understand me in Spanish. Then I began to study English so that I could talk to them and so they could understand me a little...I have to put more effort into learning more English.*

*I have always needed an interpreter. (2:20)*

Clearly, a lack of documentation is a barrier to health care coverage.

*For me, those that have documentation don’t have a problem because I wanted to get insurance and they didn’t want to give it to me because I did not have documentation... (2:21)*
IMMIGRANT HEALTH SERIES: PROVIDER QUALITATIVE REPORT

This report presents the results of 1 of 2 focus group discussions concentrating on immigrant health issues. This group was conducted Thursday, October 15 at the offices of the Healthcare Association of Southern California in Santa Ana. The 10 participants included an admitting supervisor from a hospital in Santa Ana, a health educator, several community clinic personnel including a physician and front and back office workers, a representative from a community-based prenatal care program, a health care provider serving farm workers in Orange County, and a public health nurse from the county Health Care Agency.

Defining the Immigrant Population in Orange County

The providers group described the immigrant population in Orange County as very diverse although a large portion of this population is clearly Latino/Hispanic.

...I know in...one of the local elementary schools had something like 26 different...languages that were spoken by children...that arrived at the school with that as their primary language...We have people [that come) from all over for economic reasons...Some of them are here for political reasons. (1:5)

It was noted that many people in Orange County are inclined to associate the term “immigrant” with “illegal.” Even though the immigrant population in Orange County is quite diverse, there is a tendency to think of this population exclusively in terms of the Mexican people.

...for some reason when they [people] say “immigrant,” it brings the word “illegal”...the word “illegal,” brings the word “Mexican...” (1:5)

One participant in the provider group added perspective to the distinction between mainstream residents of the County and more recent arrivals by noting that the term “immigrant” applied equally well at some point to most Americans.

Perspectives on Health

Participants in the provider group articulated the view of health held by Mexican immigrants in the United States:

I believe that in our culture, the Mexican culture, we have a holistic approach to health...God is very real...and...there are some things that are going to happen no matter what you do...there are illnesses that...are maybe punishments because of our behaviors. There’s a lot of cultural...dynamics that come into healthcare with Latinos...preventive care is sometimes not as real to us because it is not available most of the time. (1:6-7)

These providers noted the world view of the target population has great relevance to the design and delivery of health services. If the geographic and sociocultural realities of immigrants are not taken into consideration they may not take advantage of low or no cost services.

We’ll find a lot of the Mexicans tend to be...If it’s God’s will, it’s going to happen. ...in the Asian populations, when we offer them a service, they don’t want to impose... (1:7)

Interventions emerging from the western medical paradigm are often a result of categorical funding that is awarded to motivate to action or to educate a target population about a particular health concern. The presumption that “at-risk” populations will be responsive to such issues is not supported by the experience of these providers, nor by the providers who participated in the cultural issues behavioral health discussion. Both groups of professionals emphasized the necessity of engaging the population to be served in terms of its own concerns and issues. Understanding how immigrant populations view health is essential in order to serve them effectively.
Working with a community you have to be very flexible. They [immigrants] have to be active in the process. ...when we implemented a survey, to them, health was safe streets... less domestic violence. They have the idea of health as an overall wellness type of issue... and always understand that you need to maybe move on to another project... (1:17)

That’s one of the problems we have with some of the funding that comes through for healthcare; it’s to target a specific disease. We’ll give you money to go out and talk to people about tuberculosis [but unless you] come in to do the assessment and find out what they need to talk about and what’s their concern, you’re not going to be effective. You have to go where they are. (1:17-18)

Providers participating in both the cultural issues behavioral health discussion and the immigrant health group emphasized that among immigrants, health is conceptualized as encompassing one’s immediate surroundings: a safe environment, adequate housing, and sufficient income to take care of the necessities. When these basic needs are not met, a greater, more immediate hardship is created. Consequently, the issues and topics promoted by public health providers hold little value or meaning.

Adequate housing in a safe neighborhood was repeatedly given as a response to questions related to health concerns. This basic concern, together with the demands of assimilating into a foreign culture, comprise the most immediate concerns of an immigrant population. Experienced providers recognize this reality and, by acknowledging it and responding to it, they gain the trust and attention of the populations they serve. Failing to recognize this reality usually results in polite tolerance.

When I was afraid to talk about the things that they wanted to hear, I will have two or three women sitting there kind of falling asleep, being polite with me. When I started talking about what they wanted, then I started having a larger and a larger group. And, believe me, they are going to ask about family planning at one point. At one point, they are going to ask you for tuberculosis, STDs. They start asking you because... now they start feeling comfortable with you. (1:16)

Disseminating Health Information

Providers agreed word of mouth was an important mechanism used to disseminate health-related information. This concept converges with the observations reported by providers in the cultural issues behavioral health group. One provider characterized word of mouth in the immigrant community as “faster than AT&T.”

I’ll try my hardest to get them in a little room and talk to them... And it’ll work for you... from just this person, she’ll go tell 20 other girls... And it’s because you get out to them and let them have your trust... (1:12)

The people are so isolated that really what works best is the word of mouth. It’s someone they trust who they’ve established a relationship with who says, I got this service here. (1:15)

Approaches to disseminating health information must be linguistically as well as culturally appropriate. Word of mouth is powerful in the immigrant community, but the method of disseminating information still must be consistent with the needs and world view of the population being served.

We teach them and play games... we have a lottaria that... we teach people... about disease, playing games, where they can... they can bring in their own life experiences into it, and they can talk about situations... that they had a neighbor, that they had a cousin, that this happened. And that’s how we... take the message across, is make it informal and base it on their experiences of health access and healthcare... (1:13)

Even though providers in the cultural issues behavioral health group advocated the use of Vietnamese radio and Spanish television as effective avenues to disseminate public health information, providers in the immigrant health group reported less positive experiences with the media.
The problem that I have with using the media...We have major media campaigns. We have the media there. And the next day you have people complaining about illegal immigration...immigrant programs for health. The media doesn’t support it because the PSAs are shown at what...two in the morning...They’re very expensive... (1:15)

Providers agreed the Catholic parish was a successful collaboration when attempting to reach certain segments of the immigrant population. They emphasized the use of market segmentation to target different segments of the population will yield a higher degree of success rather than taking a general approach. Each segment of the population must be approached in a manner that is consistent with its style and customs rather than conventional mainstream methods.

...[O]ne of the avenues that we’ve used, because we want to target the Mexican population, is the Catholic churches, and... not all Mexicans are Catholic, but the majority are. And there’s trust in their church. So whenever we want to have a health fair, we collaborate with the church...and...it’s not just about, oh, come and get your blood pressure checked, it’s about coming to share some food, to try some recipes. It’s...to share our neighborhood. (1:15)

Deficiencies, Gaps and Barriers to Healthcare in Immigrant Communities

Providers indicated that many immigrants residing in Orange County regard health care to be inaccessible to them. Whereas they may have accessed low cost health care in Mexico by going directly to a hospital, this practice in the United States results in inappropriate use of emergency room care and high fees (relative to what they are used to) charged to the immigrant.

...in my experience, the perception on healthcare is (that it is) inaccessible... It is unaffordable...In my experience, coming from Mexico, if you are sick, you may not work, but you have this social service... You can go there anytime. You go to the emergency room anytime. You don’t get charged. It maybe not be such a perfect system, but at least you have access... (1:10)

Cost is not the only barrier to accessing health care, as explained below by the providers group:

There’s definitely a fear factor there for the immigrants...of being found out... (1:6)

...[I]ndividuals that have tried to become legal residents have been charged with a public charge and asked to pay back. And there are departments that are working that way... (1:8)

In addition to the fear that accepting subsidized health coverage may adversely affect the process of obtaining citizenship, members of the provider group suggest that pride may deter some immigrants from seeking assistance.

There’s stigma with the Welfare. They don’t want to receive it.

It’s a pride thing. (1:8)

Participants in both the cultural issues and immigrant health discussions emphasized that the manner in which immigrants are treated has a lot to do with repeat visits to a provider.

...the patients, they feel the attitude and they can feel the tension, and then they are more reluctant to open up and tell them really what the problem is. And they may go home with the same problem. (1:29)
By no means a concern exclusive to immigrants, basic communication with a physician is regarded to be
critical to patient satisfaction and compliance with a medical regimen. A cultural predisposition to refrain
from questioning members of respected professions complicates this barrier, and the proposed
interventions to educate immigrants about patient rights.

We conducted a patient satisfaction survey, which is a very critical tool to use. And we did it with the focus
of our community outreach workers. And what they said... But what we wanted to evaluate was how they
felt about healthcare and about services. And what they said was that... if they understood the treatment, if
they were told why they did a lab test, okay, and if they took something away from them that day that
could apply to their lives right away... this is a urinary tract infection. This is how it works. This is how you
treat it. This is what is happening to your body. If they went away with all that information, they were
satisfied.

...[Y]ou’ve got maybe a 5 minute with a provider, if you’re lucky... and you cannot build trust with that at
that level. We’re not an assertive community, and it isn’t because we don’t have any self-respect or self-
esteeem. It’s that we don’t question physicians. We don’t question priests. We don’t question teachers.

This is just our culture. And we’re not going to tell a doctor, well, are you sure? I don’t understand what
you said... (1:18)

From the provider perspective, lack of or inadequate transportation is a serious barrier to obtaining health
care among immigrant populations. One provider related a story about opening a new WIC center
approximately 1 mile from the main bus route. Attendance was poor. Poor transportation is complicated
by the necessity of traveling and caring for children, a task not made easier by long wait times and
prohibitions regarding child feeding in clinics. The use of bottles to feed children and mixed messages
regarding breast feeding are particular issues in this regard. Day laborers did not mention transportation
as a specific barrier but young men competing for employment are likely to be far more mobile than
women and families.

...[F]or the patients that we have in our clinic... a lot of times it’s really hard for them to get to the clinic
because of the transportation... they don’t know how to... go on the bus. A lot of times they have to ask... for a
ride... a family member...

...[T]he bus driver is not going wait for you that long. You know, hurry up and get in here. The bus driver
will tell you. You should have folded your stroller outside... I’m sorry. I had to keep the kids in here. I
couldn’t let them run off into the street. And they have that problem. Well, when they make an
appointment, well, are you taking the bus or are you coming in the car? Oh, I’m taking the bus. And I’ll
tell them, well, just grab a little bit more time so you can get here on time [so] we can serve you the way you
want to be served. And they say, oh, you know what, I have three kids. I don’t think I’m going to be able to
make it on the bus. (1:24)

And the rapid transit system that we have here is really semi-slow, at best... it’s... not big enough. It doesn’t
go to the locations that you have to go. You know, our offices are on Main Street. I know our communities
aren’t going to get there by bus... The bus runs like every two hours. (1:25)

Or if mom has children in school, she needs to go meet them or walk them to and from school, so depending
on what age and what time of day they’re getting in and out, she has to schedule her appointments... if
you’re scheduling people in a block because you have a class before they see the doctor, or all the new people
come for an orientation, and you schedule that at eight in the morning, and the bus doesn’t arrive until
8:30, you can count on them all being... you know, a good percentage is going to be a half an hour late. The
other thing we would see frequently is when it rains and the family only has one car, and dad is in a
business that is in construction or the farm where they might be closed on the day of rain, then suddenly
the whole family comes into our clinic. We’ll get real busy on a rainy day, because they suddenly have
transportation and so they’d all come. (1:26)
Providers identified the days and hours of clinic operation as barriers to immigrant health care. To be effective, services must be designed in a manner consistent with the perceived needs of the target population:

...[A]nd we realize that if we really want to serve them, and we want to do quality work, then we need to do it when they can come. And ask them what is it that they want? We...can say what our perception of healthcare is, but if we’re going to serve a community, we should ask the community what their perception of health, of well being is, because it could be totally different than ours. Often we hear, oh, well there’s child abuse, alcoholism, and domestic violence, and it’s time that people should come...they should get prenatal care, and they should come and get a Pap smear. But we tell them what they should do, but...we should ask them what they want to do. What they think is important. And then we really could address...issues. And sometimes we say, well, we’re here to serve the... immigrant, but we’re here to serve the immigrant when the immigrant is working, then they can’t come. (1:10)

Providers have acknowledged they have to be flexible in order to find a comfortable and appropriate way to interface with their target populations. Providers in the immigrant group and in the cultural issues group have emphasized indirect methods such as forming crafts collectives, discussion groups, and exercise classes are far more effective than traditional classroom delivery of health information.

...And when I went to a group of farm workers, I said, what do you want to learn? I mean, I want to teach you about tuberculosis. What do you want to hear about it? In that...particular case, they wanted to know about nutrition. They wanted some aerobic classes. Let me learn about computers. And I thought I’m teaching health. I mean, I want to teach you how to prevent infections and diseases...So finally I have a program that is talking about nutrition, mental health, stress management, depression, exercise...I’m doing everything they’re asking me for...I want to know more about women’s health, menopause. What are the symptoms of that? How do I talk to my husband or my children? So I’m just doing all of these things...right now I have a support group, but it’s arts and crafts. You know, women come together. They were coming once a week, just learning...just teaching each other because I don’t know how to do anything like that. But they are teaching each other. Now they are coming two days a week. And now we have to tell them...I’m sorry, you’ve got to go home now, but they don’t want to.

During that arts and crafts class, are they discussing other issues?

Yeah. They are sitting there...some are knitting, some are sewing. They bring their own stuff. We bring a bunch of stuff, too. We are buying a lot of stuff. We are donating a lot of stuff. And they start talking about the problems that they have with their children, or their husband, or they heard such and such is being beat up by their husband, or this lady wants to become a vegetarian. Have you heard of that? I mean, there are Mexicans that are vegetarians. (2:17)

**Child Health**

The health of children is a priority of among immigrant families. Discussion among day laborers also revealed that issues adults may ignore receive immediate attention when they affect their children.

Does the population you serve do anything differently when their children are sick or injured?

**Absolutely.**

**Number one priority.**

**That’s our priority.**
That’s why they’re here. A lot of people come here for better lives for their children...better opportunities...I think in any culture, children are the priority, but when I talk to fathers and mothers about...when I was working for Latino Health Access, you know, you’re feeling ill. You need to go to the doctor. No. I’m okay. But when it’s...the child has a little fever, this is the emergency of the day. This is my baby. (1:20)

Directions for Improving the System of Health Care for Immigrant Populations

The dual concerns of improving communication among health care providers and their patients and better informing patients of their rights as consumers are primary issues for these providers. Many also see prejudice and poor attitudes toward immigrants among their peers. This is viewed as particularly damaging because one or two difficult experiences have a profound effect on the immigrants seeking health care:

Obviously, we need better training for doctors on communication skills. And... to provide the training to the community about what their rights are as consumers, as patients. ...once individuals know what their rights are and what they can demand, just like parents do with teachers, then at least that gives them that sense of empowerment that they can actually demand better service from the doctors.

Every time they come into our service, instead of asking them, well, what’s your zip code? Do you want Medi-Cal? Do you qualify for Medi-Cal? Maybe we can say, these are your rights. You have the right to be treated with dignity, with respect. You have the right to have all your questions answered. Maybe that should be the introduction to our community clinics or to our private offices, or wherever we are. You have a right. I mean, these are patient rights which are not exclusive to the insured, it’s to everybody. (1:20)

I think that providers have to be told that what they’re doing is illegal. They need to be scared. They need to be sensitive to any person that comes through that door, and put their stereotypes aside, be a professional service provider. They need to be told that if they’re caught or something they’re going to be written up. I really think that’s what is going to make them react. (1:29)

The complexity and fragmentation of the county health care system is regarded as an obstacle that could be diminished by better knowledge about the services that are available, and about better networking and referral processes. Providers in both the immigration and cultural issues groups have emphasized the importance of improving referral networks. A 1-day conference on immigrant healthcare directed at front line providers is greatly needed.

Having worked in the county health system for quite a number of years, one of the problems we have is that it’s very complex and it’s very fragmented. There are clinics for pulmonary disease. There’s a separate clinic for special diseases, and sexually transmitted diseases, a separate clinic for HIV, a separate clinic for family planning, that will only see the woman for family planning, and once she has had her tubes tied or goes through menopause and is no longer a child-bearing woman, she’s not eligible to come in for a regular female exam and a Pap smear and breast exams...There is no adult ambulatory healthcare through the county. We don’t have a county hospital to send everyone to and just say, you’ve got a problem, if you can’t pay for it, go here and go that service. So that’s a problem that we address. I like the idea of talking about teaching providers how to be culturally sensitive, as well as the other thing that we’re trying to do in the Healthcare Agency right now is teach the people, at least in public health, what are the different services, because we don’t know. Who do we refer to and teaching the community how to refer to. And so if someone comes up or calls the wrong clinic, they happen to get a hold of the pulmonary disease clinic, and they’re calling about immunizations for their kid, we don’t hang up and say, I’m sorry. I don’t work in that area, but we know who to refer them to and send them on, and so the people in the community also know which clinics do what and try to integrate our clinics better so that we can maybe do more than one service. We don’t just do immunizations, but we can also do the skin test for TB at the same time. (1:33)

...[I]n this setting, have the opportunity to communicate to these 22 or 26 Orange County-based hospitals. What do you want to tell them about what you need?
I want to tell them...we talk about access to preventive care, which we don’t have. ...there are virtually no services for preventive medicine. Primary care. There is primary care, but it’s...not enough...services. Once the patient is able to get into the primary care, and they are like needs help with something else that needs more care, secondary, a specialty care, they are poor, they are insured, there...there are very few places...I cannot just single out one place, but all of them...that place, the patient may not get what they need. If they are diagnosed with something that they need to have surgery for, you’re out of luck. And patients have been told virtually why don’t you go back to the country or origin to get taken care of. You know, so really a specialty care, I wish the hospitals will do...provide this specialty care. I think if the hospitals would pay more attention to that, we will start working towards and providing a more comprehensive care. That’s one. And another one for the record is the mental health issue.

Depression, anxiety, panic attacks. We don’t have the service, and it’s just amazing that we don’t have that in Orange County. We need a county hospital, because people think UCI is county hospital, it’s not. And they don’t treat the patients right, many times. I had a case...where the patient needed to get an amputation, we’ll get it done because Medi-Cal pays for that because it’s an emergency, but once they cut your leg off, I cannot do follow up because Medi-Cal doesn’t want to pay for it. Come back when you need the other leg amputated. You know, so that’s an urgent. It’s urgent. We need a county hospital or we need a hospital, or all the hospitals, please get together and work something out... (1:34)
Pregnancy Focus Groups

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PREGNANCY AND MATERNAL HEALTH SERIES: QUALITATIVE REPORT

This report presents the results of 4 focus group discussions concentrating on pregnancy and maternal health issues. The first group in the series was conducted on Thursday, September 24 at the Social Services Agency on South Grand Avenue in Santa Ana. Participants included 3 Latina/Hispanic pregnant or postpartum girls participating in a program for teenaged mothers. The second group was conducted in Vietnamese on Thursday, October 1 at the Health Care Agency Clinic in Huntington Beach; it consisted of 6 pregnant Vietnamese women, ranging in age from early 20s through 30s. The third group, conducted in Spanish on Wednesday, October 21, consisted of 13 pregnant or recently postpartum Latina/Hispanics. It was conducted at the MOMS resource center on North Broadway in Santa Ana. The fourth group consisted of participants in a teen mothers program at the Parkside Campus in the Orange Unified School District and was conducted on November 4.

Although this input is from a small sample of women, their responses provide some practical information applicable to women of various ages, races and cultural backgrounds who are pregnant or can become pregnant (planned or not).

Effective Information Distribution

The participants agreed that even though a lot of maternal care information is available, many women have difficulty accessing it. For example, phone numbers for WIC, MOMS, and Medi-Cal could be advertised more frequently through the media.

Such information could be advertised on billboards, distributed at public places, and presented by special speakers at schools. Most important, teenaged girls who may be in denial about their pregnancies need to be reached.

Consistent with information provided by Latino/Hispanic participants in other focus groups, television, especially tele-novelas, is viewed as the most effective medium through which information can be given to the community.

I think through TV. I think the most practical thing is through TV because sometimes we receive documents and publicity in writing but we just throw it away. So I think the best way to do it is through TV. I personally think we should read to inform ourselves, but TV is easier. (1:16)

I think those commercials where they say like, ‘yea, I drank through my pregnancy…’ (2:23)

Consistent with the information provided by other Vietnamese focus group participants, radio is perceived to be an effective in Orange County:

The best is if we have messages on the radio to educate our community… (3:7)

Health care providers need to be willing to deliver information and instructions repeatedly. Repetition was seen as a great need in the Latino/Hispanic community.

Additional Barriers

Many women have to deal with being single, being alone, being new to this country, having financial problems, going through a divorce, or facing other health problems or the illness or death of a friend or family member. Some are struggling with how to inform their parents of their pregnancy. These women need additional support to deal with such problems so they can focus on prenatal health and their baby.

Scared of what parents were going to think. What they were going to do.(4:4)
Well, like if I would have aborted and didn’t tell no one, they weren’t going to find out, but...like my mom knows the doctor. He would tell her. (2:4)

It was hard telling my dad...I thought...because he’s abusive. Well, when he drinks, he’s abusive. ...But it went okay, and now he’s okay with it. (2:5)

...Because when I...I told, um, a friend of her that I was pregnant...because I was scared. And then like next day...because I got really sick, and my mom was like immune about it. And then we told her, and she helped me. And then like...my stepfather throw me out of the house. (2:5)

Service

No matter what issues were discussed, participants agreed they want to be treated as individual human beings with unique points of view, concerns, backgrounds, and experiences. In addition to having good medical care and getting help with specific problems, women want to understand and control their own bodies. They want to have their questions answered and be told what to expect and the reasons for procedures. They want their concerns to be taken seriously and dealt with in such a way they can understand.

...It was my first baby and I had a lot of questions. And all they would say is ‘its OK, everything’s fine’, ‘you’re fine, you’re baby’s fine.’ I also had problems because I had anemia. During the first months it was very hard for me because I didn’t eat, I had a lot of vomiting. I couldn’t sleep... (1:5)

They also want to be treated with consideration and dignity. They do not want to be kept waiting or left alone for long periods of time. They do not want to be ignored nor treated as though they are interruptions.

...When the doctor sent me to be admitted to the hospital they gave me an IV and then just left me there. They didn’t even explain to me why, or how. They did some tests and they didn’t even tell me what happened. I think it might have been due to the language problem because the nurse only spoke English and so I couldn’t understand her. But I was there for about seven hours and no one told me anything about what they were doing to me. (1:15)

...But then I got an ultrasound done at about 4 months, but there was a little mistake on the part of the doctors. When they read the ultrasound results they told me that my baby had a cleft lip. I think mostly I was emotionally shocked. And well, they told me that they could try to give me some counseling... But I don’t think it was so much accepting or not accepting what had naturally occurred, but it was the way that we were given the results, it was done so insensitively... (1:4)

...I asked a lot of questions because this was my first pregnancy. I would even write them down and all they would tell me is, ‘it’s normal, normal, normal’, but they never explained anything. So when I would come in they would be done with me very quickly. They would just say, ‘everything’s OK’, but all my questions would never be answered and that was very difficult for me and I would get frustrated because I was used to a different way... (1:4)

...So I think that if she would have paid attention to me when I told that I wasn’t eating maybe we would have been able to avoid hospitalization. (1:5)

...The only problem was that they would give me an appointment at 9:00 a.m. and they would see me at 1:00 or 2:00 in the afternoon without eating. And if I would get up and say, ’Excuse me, I’ve been waiting for a long time’, they would say, ‘Oh, yeah, keep on waiting’. And if I would ask again they would say, ‘Just wait, and if you don’t like it go to another clinic’, and so I did. I changed doctors. (1:5)
Support Systems

Support systems are critical for pregnant women. Women with strong familial support systems (especially from a significant other) and other resources reported the best outcomes overall.

...My husband is very happy and very helpful to me. (3:2)

Thank God I have had support from all my family and also my husband has been very supportive... (1:6)

For me, my husband is very concerned about the fact that I was pregnant because both of us are older. On this topic of pregnancy, he has more understanding because he reads. He wants to support me and whatever I need he is happy to provide. (3:2)

My husband is very understanding. I had lots of depression during all 9 months of my pregnancy. He was always taking care of me and for me that was very important that he was always there making sure that I was OK. My husband was always there for me. (1:6)

Thank God that I had all the support that I needed. At work, during my first months, my friends would bring me food because I love to eat... At home; my husband was also very supportive. When my baby girl was born, my sister helped me. I had all my family with me. My mom was with me during the last month... (1:7)

Additional Resources

All the women found assistance they valued at community agencies. Even women who had familial support systems and/or used physicians from their particular community used these services. The agencies mentioned were WIC, MOMS, and Teen Mom programs. Community agencies provide critical services such as support and solutions that promote healthy mothers and healthy babies.

The participants agreed they appreciate many of the services that are available and they are willing to take responsibility for obtaining what they need. Yet, women want some services to be replicated (at their hospital, closer to their homes). Teen mothers want improved access to information about the birthing process and they want classes to help them prepare. Women want to be educated about their bodies and what their children need. They want to be good mothers so their children will be safe, happy, healthy, and respectful.

My concept about prenatal care changed because before I used to think that we didn’t need pre-natal care. Other people that were older than me were telling me, ‘how come you have to go to pre-natal care, in Mexico we have healthy babies and we didn’t have prenatal care. And sometimes we have healthier babies without pre-natal care, why do you go?’ And that’s the idea I had but then when I started going I realized all the things that I was missing out on. (1:9)
This report presents the results of a focus group discussion that concentrated on pregnancy and maternal health issues. The group consisted of 9 professionals in the health care industry including a physician, a supervisor with the Orange County Health Care Agency, a county public health nurse, a certified midwife/nurse practitioner, 2 nurse practitioners from clinics, and 4 administrators from various community agencies. All participants are involved in providing services to women, and at least half them work specifically with pregnant women. Most provide services to low income women. The participants discussed their opinions about maternal health, difficulties they have in helping women receive health care, and the changes they would like to see in the system of health care provision.

The depth of knowledge and thoughtfulness of these health care providers and the obvious commitment to their work and clients or patients are noteworthy. Our collective experience is enhanced by their work in Orange County.

**Maternal Care Defined**

What is maternal care? Participants agreed maternal health care for any woman who can become pregnant needs to encompass both prevention and treatment. This care would include birth control, genetic counseling, testing and screening, and fertility counseling.

> ...I think there’s a lot of things that can happen with maternal illnesses, perse, or with congenital defects and anomalies that may affect the outcome, but to get her in for early and consistent prenatal care is going to give her the best possible chance of having a good outcome. There are some things not in control. That’s what I’m saying, that you can’t control, but getting here early and doing the correct amount of tests by the appropriate provider is going to give you the best possible outcome.

Healthcare for women includes educating them about how to take care of their children and themselves before, during, and after pregnancy. Women want to know about nutrition, exercise, and parenting. However, this information needs to take cultural differences into consideration.

Maternal care includes early education and prevention. Because girls are getting pregnant at a younger age, providers emphasized the importance of prepregnancy education and counseling for teen and preteen girls.

> ...And I really wish that there will be enough time and enough money to take family planning classes to the schools. And I’m not talking about high schools. I’m talking about elementary schools, because the number of teen pregnancies between 10 and 14 is astronomical. So I really think that...that planning the pregnancy is very, very important. But I do not think that, at least the patients that I care for even realize that that is a problem. And I feel that that we need to educate the mother of 10 and 14 year olds about family planning before we can even begin with the children, and that has cultural ramifications and religious ramifications and a lot of that. But I did a lot of...I spent a lot of time looking specifically at that group. (1:6)

**Gaps and Deficiencies in the Maternal Care System**

**Access and Coverage**

Maternal care must include answering women’s questions and concerns. Women need to know what possible outcomes they can expect and what treatment they are receiving and why. Sometimes they need to be told repeatedly until they clearly understand.
Many pregnant women have additional problems that affect their pregnancy and prevent them from obtaining maternal care. Therefore, maternal care should be directly linked to other supportive services such as transportation, child care, food, and shelter. Such women may also need help dealing with domestic violence and drug and alcohol addiction.

The support system... We’re looking at, everything that increases her access to care, that can be transportation to get to the doctor or the clinic, and child care, the whole realm of supportive services she’s going to need to follow through with her care. (1:5)

Then she found with the site that she went to for her WIC visit had nothing in English and she thought she was probably the only low income White woman in the South County, so that was kind of a wake up, too, that there are people who are college educated, who, for a period of time, need some help, and none of the educational materials and the videos were in English. (1:12)

Transportation, child care. Those are big blocks. (1:10)

And there are a lot of food banks, but they have to be able to get there. (1:28)

Besides food, there’s the cost of diapers. I mean, there’s... for women in poverty, they may get along as best as they can, but there are still a lot of expensive issues to living in Orange County. I mean, rent is a whole other focus group, but it does impact pregnant women. (1:28)

Living in apartments with too many people and with very poor... with things that are falling apart. We had a client who the floor had fallen through in the bathroom, and the landlord wouldn’t do anything about it. (1:28)

What issues are involved in providing and obtaining maternal care? Many women, dependent upon government assistance, consider having to deal with the bureaucracy a major problem. Eligibility for assistance can be difficult to figure out. Filling out forms is time consuming and confusing. Information provided by people in the same department can vary. Even critical care may have to be delayed until processing is complete. As discussed below, some women especially noncitizens are also confronted with changes in policy and are confused about their immigrant status.

Fear of accessing healthcare for deportation reasons. Sometime they won’t even come in at all until they’re almost ready to deliver or show up in the emergency rooms... (1:7)

They do not want to apply for Medi-Cal, for example, because they have the fear not of the deportation so much, but they have the fear that applying for Medi-Cal is going to jeopardize their legal residence or the future legal residence in this country... (1:7)

They’re told if you use public services, that will negatively impact your application [for citizenship]. (1:8)

Cultural Issues

An issue mentioned by the providers was that of cultural diversity. Latino/Hispanic women have different cultural values and attitudes about pregnancy and maternal care which need to be taken into consideration. Vietnamese women, while accepting new attitudes and information about maternal care, prefer the services offered in their own neighborhoods from Vietnamese providers.

But a lot of [Hispanics] feel like when they start to show or when they feel fetal movement, that’s the time to come into the doctor, so, a lot of times, don’t see them until the second trimester or later. (1:6)

Because many Vietnamese women are refugees and therefore legal residents, they have fewer problems accessing Medi-Cal. For some Latino/Hispanics who are not here legally, they are faced with changes in
laws and policies pertaining to public assistance. Often, they receive contradictory messages about their eligibility.

Providers agree the belief that people who are not here legally should not receive assistance creates a problem.

One of the major differences is that those people are refugees, and they're here legally. (1:31)

And there's doctor in their community. (1:31)

So access to care is not a major issue. (1:31)

Providers suggested a centralized information system is needed. Such a system would make it easier for women to access health care information.

...It seems like there's not a centralized bank of information that they can access, I find that. I try to get them as much information as possible. But sometimes they'll go...you know, or they talk to a Medi-Cal person and then from there they need to go somewhere else. And I think we all try to keep up with what other resources are out there, but sometimes it's really hard to counsel a woman or tell her where...really where to go and what her options are. (1:26)

The participants have a "big picture" perspective about many of the issues. They see a disparity of services, especially with respect to economic status. Poor women have fewer providers to choose from to receive care. Women who have limited insurance coverage because of managed health care face similar problems.

...I hate to say it, but it may be two different kinds of healthcare or...I mean, reality is if you're poor, I think resources may be a little bit different than if you have insurance. (1:13)

Well, that's been one of my concerns. Look at the CPSP Program. I mean, that's really an excellent program in what we're looking...and women who are fee for service or PPO, they don't get that. (1:13)

The patient base of the providers has grown to include women who do not qualify for government assistance, do not have insurance, and do not have the money to obtain the care they need.

Providers are concerned about the lack of coverage by Medi-Cal for medical treatment. They cited examples in which Medi-Cal refused to pay for medical services that, although were not directly related to the pregnancy, were necessary to maintain the health of the patient and her baby. In order for the treatment to be covered, it must be directly related to the pregnancy.

Some physicians do not have set fee schedules and/or are unwilling to specify what they will charge for their services. Other times, what is charged is different from what was originally quoted.

...What we find out a percentage that does not cover everything that is required for prenatal care. And we are saying in one sentence, yes, we want women to come in so they can get all the tests at the right time... And then on the other hand we're saying the Medi-Cal card that we're giving you really does not cover everything... (1:21)

They may be able to get the prenatal component, but not the ancillary things that they need also. (1:23)
Directions for Improving the Delivery of Maternal Care

What changes need to be made and what can be done to achieve them? Providers agreed getting information out to the community through word of mouth and through medical personnel or staff who are members of the communities served is essential.

Providers included the following in their ideal maternal care system: regional health care, choice of providers for clients, access for everyone, continuous care, early education and prevention, elimination of red tape and bureaucracy, and a centralized information system.

...Getting people in the community to be talking about it. ...Your neighbor to be saying, you need to go to the doctor. You’re pregnant. That’s wonderful. Go to the doctor. That’s really what works. You know, all this outside kind of information just doesn’t reach, because it’s not...it doesn’t come from where they take their information. (1:32)

...The mere fact that you have a positive pregnancy test should get you into care, without having to wait around and prove eligibility here and eligibility there, and you know. (1:35)

And so once you get a positive pregnancy test, you find out where they live, and give them a source...resources of where they can go to get their whole prenatal care right from the very beginning, to get started on prenatal vitamins, to be able to get there, to get their child care, to have... (1:36)

Education is crucial. Education encompasses all aspects of health such as nutrition, exercise, pregnancy, delivery, and care for the child. Fathers need to be educated too.

And so it’s looking at parenting classes given to dads by dads, and those kinds of things. And whose doing what. Where are the gaps? Where there needs to be additional services. (1:34)

Provider participants saw value in continuing this conversation with other health care providers who provide other services and/or work with other populations of women.

They also see value in creating coalitions with other service providers, particularly government agencies, to resolve problems and remove barriers.

...Getting all the pieces of the puzzle that the patient is going to access somehow under prenatal care, whether it’s Social Services, Medi-Cal, WIC, the provider, Moms. Like you said, get a more formalised structure together that we’re all committed for the same, um, purpose. (1:40)

One provider has established a coalition with businesses in Orange County to educate them and obtain their assistance. Such a contact can be expanded, perhaps in the form of lobbying and citizen groups, with the goal of advocating for maternal care for all women.
Community Health: Working the Puzzle
Seniors Focus Groups

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SENIOR HEALTH ISSUES: QUALITATIVE REPORT

This report presents the results of 3 focus group discussions concentrating on senior health issues. The first group in the series was conducted Friday, July 31 at the Santa Ana Senior Center. Participants included 7 even seniors: 6 women and 1 man. The second group was conducted Thursday, September 17, and consisted of 9 Vietnamese men and 3 Vietnamese women ranging in age from 65 to 76. This group was conducted at the Asian Health Center in Westminster. The third group, conducted Friday, September 25 at the Costa Mesa Senior Center, consisted of 12 seniors: 10 women and 2 men.

Summary of the Results

This report consolidates the information shared at the focus groups. It is structured in four sections: (1) Health Status, (2) The Healthcare System, to include access and barriers, (3) Staying Healthy, to include exercise, diet, use of alternative therapies, support systems, and mental health issues, and (4) Health Care Messaging. The questions asked were consistent across all 3 groups.

Health Status

The majority in this group of seniors appeared to be active with relatively few physical problems. The members of the Vietnamese focus group identified more physical problems than the other 2 groups. This finding is consistent with the refugee/immigrant experience and may be partly a function of less than adequate health care and exposure to diseases before arriving in the United States.

What are the healthcare issues that you find yourself facing as you age?

Overall, there were very few personal physical problems identified. Of those mentioned, members of the groups appeared to suffer mostly from hypertension and heart disease. Diabetes, high cholesterol, weakness, back pain, dizziness, broken hip, deafness, and poor eyesight were also identified as problems being faced by seniors.

A comment from a member of the Vietnamese focus group illustrates the level of physical problems some seniors are facing:

In Vietnam I was put in the Communist concentration camp for ten years, so my health has deteriorated. After I was released I suffered from a stroke. Then I suffered from hemiplegia. I have just had heart clean out...Now I try to use a cane to walk. Every month I go to the doctor...and have medicine regularly. (2:2)

This example of multiple physical problems was not the norm among the senior focus groups, however. A more common response to the question of health care issues among seniors came from these participants:

I don’t go to the doctor very often. I have little problems with arthritis, here and there, different places. I’ve had to do what the doctor tells me to get some relief. (1:4)

...I have high blood pressure, but I pop three pills a day. Can’t smoke anymore, but, other than that, you know, I’m fine. (1:6)

What was remarkable about the responses received from this question on the health care issues associated with aging was that the seniors’ answers focused relatively little on their individual physical issues with aging. Instead they answered this question by talking about the problems they are facing with the health care system.
The Community Speaks

The Health Care System

Access
Collectively, this group of seniors was very knowledgeable about coverage, insurance, and access to care. One issue that came up frequently in the discussions was the problem of gaining access to physicians. There were concerns about the ability to see specialists, the time involved in getting appointments, and the frequent changes in health care providers.

For Medi-Cal, we have to join a health group. If we want to go to specialists, we have to go through primary care physicians. Very complicated and troublesome. Before the time I joined CalOPTIMA, I could go straight to my heart doctor... (2:5)

...We have a primary care physician, but he’s in a...new group, and he doesn’t really know the other doctors. And if you want a specialist, he just kind of picks a name off the list until he gets to know these people... (3:8)

...our insurance has changed five times in the last 14 months, actually, three times since April. This is because my husband has the insurance through the...school district. And every time they can find a cheaper plan, they change it. Nobody knows what is going on. You can’t get answers...The rules are all new. Now they’ve joined a new medical group. Nobody can get lists of the doctors from them because it’s not organized yet. And everything is changing too fast that I think most of the people that work for these groups have just given up because they know that in a couple of months it’s going to change again. And, of course, every time, we get less insurance. (3:30)

I have been going to the same doctor for 42 years, and he is retired now. I have to use another one...I find that they are not the caring people that I have had before. And when I try to tell them something, they do not listen to their patients like they should. And I say to them, ‘I’ve been in this body for many, many, many years. No, that doesn’t work with me, I need something else.’ And he’ll say, ‘Well, I’m going to give this to you.’ And then he’s right out the door... (1:4)

...My doctor told me one day, I thought I would fall over dead when she said, ‘I can’t bother with you so much. I have to see 30 patients every day. I have them lined up out there waiting for me...’ (3:52)

Not all of the comments were negative. Several of the seniors had positive things to say about the healthcare system.

I have to say something good about HMOs. I’ve had HealthNet ever since I’ve been over 65. And I’ve had a hernia operation and I’ve had a complete heart work-up, and it is not costing me anything. And I am reasonably happy with it. If I need to see a doctor, I call the primary physician, and he schedules me for an appointment, usually within a few days. And if he wants me to go see a specialist...I usually get there in a week or so.

It [the healthcare system] works for me, because I really don’t have a chronic thing, and I don’t take any medication... (3:49)

Barriers

There were several barriers identified by seniors with regard to obtaining health care in Orange County. Specifically, they discussed the high cost of care and the lack of transportation as the two major barriers.

Do you have any problems receiving healthcare?

The financial issues centered on the cost of insurance, long-term care, in-home care, and medications.
Insurance. The expense of coverage...The expense of the medications...

...A lot of people put their health aside because they cannot afford it, and that’s is so sad... (3:9)

...long term care insurance is very expensive, and HMOs don’t cover it. (3:10)

For people who do not have income, even $5 is a problem. Then where is the money to buy medicines? Is there any way to help them with sample medicines? (2:15)

...Five dollars for medical check up, OK. Then where is the money for 100 capsules of medicines for the prescription? (2:15)

Transportation was another key issue faced by seniors in Orange County.

I have to ride two buses just to go see my doctor...

...I go by Access bus, and you go when they tell you to, and you come back when they tell you to. Sometimes, you may wait an hour. Sometimes, you might be lucky enough to wait just 10, 15, 20 minutes. (1:10)

The Vietnamese senior focus group spoke about using the 911 system as a way to obtain needed transportation.

...They [children] have to work. Difficult for old people. We have to rely on self-sufficiency. At night then just call 911. Shout to them! ... Very fast. They tell us to open door. There are paramedics, there is a doctor. Everything. Medicare pays for 911. For people who do not have Medicare, it is miserable. They have to pay $500... (2:7-9)

**Staying Healthy**

The seniors participating in these focus groups were, for the most part, active and involved in their communities. They knew the benefits of exercising, eating well, and being involved with activities that interest them. When probed about their active lifestyles and others, who aren’t as motivated, these seniors identified the many opportunities available for those who aren’t as active. They knew of many support groups for seniors who might need help. Groups sent mailings and had visitation programs for those who might not know about these programs.

What do you do to maintain a quality life style?

Keep busy, stay interested...And I think if we have a good feeling about ourselves, we will feel better physically. (3:19)

While this group got out of their homes and interacted with others, they did note that there are seniors who don’t do anything and never got out.

This group of seniors indicated exercise was important to them. Walking was the exercise of choice for those who exercised.

I go to the gym every day. My doctor told me I had to, and I do...I rode my bicycle over here. (3:20)

I take a walk for one hour every day and go to the fitness center for one hour every day. (2:10)

This group also knew the benefit of a good diet. They did acknowledge, however, that it was sometimes difficult to get nutritious meals.

[I] abstain from eating fat, because am afraid of heart blocking... (2:11)

...a good diet is very expensive. You cannot survive on food stamps and be healthy. It’s totally impossible ...
...they can’t eat healthy. It’s too expensive. The difference between a loaf of bread that’s white and a loaf of bread that’s wheat, is 2 times as expensive. Fresh fruit is very expensive. Fresh vegetables are very expensive (3:14).

These seniors were very accepting of alternative therapies. They advocated for prevention, used vitamins, acupressure and acupuncture.

But one of my main gripes with healthcare in general is that we are not treated as entire bodies. You’re treated by symptom. They never take care of your entire body (3:37).

Let’s talk about the support systems that you have, and whether these systems are adequate?

The availability of support systems is important to maintaining a quality life. The seniors received support from a combination of family and friends. These seniors also relied on their social interaction and community programs for support.

...My biggest support group is my daughter and son-in-law, my neighbors, my friends, and my church. (3:39)

...After my husband died, I started...coming down here [the senior center) to get out of the house and be with people. (1:20)

The issue of depression, loneliness, and mental illness came up in the focus groups. The participants had very little personal experience with these issues. A few knew of someone who suffered from depression and several knew of support systems available to deal with loneliness and depression.

I find one of my friends is like that [depressed). He came here from Vietnam... Life here is different from that in Vietnam and he became nervous. Now he has entered a mental institution and he doesn’t remember anyone. Just after a few years. He has his children and grandchildren, but no one can help him. He is still living but he is no longer aware of anything. (2:14)

...I know this one lady...she was bad depressed after her husband died. And so she went over to [the] Senior Center...and they brought her out of it and she’s very happy...But at the time she needed to talk to somebody. (1:24)

Members in two of the focus groups mentioned the practice that some seniors have of sharing medications. Clearly, this is an alarming practice that requires some additional investigation.

...You go to visit your friend and they said ‘Oh, you know, the doctor gave me this medicine for my arthritis and it’s just done wonders.’ And the other person will say, ‘Oh, what is it?’ She’ll say, ‘Here, try mine.’ And they have found that a lot of seniors share their medications. Oh, try this, try that. (3:22)

Effective Information Distribution

The members of these groups were the recipients of various forms of healthcare messaging. They saw ads on television for different health care plans, they received literature in the mail, they were the recipients of telemarketing that solicited their business for insurance coverage and HMOs, and they heard advertisements and health-related topics on the radio. The health-related materials on topics that related to their personal experience were perceived as being helpful. However, the advertising was not as well received, and much of it was perceived as being negative in tone.
What kind of messages do you receive regarding health care?

I often listen to [Vietnamese] radio. [They say] many interesting things about diseases to keep us up to date. Those programs are very interesting. I often tape them to practice. (2:12-13)

They [the HMO] send a magazine out...

...education and programs. If you will go to them, you will get educated. You can ask all the questions you want. (3:34-35)

Well, I am sick of reading about doctors, illness. I mean, I’ve got the message and I’m sure most of us have (1:17).

The messages through the phone and the flyers, yeah, that’s a turnoff. We get a lot of them here that come and talk about different insurances. (1:19)
FRAIL ELDERLY SERVICE PROVIDERS: QUALITATIVE REPORT

The frail elderly provider group was conducted at the offices of the Coalition of Community Clinics, in Tustin.

Summary of the Results

This far-reaching discussion among 10 influential service providers concerned with the frail elderly in Orange County began by defining and functionally categorizing the elderly population. Next, the group identified the issues facing the elderly. The group concluded by offering suggestions for the ideal system of care for the elderly.

This report is structured to reflect the flow of this enlightening discussion. The first section consists of definitions and categories of elder care. The second section focuses on the issues faced by the elderly with subheadings of the identified issues. The third and final section is devoted to designing the ideal system of care for the elderly.

Definitions and Categories of Care

First, it was important to determine how the population of seniors is categorized. Most of us tend to categorize seniors in very simple terms: lumping anyone over age 65 into 1 group or, at best, dividing the group into active seniors, ambulatory seniors, and nonambulatory seniors. For some providers, it is appropriate to divide their clients between the “homebound” and the “community-based.” (1:5)

As the general population changes, likewise our definitions, especially in health care, need to be more refined. The elderly are not an homogeneous group.

…the 60 and 80 and 100 year olds are not going to want the same kinds of services. (1:4)

…I think we need to start looking at…putting more money in the pot for the really old. (1:3)

Functionality, which is defined in terms of activities of daily living, is more accurate and useful than age to describe the senior population. According to these discussants, more providers, insurance companies, and government agencies are using some variant of this method.

This system supports assessing individual seniors and identifying the specific needs they have. The providers gave some explanation regarding the use of activities of daily living (ADLs).

There’s a list of ADLs that are standard ADLs by categories, that might cover 10 to 12 different functions.” (1:6)

Each person being assessed is rated with regard to ability or functionality in each of the physical functions which include activities such as ambulating or dressing.

Are they able to do it independently? Do they need assistance? Do they need full assistance? (1:6)

Then, the functionality in each ADL is analyzed as a whole.

…how many areas do they need assistance in? (1:6)

Another form of assessment is used called IADL’s (instrumental activities of daily living) for those diagnosed as cognitively impaired or to identify people who may be starting to experience some cognitive impairment.
...[They] may need assistance with some of the IADLs ...They maybe can get dressed...[but] not dressed as appropriately or as cleanly as they did 10 years ago... If you use strict ADLs, you’re going to miss a lot of the early_earlier stage dementia population, who_have needs and are at risk in various ways in the community.” (1:6)

IADLs address activities in which seniors could put themselves and/or someone else in danger. Some of the examples cited:

‘Can you write checks?’ ‘Can you manage your money?’ ‘Leave the stove on?’ Endangering. Things to do with danger... [M]edication confusion is one of the biggest problems with this group. (1:7)

Another distinction, made later during the discussion, is based on the distinction between morbidity or disease and the aging process itself.

...Define when an old person is sick and needs healthcare, and when an old person needs care for being old.” (1:12)

For the purpose of these participants, senior capability is categorized by functionality and instrumental ability as related to accomplishing the activities of daily living. For the most part, the senior issues discussed in this focus group relate to those seniors with a decreased or diminished level of functional and instrumental ability to carry out ADLs, hence the designation “frail elderly.”

**Issues Facing the Elderly in Orange County**

Seven specific issues were identified by this group. These include the need for personalized services, isolation, transportation, the decision to seek help, cultural/ethnic barriers, the need for specialists, and end-of-life issues.

**Personalized Services – One size doesn’t fit all**

These providers see important distinctions that need to be made when designing, organizing, implementing, and offering health care services to seniors. People differ in what they need and want, in part because of their particular preferences, culture, and backgrounds. Additionally, individuals’ needs and wants vary as they grow older. The need for programs for seniors is growing rapidly.

...some of the programming seems to not fit people of different educational or class backgrounds either...they...don’t fit in because that’s more a homespun group and they’re the fancier groups. So, as you see in the retirement housing community, there are different settings for people of different economic and/or...it’s not always economic. It’s their comfort level. (1:5)

That provider also said,

...We have this category of the aged of being over 65, and there’s a vast difference between the 65 and the 95...the one size fits all of the HMOs, etc., bugs me... (1:3)

...she [a doctor] was talking about...that, in the near future, there will be three generations of older people and that nothing in society has prepared us for this. (1:4)
The needs and wants of 80-year-old people 30 years from now are likely to be different from what 80-year-old people need and want today. Remember, what it means to be 50, 60, or 70 today is very different from what it meant only 20 years ago. Ongoing medical and technical advances are likely to help people to stay healthy and vital even longer.

**Isolation**

Isolation can be a critical problem for seniors. They may be afraid or unable to venture out into the community because of some disability. Isolation contributes to a deficit-amplifying cycle, as strengths not used devolve into weaknesses. Isolation can also lead to depression which contributes to further debility.

> What we’re finding is that people do not want to leave their homes...No matter what...No matter how bad things get. How isolated they might get...They do not want to leave their home. (1:8)

> ...in terms of fear, that once you leave your home, you’re on your way to dying. (1:9)

> depression is what evolves out of this isolation and inability to socialize. And then depression itself is a major factor in terms of medical problems and physical illness, and can bring the death knell in essence for these other conditions becoming more complex...it’s a problem that most people seek out their primary care physician [to treat]. (1:17)

Isolation means that seniors don’t get the health care they need and service providers have no way of knowing about them.

> the physician will write an order to have the...a Medicare agency come in to help with medications or various things, and the person is shutting them out...happens is it gets refused enough times that they go away. That doesn’t mean the need goes away... (1:10)

Another reason for isolation is lack of transportation:

> She was still able to attend the Senior center, but lived alone, was in her late 70s, and she said, ‘I don’t know how much longer’...because she had to...transfer to two buses to get her groceries. (1:13)

**Transportation**

Health care providers usually don’t have the personnel, financial resources, and equipment to take their services to consumers. Many seniors, who are no longer able to drive must rely on public transportation, which presents a variety of difficulties.

Public transportation is not available in all areas. Services in one area are not always coordinated with those in another area. The transportation may not be easily accessible to people using wheelchairs or walkers, those who walk slowly, and others who need special consideration. There may be interruptions in the services provided. The transportation schedule may not coincide with the user’s needs. Some forms of public transportation, such as taxi service, can be quite expensive.

> I think that if you want to talk about improving the healthcare of Seniors in this county, you have to put dollars in organized transportation to get them to healthcare sources, period. (1:16)

> It’s threatening...I know many of our people...if they call early enough they can get an appointment for a ride to the doctor, and coordinate it with their appointment, but there’s no assurance that they’ll get home. (1:10)

> Or they’ll have to wait so long to get home...And they’re tired. You know, after tests and everything else, they’re exhausted. (1:10)

> It’s [Dial-a-Ride] limited. It’s very patchy...and it’s now being targeted for... chemotherapy, dialysis, cardiovascular...exams, so they’re targeting the...most critical, you know, needs at risk. (1:17)
While seniors living in special developments or retirement homes may have transportation provided, such arrangements are not without disadvantages.

...She needed to get on the handicapped bus and they already had 20 people scheduled for this week, and the next thing was the 25th, and they were irate... (1:29)

Yeah, we need an integrated system. We need buses with hydraulic lifts. We need assistants on the bus to help people on and off, and we need flexible scheduling because it isn’t easy for Seniors to call up and make a date. (1:30)

And we don’t need punitive rules that...if they miss once or miss twice or if they get sick, you can’t use it next time. (1:30)

Providers agreed that transportation is needed not only for medical purposes.

But just for errands. If people can’t get to the market...they’re not going to eat as well, if they don’t go to pick up their prescriptions...I mean, it can snowball really quickly into a medical crisis... (1:17)

The Decision to Seek Help
It is a big step for a person to decide they need help to care for themselves.

...It’s kind of that threshold of acknowledging that you’re at the point where you’re not independent. And whether it’s because you’re going to move or because you say, yes, to having a homemaker companion...That’s a big step. (1:10)

...It’s not always a financial barrier, it’s sometimes that acknowledgment of their own aging, like a first step toward death...You know, hold out, hold out to be independent, even when there’s really no independence going on. (1:11)

Whether for financial reasons, lack of options, or because of preference, the number of seniors who stay at home is increasing.

...They [The International Year of the Older Persons Conference] said we’re not building more nursing homes in not only this country but around the world. The interesting phenomena is that assisted living, of course, is becoming the catchall for these individuals. (1:11)

...92% of the people are still living in their homes. (1:11).

...if you have to move out of your own home into a different kind of setting, you not only are giving up your home and your independence, but you’re giving up a feeling of...of a quality of life and environment. (1:47)

You also lose your neighbors. (1:48).

While there are distinct advantages to home care versus institutional care (hospital, convalescent center, assisted living center), there are challenges to be resolved. The first is who the care giver will be.

...Here, we tend to look more toward the government, other individuals outside. They’ll be taken care of by this, or that alternative. And so it’s a whole different mentality. (1:26)

Well, the children may not be nearby, working an hour away, and the demands on them are such that...they cannot...fill that gap. (1:26)

We find, many times, that the older people don’t want the children to even know that they’re not doing well. They’d rather depend on outside people and other people. They’re kind of protective of their kids. (1:26)
They’re still being cared for by a spouse or indirectly by someone from the family or neighborhood. (1:11)

Another challenge is the lack of financial coverage for home care providers and assisted living, which becomes even more complicated depending on the rules governing financial assistance such as SSI.

...there really isn’t any family policy that supports...the caregiver, to speak of. Pennsylvania and California are really the only two states that have put public dollars into supporting caregivers. (1:12)

...They [insurance] give more benefit to a nursing home placement than an adult day care center or home care, or even assisted living placements...It can force people into the highest level of care, when they may not really need it, but economically, it’s the only way they can do it. (1:12)

Family caregivers not only receive little if any financial compensation now, but may not have any resources in the future either.

...younger adults may be with a husband with a head injury...They’re trying to provide care at home. They’re...not using MediCal and the nursing home, meanwhile all the time they’re out of the workforce, they’re increasing their likelihood of being stricken themselves with major health issues... (1:46)

Health care and other supportive service providers are challenged to deliver these services in the home.

So how do we deliver healthcare to these people in the home that is consistent, reliable...How can they set up some kind of a delivery system that would work? (1:9)

Providing support services to caregivers is equally important.

...While the spouse is providing that care, we know that the caregivers become very depressed. We know that depression increases health problems and that care givers ignore their own health, so you really have two people going downhill, not being able to access the kind of supports they need... (1:10)

Cultural/Ethnic Differences and Barriers

These focus group participants have comparatively little experience or knowledge about health care for seniors in various cultural and ethnic groups, and they are highly cognizant of the need for better information in this area. It is often assumed that ethnic seniors are getting assistance from their families and within their communities.

I don’t think we know anything about what’s going on in ethnic groups. They’re not at all integrated in any of the services that are available. (1:14)

...they’re not as quick to access health screening opportunities, either...when hospitals do advertise these health screenings and opportunities to go and get free inoculations or whatever, it’s a high, high percentage of Caucasians that go... (1:14)

According to one provider, that is not always the case.

...we opened two senior centers for our services, and that was the Korean and the Vietnamese...we always thought that they were so family oriented that you could get the families to help. But, they would say to the nurses, my children are all working, and my grandchildren are in school. And we couldn’t even get a ride to a provider for the medical care...they didn’t have any outreach in their...centers and they wouldn’t drive each other...they said it’s a fallacy that the families are all taking [care] of their own. (1:15-16)
Linguistic and cultural competencies are also required to do research, and are not abundantly available.

But see administration still does not get it. Because no matter how culturally sensitive you are to that population, if you don’t speak the language, you can’t do a program. (1:16)

...[We don’t know] whether or not we’re meeting the needs [of the different cultures]... if we’re trying to... do assessments, you have to have people who are translators or who can speak the language, and that’s becoming very difficult. (1:15)

Some providers see indications of demand for services among cultural and ethnic groups.

...We did start a Vietnamese caregiver support group and a stroke support group... But just from our little mail list of 50 monolingual Vietnamese families... almost all of the families that are on that mail list, there are multiple impairments within that home, and the caregiver is stressed... (1:14)

...If we offer a resource program on in-home support services or on accessing healthcare, they come in big numbers. (1:15)

Need for Specialists
As the population of seniors grows in number, the need for geriatric specialists becomes more critical. Additionally, seniors need specialists in mental health, nutrition, and other practices who can apply their expertise to geriatrics.

The first part of the problem is that physicians may not know what they don’t know.

Many general practitioners, either internal medicine or family practice, don’t realize how ignorant they are about... geriatric patients. (1:18)

They don’t understand that there has never been in the past the large number of people who are old, and that there is so much information on how to treat the illnesses of old and the changes that the body goes through as it ages. And they assume that because they graduated from medical school in 1951 or 1965, they have some sense of what goes on with the bodies of older people. (1:19)

From one provider’s perspective, the problem is being ignored -- with critical consequences.

...And hospitals don’t pay any attention. They ignore the fact that geriatrics is a special kind of primary care, just as pediatrics is, and just as gynecology is... And they end up killing our people... Hospitals and physicians who treat older people, with no knowledge of the fact that they don’t know an older man from an older woman. Have no idea how to treat a person whose cardiovascular system has drastically changed, and medicate them improperly. (1:19)

When it comes to medical care, the elderly need to be treated differently and deferentially. Expertise in geriatrics is needed, especially in critical specialties such as psychiatry. According to the providers, that is not happening.

There’s only 8,000 certified geriatricians in the entire United States. (1:19)

Substance abuse is not restricted to youth.

...Because of depressed elders, an increase in the amount of suicides, especially among men. And we don’t think about the fact that some of those suicides may be medication driven, and not necessarily a man growing up, growing old and his ego getting out of whack just because he’s growing old. (1:22)

It is hoped that more physicians will take advantage of the opportunities to expand their knowledge and more hospitals will start demanding that their physicians do so.
**End-of-Life Issues**

End-of-life issues, as discussed in this group, include “dying with dignity” (1:41) and opting for no heroic measures: choosing how, when, and under what circumstances to want to die so that ultimately some element of control is maintained until death.

End-of-life issues have been a controversial topic for a long time. Religious, medical, legal, ethical, humanistic, personal, and cultural factors influence individual and social decision making. The outcomes of legal cases have varied greatly. In the minds of many, the patient doesn’t always win.

> A good friend of mine, recently, lost a friend of hers that she was kind of the caretaker for. And this person knew he was going to die, and he didn’t want to live. And she had a big fight [with]...the hospital and one of the best convalescent places, and they still have to come up with life saving stuff. (1:41)

> Hospitals are fearful because they have been sued so many times by surviving family members or someone, you know, that surfaces, so that’s why it’s...they’re not necessarily, uh, observing [patient wishes]. (1:42)

Some providers see patients who are successful in having what they want.

> I feel that there has been progress made considerably in that area...I’ve seen cases where an older [person] who wanted to do everything [to survive]. And there was a lot of kind of informal, getting her to sign things at the time she was maybe a little less alert, etc., to move in the other direction... (1:42)

Another distinct disadvantage arises when arrangements have not been made and discussed with family members early on.

> ...[O]ften times, there’s no communication between the family members when they come. I mean, the family member that has the durable power of attorney says this is what was decided and the siblings say, no. (1:42)

**Designing the Ideal System for Seniors**

If you were charged with designing the ideal system of care provision for the elderly, what would it look like?

Numerous and varied responses to that question emerged. They addressed funding, essential attributes of the ideal system, housing integrated with a broad range of medical care, and the need for leadership dedicated to ensuring that seniors in Orange County are well cared for.

**Funding**

As discussed earlier with regard to home care, current funding from public and private insurance coverage limits alternatives for elder care. Profound improvements in the system might result from altering policy at this level.

> I think we need to change the entire funding network. I mean, the funding system...and the laws today, are pushing people past 80 into nursing homes without any viable alternative. Because even the spousal impoverishment bill...only will pay or allow an individual to separate their assets if they are permanently placed in a nursing home...So we need to look at how we can expand the spousal impoverishment to include once they enter a long-term care network...It may just simply be the first step or the first stage where they may need to be case managed, and we have a determination that they need to be on like Meals on Wheels, for instance. (1:23)
Essential Characteristics of an Ideal System

Models that have been proven to work in particular circumstances are worthy of attention. While noting the differences between countries and even cities within California which impact the structures of various systems, these references served to help providers describe their ideal system.

I think...we’ve spent time in Italy and worked with some geriatricians there... It’s so complicated that...I look at sort of the Italian model, where even people...I mean, there’s very little mobility in that society, generally. I mean, in sense of people are...uh, they go to college, they become professionals, and they may live in the same neighborhood as their parents, and they’ve lived there for generations, and so have all their friends...The upshot is that there’s a lot more integration at the neighborhood level that has nothing really to do with healthcare, but when people become frail, the shop is three doors down, the shopkeeper they’ve known forever are maybe more inclined to bring something over... (1:25)

...A strong sense of community, and that’s why it’s been so successful. (1:25)

But it has a residential facility associated. (1:25)

It has a nursing facility. It has an adult daycare center and an adult day healthcare center. (1:26)

They also compared the ideal with what they see now.

See, here, we tend to tuck seniors away out of sight somewhere. (1:26)

Other elements of the ideal system include the following:

I think it’s got to be family focused, functional impairment focused, rather than discrete ages and economic statuses, certainly culturally. (1:27)

...Set up a safe haven for seniors found wandering and for seniors who, you know, like mercy bookings, where the police have somewhere to take seniors... (1:32)

Comprehensive... Not just looking at long-term care for the medical component. (1:27)

I think knowledge about what’s available. And I find that people don’t even bother to know what’s available until they have a crisis. (1:28)

Housing

In addition to improving transportation, housing is becoming a critical need, which needs to be coordinated with medical services for the elderly.

...where are people going to find affordable housing. ...people can’t find it now. (1:28)

...Let’s say they are willing to go, to even a HUD or a certificate, dwelling, you can’t get them. You’re on the waiting list for five or seven years. It’s not accessible. And housing certainly is going to impact health if you are not living in a place that’s appropriate or safe, or, you know. It’s going to impact the healthcare system. (1:28)

...all of the regulations that were probably very well intended at a different point in history, when we didn’t have these problems. And I think the thing that frustrates me is no one seems to be willing to look at (how) times have changed... (1:28-29)

Also under consideration is housing for the elderly – not necessarily like the Leisure World developments but accessible to service providers.
I was listening to two states... they have taken a very strong posture that they’re building homes closer to the medical system, closer to the medical buildings, and are encouraging them to come and live there off the farms, because there’s absolutely no way you can bring the services to them on the farm... (1:31)

...Even though people want to age in place, to some extent, there are only so many... so much individualized service you can bring to people’s homes... without it being extraordinarily expensive... (1:32)

A Broad Range of Medical Care For All Who Need It

In addition to increasing the number of experts in geriatrics, there are certain medical services that are limited, if not missing entirely.

One of the things that I think that the hospitals have to realize that HMOs don’t care about because HMOs are run by people who don’t even know anything about medicine... They don’t think of a 92-year old as being worth doing preventive healthcare, because they figure, why prevent anything, next week they’ll be dead. Well, maybe not. (1:40-41)

...Healthcare for aging is removed from the hospital... So you have a larger number of very poor people, or people who have been poor before, with limited resources for healthcare, and most of the healthcare is removed from the hospital setting. And there are very few and no coordinated... nationally coordinated services or organizations... to maintain the healthcare needs of older people... (1:11)

But there are others who get no care at all.

Leadership

Who needs to be involved in the effort to improve senior options in Orange County?

...I was just reading, in Seattle, there’s a big meeting going on up there, where the City, in conjunction with four or five major corporations, is going to build a lot more affordable housing... And it’s coming about through kind of a coalition of effort between, the City and these, four or five major companies that have a lot at stake, because they don’t even have workers that can find places to live... (1:35-36)

I think we need all the hospitals’ CEOs to sit down with this group and let them know these concerns. (1:37)

And maybe some other CEOs from... the business community. And we need to start a dialogue. (1:37-38)

And the HMOs. (1:38).

Politicians and the business community may be slow to mobilize to improve elder care.

...We sent this out to all the politicians. We sent it out to some corporations. We sent it out to many foundations, and we’ve gotten some interest back, and I’m hoping that we’ll get more, but, the response we got from the Board of Supervisors, was, oh, ‘we’re already doing this.’ (1:40)

Education regarding the issues and advocacy for Seniors needs to increase. Attitudes about aging and the aged need to change if improvements are going to be made in services provided to the elderly.

...There’s a stigma around getting old. And even older adults feel it... (1:38).
There is a great deal of work to be done to prepare for the wave of senior citizens to come. These professionals recognize their collective expertise. The ideas are here. A political and economic will to implement them is needed.

I think another way to look at it, though, is what’s keeping us from doing it? You know, we’ve got good plans here. We’re talking about a lot of good issues, got a lot of good ideas. (1:38).

So I think the professionals are going to have to take the lead. (1:38)

Professional who? (1:38)

We’re sitting here. All of us are sitting here. (1:38)