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Center for Disability
Issues and the
Health Professions

The Experiences and Perspectives of Medi-Cal Consumers with Disabilities

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*Alternative formats available upon request
(braille, large print, disk, audio cassettes)*

The Experiences and Perspectives of Medi-Cal Consumers with Disabilities

Why study the experiences and perspectives of Medi-Cal consumers with disabilities

We believe there is an opportunity to improve health care delivery and health outcomes for people with disabilities. What better place to start than by asking people with disabilities about their experiences with Medi-Cal?

How this study was conducted

IEHP, Inland Empire Health Plan, is a not-for-profit health plan providing care to over 9,500 people with disabilities enrolled in Medi-Cal. In December 2003 IEHP asked the Center for Disability Issues and the Health Professions (CDIHP) at Western University of Health Sciences to conduct a series of phone surveys and focus groups to look at the experiences of Medi-Cal consumers with disabilities.

CDHIP worked with local Community Based Organizations (CBOs) to conduct 200 phone surveys with individuals who use community services. The results provided information from a range of individuals with disabilities – physical, hearing, vision, developmental, and psychological – as well as people with chronic conditions.

After the telephone surveys were complete, 53 individuals with various disabilities were asked to participate in a series of 6 focus groups held throughout San Bernardino and Riverside Counties, to further discuss the issues that were identified as limiting access to health care services.



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Findings

Lack of information on options

Most of the phone survey respondents (62%) did not know they could choose how they received Medi-Cal benefits – through Medi-Cal Fee-For-Service or Medi-Cal Managed Care. This finding echoes similar CDIHP findings conducted across other larger geographic areas.

When phone survey participants were asked about their perceptions of the Medi-Cal Fee-For-Service and Medi-Cal Managed Care systems, 45% did not know or were not sure if there was a difference in the "ease-of-use" between health care systems. For example, 65% of respondents did not know, or were not sure, in which delivery system it would be easier to obtain durable medical equipment (DME). In addition, 67% did not know if they could obtain materials in alternative formats (braille, large print, disks, audiocassettes).

Focus group participants stated two concerns regarding choosing the most suitable delivery system:

1. Individuals would lose coverage if they switched

"One of the things that would make me resistant to changing plans would be the fear of having a period of time during which I would not be medically covered."

~ focus group participant

2. Individuals would lose their current doctor

The fear associated with loss of a provider relationship may be linked to perceived difficulty in finding providers who accept Medi-Cal coverage.

"Why couldn't Social Security or Medicare, Medi-Cal, [Fee-For-Service] have their own directories [like Managed Care] available for their clients? I've had to call around, sorry, we don't take Medi-Cal, sorry, we don't take Medicare. And it gets very inconvenient and frustrating to just try to find somebody who takes it."

~ focus group participant

Assistance with care coordination

Focus group participants expressed the need for help coordinating their care:

"The biggest problem that I have ever had is the continuity of care, which is having doctors that are communicating and ...even though they are communicating there is a lot of cross wires." ~ focus group participant

Focus group participants stated that care coordination was a service not available in Fee-For-Service Medi-Cal:

"I have Straight [Fee-For-Service] Medi-Cal and nobody helps me find any doctor, specialist, dentist, physical therapist, etc. I would appreciate [healthcare coordination] from the bottom of my heart."

~ focus group participant

Ninety-seven percent of the participants did not know that care coordination was available through Medi-Cal Managed Care. One person, who knew of this service, was a member of a Medi-Cal Managed Care Plan and was happy with the service.

When participants were asked how care coordination could assist them, responses included finding specialists and community resources, coordinating communication with their doctor, and assistance with getting prescriptions.

Regarding mental health

"I have Medi-Cal and I would love to have a health care manager to provide me with specialists, getting prescriptions and to use our local community resources where support groups are concerned." ~ focus group participant

Those who reported that they would not use a service to assist with care coordination feared that they would lose control over their health care:

"I do my own health care management. So I think I would not want to allow someone else to take that over...I have to know about everything that is happening to me and make those decisions. " ~ focus group participant

Written materials in alternative formats

Many participants expressed frustration with the printed information received from their health care providers. They had difficulty understanding the language used in these documents. Some people needed the information converted to braille, large print, disks and audio cassettes.

When phone survey participants were specifically asked how they would like to receive information on Medi-Cal benefits, 42% wanted information in an alternative format (large print, audio, braille, or through e-mail or a website). Of those 50% preferred materials in large print.

Available quality transportation

Many focus group participants had a need for transportation to get to medical appointments. When asked:

Do you think lack of transportation keeps you from going to necessary doctors' appointments? All of the respondents indicated that it did. One participant enrolled in managed care shared a positive experience:

"I had an appointment and I didn't know how I was going to get there. I didn't have no transportation and no money. So I said that I was going to call IEHP and I picked up the phone and I called IEHP and that is when they told me that I have service and transportation to and from the specialist." ~ focus group participant

Eighty nine percent of the participants did not know that transportation was available through their Managed Care plan. Participants also had concerns regarding the reliability and the quality of the transportation services. Many were concerned about whether the transportation service would be on time, safe and trustworthy.

Office accessibility

Sixty five percent of phone survey respondents reported that it was important to be told how accessible their doctor's office was before their visit and that this information needs to be accurate.

"...I barely fit in the exam rooms that they have and as for accessible medical tables ... most of the time they don't even check me because they can't get me on the table." ~ focus group participant

Quality and availability of sign language interpreters

The primary concern of participants who use sign language interpreters was the quality of interpretation services available. Often they reported not using the service that was available because of fear, or experience, of poor quality of care due to the inability to communicate effectively through these interpreters.

"I would rather go with [a health plan] that provided the interpreting services. I would rather choose the doctor's office that has the interpreting services already provided but they need to make sure that they understand the consumer's needs." ~ focus group participant

Availability of preventative programs

Many participants were unaware of existing preventative programs. Ninety-four percent of participants said they would use preventative health programs and classes. Participants were concerned with barriers that would limit their ability to participate in these classes such as accessing information in alternative formats, the availability of transportation, and interpreter services.

Availability of durable medical equipment (DME)

Some participants explained that in order to ensure good quality equipment, they would often purchase the DME themselves. In extreme cases, the otherwise independent individuals were confined to their beds or homes without the necessary equipment. Participants stated that they had to stay close to home, or close to a repair service, in case their equipment broke. Many participants indicated that lack of durable medical equipment and repair, and the availability of loaner equipment keeps them from living in the community and significantly impacts their quality of life.

Conclusions

The results of the phone surveys and focus groups underscore a need for informing individuals with disabilities enrolled in Medi-Cal of the options and differences between the Fee-For-Service and Managed Care delivery system. This information is critical to making an informed choice.

Disability-specific community based organizations can provide an important service by providing information about health care options. When people understand the differences between Medi-Cal Fee-For-Service and Managed Care systems, they can choose the system of care that best meets their needs.

About CDIHP

The Center for Disability Issues and the Health Professions (CDIHP) at Western University of Health Sciences (www.cdihp.org) focuses on:

- Improving the capabilities of health care providers to meet the needs of people with disabilities by integrating disability content into the curriculum at pre- and post-graduate levels of provider training.
- Increasing the number of qualified individuals with disabilities who pursue careers in the health professions through development and implementation of a recruitment program and university support services.

- Supporting people with disabilities in becoming more vocal and active participants in their health care.
- Conducting and disseminating research on community-based health education, prevention, and health care services for people with disabilities.

CDIHP and IEHP's Partnership

Over the last four years, CDIHP has worked with IEHP to improve the health care delivery system for individuals with disabilities. CDIHP has assisted IEHP with reviewing access policies and procedures, and advising on the creation of new services:

- **Specialized provider office audit for access features** which includes evaluation of parking lot, building access, office environment, and availability of adjustable exam tables. Information is listed by Primary Care Doctor in IEHP's provider directory.
- **Opportunities to work with disability community organizations** to develop services such as listing bus routes in the provider directory, producing member materials in braille and audio, providing quality sign language interpretation, and delivering disability-specific wellness services.
- **Community Resource Guide:** lists more than 200 organizations and supportive services for IEHP Members, including those with disabilities. Topics include housing, personal assistant services, caregivers, counseling, training classes (orientation and mobility skills), independent living skills, and braille transcription.
- **Wheelchair-fitting clinic:** an assessment clinic to ensure that all IEHP Members who use wheelchairs receive high quality equipment as well as a consistent standard of care. Professionals knowledgeable about positioning and the latest wheelchair equipment will do the evaluations.

Thank You!

IEHP and the Center for Disability Issues and the Health Profession (CDIHP) would like to thank the following community organizations for helping to make this community survey possible.

Ability First

Blindness Support Services

Circle of Hope Shelter

Center on Deafness Inland Empire

Community Access Center

Easter Seals, Inland Empire

Foothill Aids Project

Inland Aids Project

Rolling Start

**For more information, or if you have thoughts regarding health care
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