

California Community Choices: Public Input Survey Findings Strategic Planning Phase

California Community Choices is a Real Choice Systems Change Transformation grant sponsored by the federal Centers for Medicare and Medicaid Services. The initiative, awarded to California in September 2006 and administered by the California Health and Human Services Agency (CHSSA), is dedicated to building California's long-term care infrastructure. Specifically, the project seeks to increase consumer access to home and community-based services and provide persons with disabilities and older adults greater choice and independence in the selection of long-term supports through the following three goal areas:

- Establish one-stop resource centers in two county/regions to provide a coordinated system of information and access for any person seeking long-term care services and supports;
- Develop a website in the two county/regions hosting the one-stop resource centers to provide up-to-date information on home and community-based long-term care services and supports; and
- Complete a comprehensive study to improve the State's understanding of the financial and structural barriers to increasing access to home and community-based services.

To inform and guide development of the project, a 15-member Advisory Committee comprised of consumers, advocates and providers representing persons with disabilities and older adults was established to advise CHHSA on development of the project and to monitor project activities. To complement the ongoing work of the Advisory Committee, the project recognized the need for public input at various points throughout the project period. The following survey items were developed to solicit public input on key issues associated with the initiative during the formative strategic planning phase of the project:

Survey Items

- What are the best ways for you to obtain information, referrals, and assistance about community services and programs that would assist you or a loved one to remain at home or in the community?
- Please describe any difficulties you or a loved one has experienced with obtaining information, referrals, and assistance about community services or programs for persons with long-term care needs who wish to remain at home or in the community.
- If you are an Internet user, what information would you want on an Internet site devoted to home and community-based long-term care services and programs?
- For individuals who do not have access to the Internet, what non-computer resources should be made available to provide information, referrals, and assistance with home and

community-based long-term care services and programs? For example, phone-based information system, in-person support, etc.

- Are you familiar with Medi-Cal?* If yes, please answer the following:
 - How could the Medi-Cal benefit be improved to financially support and increase access to home and community-based long-term care services and programs?

*Medi-Cal: is California’s version of the Medicaid program – a federal and state health insurance program designed to provide access to health services for persons below a certain income level (Centers for Medicare & Medicaid Services, 2004).

The survey was posted on the project’s website: www.communitychoices.info and was provided to participants attending several in-person public meetings. The following are key findings from the survey:

Respondent Characteristics

Approximately 25 people responded to the survey items during the in-person public meetings, held in both southern and northern California; 156 responded to the online survey; one responded by fax. Before answering the survey items, respondents were asked to indicate which categories, from a list of categories, best described them. Respondents were asked to list no more than two categories. Below is the list of categories: reported percentages are based on both the number of responses per reported item and the number of completed surveys.¹

Category	Percent Response
Older Adult	23%
Person with a Disability	19%
Family Member	21%
Service/Program Provider	38%
Advocate	30%
University/Academic Organization	5%
State Government	6%
Local Government	10%
Other	15%

¹ Although respondents were asked to identify up to two characteristics which best described them, some chose to report more. We have included all responses in this set of percentages.

Respondents were also asked to report their affiliations – no limits were given to the number of affiliations. Below is the list of affiliations. As with respondent characteristics, reported percentages are based on both the number of responses per reported item and the number of completed surveys.

Affiliation	Percent Response
AARP	27%
Adult Day Care/Adult Day Health Care	12%
Aging and Disability Resource Center	4%
Aging Services of California	6%
American Society of Aging	10%
Area Agency on Aging	19%
Association of California Caregiver Resource Centers	3%
Assisted Living/Residential Care Facility	3%
California Assisted Living Association	1%
California Association for Adult Day Services	3%
California Association for Health Services at Home	2%
California Association of Public Authorities	2%
California Commission on Aging	2%
California Foundation for Independent Living Centers	6%
California Hospital Association	3%
California Medical Association	1%
California Nurses Association	1%
Californians for Disability Rights	10%
Foundation	7%
Gray Panthers	1%
Home Health Provider	9%
Hospital	9%
IHSS Consumer	10%
IHSS Worker/Provider	6%
Independent Living Center	10%
MSSP/Linkages	5%
Nursing Facility	2%
Older Women’s League	2%
Protection and Advocacy, Inc.	6%
Regional Center	7%
Senior Center	13%
State Independent Living Council	6%
State Rehabilitation Council	2%
Employees Union	2%
Other	29%

Survey Responses

Each item yielded an array of responses; hence, a summary of the most frequently cited responses, with sample narrative comments, is listed with each item.

1. What are the best ways for you to obtain information, referrals, and assistance about community services and programs that would assist you or a loved one to remain at home or in the community?

Respondents indicated that the best ways to obtain information would be through the following: the Internet; phone system (Info Lines); doctor's office and medical facilities; an ongoing campaign of community outreach and community education (speakers, workshops, seminars); printed materials in large print (newspapers, brochures, booklets, flyers); Senior Centers; television Public Service Announcements; and Ombudsmen. While participants elucidated these mechanisms for enhancing current opportunities to obtain information, referrals, and assistance about community services and programs, they also noted that Internet sites must be fully accessible (W3C and Section 508); phone and in-person assistance centers must have time to assist folk; and, interpreters must be available to assist those who speak languages other than English. Some examples of comments include:

"Publications in large print, internet, newspaper articles, senior organization newsletters"

"In order of highest priority: online (web); telephone (real person, not recordings); booklets; and seminars/workshops with a variety of speakers."

"Need competent interpreters in various cultures..... Spanish, Chinese, Japanese etc."

"The Hmong community is afraid. No telephones, we need a place. Person-to-person contact is important."

2. Please describe any difficulties you or a loved one has experienced with obtaining information, referrals, and assistance about community services or programs for persons with long-term care needs who wish to remain at home or in the community.

The mostly commonly identified difficulties were: discharge from acute hospitals to home without adequate preparation or benefit carryover (e.g., some patients lose their In-Home Support Services (IHSS) workers while hospitalized for an extended acute stay and consequently are discharged home without appropriate care supports); lack of accurate and complete resource information; Internet website links that lead to inaccessible resource sites and inaccurate or out-of-date information; delays in service delivery; poor service coordination; phone mazes that leave consumers frustrated and without concrete information or assistance; language and cultural barriers; inadequate information about financial and insurance options to cover home and community-based services; and institutional bias. Some examples of comments include:

“Doctors pressure families to send the family member to a facility; hospital professionals’ pressure families to send the family member or self to a facility; rehab professionals pressure person to go to a facility; and discharge planners discharge patients without necessary adaptive mobility equipment...”

“We have to have accurate information. Information is critical to not only clients, but family members and care givers.”

“It’s the usual litany: unhelpful, rushed, discourteous civil employees; constant referral to other parties and telephone numbers; guaranteed follow-ups within certain time periods that never occur; having to start over ... too much talk information, too little print information; too much assumption that computers are universally used; too much patronizing of persons in need.”

3. If you are an Internet user, what information would you want on an Internet site devoted to home and community-based long-term care services and programs?

Respondents identified the following elements and standards that should be integrated into an Internet site devoted to home and community-based long-term care services and programs: a broad-based list of resources (housing, transportation, meals, adult day health, residential facilities, etc.); cost of programs (including information about whether the program accepts Medi-Cal, etc.); program eligibility; description of services provided; geographic location of program; hours; and transportation to and from program. Other comments focused on providing consumers with a list of intuitive questions to assist them in identifying their need for services; providing educational information on various health and long-term care topics; links to resources and benefits to help pay for home and community-based services; information specifically for adult children assisting older parents; and a quality rating system (with consumer feedback options) for each resource. Some examples of comments include:

“A broad range of resources that go beyond services for the aging or developmentally disabled. It would be great if they are geographically and categorically searchable on the website.”

“In addition to resources, educational information on a wide range of continuum of care topics could be very valuable.”

“I would like some kind of quality rating for the programs, such as a report card.”

4. For individuals who do not have access to the Internet, what non-computer resources should be made available to provide information, referrals, and assistance with home and community-based long-term care services and programs? For example, phone-based information system, in-person support, etc.

To complement Internet information systems, respondents expressed strong support for complete and accurate printed information (county or city resource guides, booklets, flyers, etc.); effective phone support systems (not “dead-end” phone trees) including emergency or “hot-lines”; in-person supports via resource centers in hospitals, clinics, adult day health

programs and other health sites, senior centers, Independent Living Centers (ILCs), Area Agencies on Aging (AAAs); yellow pages that are well-organized and easy to navigate; radio and TV announcements; and non-mainstream avenues for information dissemination such as grocery stores, pharmacies, banks, utility companies, fire stations, etc. Some examples of comments include:

“In-person support or telephone person-to-person support [NOT push a button, persons already ill cannot deal with frustration or memory issues]; books of information at senior centers, libraries, ILCs, fire stations.”

“Brochures, flyers, public service announcements on radio and TV.”

“Information centers, possibly run by local community senior service agencies which are familiar with resources.”

5. Are you familiar with Medi-Cal?* If yes, please answer the following:

a. How could the Medi-Cal benefit be improved to financially support and increase access to home and community-based long-term care services and programs?

Respondents indicated that Medi-Cal should be used for the following purposes: to cover an increased number of physician, dentist, and clinic services; to expand the IHSS program to include incomes under \$1500.00 a month; to remove institutional bias so that more funds go to personal assistance services than to nursing homes; to expand the nursing home waiver program; to provide respite for caregivers; to redirect funds to prevention and healthy living activities; to serve a larger range of people who are not at poverty level but cannot afford in home services; to cover Board and Care Homes; and finally, Medi-Cal should be restructured completely to put in practice the Money Follows the Person principle. Some examples of comments include:

“After years and years and demonstrations, pilots, special studies, etc., we still have come no further than we were 25 year ago. Medi-Cal needs to be incentivized to pay for home care and not nursing home care, to pay for preventive nursing visits rather than more costly emergency room admissions to the hospital. Why is something that appears on the surface so simple, so difficult to understand and implement.”

“The Medi-Cal program should be modified so that the money follows the person. In this way an individual in a nursing home whose condition has improved would have the funds available to pay for community-based services when they return home.”

“Increase the income and asset limits so that more lower income people can qualify for the in-home care; and state and federal funds should pay for Board and Care homes for people on Medical.”

Discussion

Several ongoing themes emerged from the California Community Choices Survey findings: (1) accessibility; (2) diverse and effective information dissemination; (3) comprehensive assistance and service delivery; and (4) Medi-Cal flexibility with increased options for financing home and community-based services.

Increasing and enhancing accessibility proved to be a widely reported priority. Accessibility was broadly defined and included the following: compliance with W3C and Section 508 of the Rehab Act of 1998; linguistically and culturally appropriate services and information; and, non-computer based information complements such as in-person assistance in community settings which are sensitive and responsive to diverse needs, phone support, and printed material.

Diverse and effective information dissemination referenced the need for supplying far-reaching and accurate information through established channels (ILCs, AAAs, Internet, Senior Centers) as well as non-mainstream avenues (banks, pharmacies, grocery stores, etc.). Regarding addressing difficulties obtaining home and community-based service information, respondents strongly supported **connected and coordinated service systems** able to provide consumers with greater independence and choice in the selection of long-term care supports, and assistance with transitions from one care setting to another. Last, in response to the question of how could the Medi-Cal benefit be improved to financially support and increase access to home and community-based long-term care services and programs, respondents overwhelmingly recommended that the **Medi-Cal benefit be flexibly constructed** with increased options for covering home and community-based services. As noted, many respondents suggested that Medi-Cal wholly embrace the Money Follows the Person principle.

The survey yielded thoughtful, creative, and diverse responses. Although only the most common responses were cited in this summary, all survey responses have been reviewed and will be considered fully in the further development and implementation of the California Community Choices project.