

California
Statewide
Independent Living
Needs Assessment

2003-2004

Prepared by:
Susan Stoddard
Joan Ripple

InfoUse
2560 Ninth Street, Suite 216
Berkeley, CA 94710
510-549-6520

March 10, 2005

Prepared for:
California
State Independent Living Council (SILC)
and the
Department of Rehabilitation
Sacramento, California
Contract #ILC02-03-011

Acknowledgements

InfoUse Project Team

Joan M. Ripple, Project Manager
Susan Stoddard, Ph.D., FAICP, Principal Investigator
Lita Jans, Ph.D.
Lewis E. Kraus, MPH, MCP
Nick Despota
Jeff Pflueger
Alice Wong
Kirsten Zellmer

InfoUse extends special thanks to Christina Mills, Chair, State Independent Living Council (SILC); Michael C. Collins, Executive Director of the SILC; Catherine Campisi, Director, Department of Rehabilitation (DOR); Benjamin Harville, Chief, Independent Living Section, DOR; and members of the SILC.

InfoUse extends appreciation for those individuals and organizations involved in reaching out to diverse groups of Californians with disabilities, especially our focus group partner Independent Living Centers and other collaborating community organizations. We also thank the Californians with disabilities who participated in the hearings, forums, interviews and focus groups, or who responded to the web-based survey and provided the information summarized in these pages.

Executive Summary

This Statewide Independent Living Needs Assessment provides the California State Independent Living Council (SILC) and the Department of Rehabilitation (DOR) with information about the concerns and hopes of people with disabilities in California. The 1999 U.S. Supreme Court decision in the *Olmstead* case reaffirms the right of people to live in the community where appropriate. To exercise that right, a person with a disability faces many challenges, despite the existence of a complex network of laws, regulations, services, and providers designed to support independent living. This updated Independent Living Needs Assessment provides another important tool for policymakers to use when trying to implement the Supreme Court's 1999 decision in the *Olmstead* case in California. That tool is the voice of the people with disabilities who live in our communities now and who have expressed their concerns in this study. Needs Study participants have contributed many ideas and experiences regarding the challenges of living independently in California in 2004.

Successful community living for people with disabilities requires accessible infrastructure, as well as a combination of public and private benefits, services and resources. Since the early 1970s, Independent Living Centers (ILCs) have addressed barriers to community living, and have provided information, advocacy, and services to help individuals achieve independent living goals. California's ILCs have expanded in numbers and in scope of services in the past three decades. During that same period, the enactment of the Americans with Disabilities Act (ADA, Public Law 101-336) has defined the civil rights of people with disabilities nationwide. While the ADA has offered many broad protections of rights to access facilities and services, it is important to remember that, in the area of disability, California law provides protections independent of those in the ADA. Although the federal act provides a floor of protection, this state's law has always, even prior to passage of the federal act, afforded additional or even greater levels of protections. Despite such efforts and protections, there is still work to be done to assure a place in the community for people with disabilities.

The Needs Assessment study utilized several methods to directly involve people with disabilities, especially those who are unserved or underserved, in the needs assessment process. During 2003 and 2004 the study team conducted focus groups, a survey, phone interviews with key informants, hearings, forums and meetings. The final report includes detailed findings based on participant input in each of these processes as well as major themes that were identified by participants throughout the study:

- **Health care** from disability-aware health professionals, including Medi-Cal providers
- **Health insurance**, including provision for personal assistance services
- Accessible, affordable, safe **housing** located close to available transportation and services

- Help in understanding and supporting **disability rights and disability awareness**
- Accessible, available, reliable **transportation**
- **Emergency services** for medical emergencies and disasters
- Help in obtaining **assistive technology** and accessible **information technology**
- **Access to information and resources:** finding the resources needed to live in the community and securing financial and economic support
- **Employment** matching personal skills and interests
- **Isolation, self-esteem and the need for peers**, including recreation and social programs and choice of integrated programs or special programs with peers
- **Enforcing existing regulations** appropriately
- **Reaching out** beyond the traditional ILC community
- Serving **new immigrant communities** with new issues

This Statewide Independent Living Needs Assessment provides the SILC with information on the basic independent living needs of people with disabilities, the barriers to independence and the gaps in services and supports in California. This study provides information to assist the SILC in fulfilling its mission “to promote appropriate policies, programs and activities that maximize options for independence for Californians with disabilities” and ultimately to reach the SILC’s vision of a society where persons with disabilities have the choice to live without barriers and to participate fully in all aspects of the community.

Table of Contents

Acknowledgements	1
Executive Summary	2
California SILC Statewide Independent Living Needs Assessment 2003-2004: Introduction	5
Methodology	6
Major Themes	7
Chapter 1: Focus Groups	17
Participating ILCs and Areas of Focus	17
Characteristics of Participants	18
Focus Group Process	18
Findings: Frequency of Concerns	20
Findings: Detailed Focus Group Comments	23
Chapter 2: Independent Living Needs Survey	30
Characteristics of Survey Respondents	30
Process	31
Findings	31
Summary of Survey Comments	41
Chapter 3: Key Informant Interviews	48
Interviews	48
Interview Process	49
Findings	49
Chapter 4: Hearings, Forums and Meetings	64
San Rafael - Marin Independence Forum April 30, 2003	65
Oakland Hearing - May 1, 2003	68
Woodland Hills Hearing - May 5, 2003	71
Sacramento Public Forum: Issues of Concern to People who are Blind or Visually Impaired - February 25, 2004	73
Los Angeles and Riverside Forums on Deafness - April 1 and April 9, 2004	74
Conclusion	79
Appendix A: Californians with Disability: 2003 American Community Survey	80
Appendix B: Outreach by Community Organizations	83

California SILC Statewide Independent Living Needs Assessment 2003-2004: Introduction

This Statewide Independent Living Needs Assessment provides the California State Independent Living Council (SILC) and the Department of Rehabilitation (DOR) with information about the concerns and hopes of people with disabilities in California. The 1999 U.S. Supreme Court decision in the *Olmstead* case reaffirms the right of people to live in the community where appropriate. To exercise that right, a person with a disability faces many challenges, despite the existence of a complex network of laws, regulations, services, and providers designed to support independent living. This updated Independent Living Needs Assessment provides another important tool for policymakers in California to use when trying to implement the Supreme Court's 1999 decision in the *Olmstead* case. That tool is the voice of the people with disabilities who live in our communities now and who have expressed their concerns in this study. Needs Study participants have contributed many ideas and experiences regarding the challenges of living independently in California in 2004.

Successful community living for people with disabilities requires accessible infrastructure, as well as public and private benefits, services and resources. Since the early 1970s, Independent Living Centers (ILCs) have addressed barriers to community living, and have provided information, advocacy, and services to help individuals achieve independent living goals. California's ILCs have expanded in numbers and in scope of services in the past three decades. During that same period, the enactment of the Americans with Disabilities Act (ADA, Public Law 101-336) has defined the civil rights of people with disabilities nationwide. While the ADA has offered many broad protections of rights to access facilities and services, it is important to remember that, in the area of disability, California law provides protections independent of those in the ADA. Although the federal act provides a floor of protection, this state's law has always, even prior to passage of the federal act, afforded additional or even greater levels of protections. Despite such efforts, there is still work to be done to assure a place in the community for people with disabilities.

This Needs Assessment study utilized several methods to directly involve people with disabilities, especially those who are unserved or underserved, in the needs assessment process. During 2003 and 2004 the study team conducted focus groups, a survey, phone interviews with key informants, hearings, forums and meetings. This Introduction provides an overview, identifying the major themes that emerged in the study. More detail on study methods and results is available in subsequent chapters on the focus groups, surveys, hearings and forums, and key informant interviews. The Appendix includes tables with estimates from the American Community Survey and a list of community organizations that assisted in outreach for the focus groups.

Methodology

The InfoUse study team used several methods to draw on existing information and to provide extensive opportunity for input from the community. Methods included focus groups, a survey, key informant interviews, public hearings and forums. By providing varied ways for the public to participate in the needs assessment, we encouraged participation throughout the state.

Statistics on disability in California

The American Community Survey (ACS), conducted by the US Census, provides statistical estimates of population that are used as the basis for planning and funding decisions for many Federal programs as well as used for state and local planning and decisionmaking. Since 2000, the Census and the ACS provide, for the first time, statistical estimates of some measures of disability that can be used at the state and local level. Many of the other national surveys of disability do not support state, County, and local estimating. California statewide estimates from the ACS 2003 show that approximately four million people in California age 5 and over (12.9%) have a disability, and 2.4% report difficulty in self-care activities (dressing, bathing or getting around inside the home). Seventeen percent of people reporting a disability describe family income as at or below poverty level, compared to 12% of people without disabilities. For those reporting a self-care disability, almost 20% of families are in poverty.

In California, almost 20% of people with disabilities live alone, compared to 8% of people without disabilities.

Over 70% of people without disabilities in California report being employed, while for people with disabilities, 36% were employed. Only 14% of people reporting self-care disabilities were employed.

Over 80% of those in California with self-care disabilities are not in the labor force, compared to 20% for those without disabilities and 57% for those reporting any disability. (Appendix A)

Focus groups

In this study we used county-level statistical information from the 2000 Census and the subsequent ACS to identify candidate locations for the focus groups, and worked with Independent Living Centers (ILCs) to assure that diversity was represented. Over 85 community service organizations collaborated with our partner ILCs to help reach out to people who do not usually work with the Centers. In the focus groups, 130 people with a range of disabilities participated, from young students to people over 75. About one third were white, one quarter were Hispanic, one fifth were Asian, and African Americans and Native Americans were each about one tenth of the total respondents. Members of five Native American tribes and several Asian communities (Chinese, Korean, Hmong) took part. Over 10% of the focus group

participants had never used Independent Living Center services, and the focus group meetings themselves resulted in new service linkages for several people. The focus groups were lively and informative, and participants and participating ILCs benefited from the meetings.

Focus group discussions were recorded and analyzed; we used qualitative methods to code individual comments into categories, and to relate comments to participant characteristics. Summary tables for the report show the degree to which different concerns were expressed, by focus group meeting, by gender, and by whether the individual had previously used an ILC. (Chapter 1)

Survey

Throughout the study period, we posted a needs survey on the Internet, inviting people to answer questions on the Web or to order a paper and pencil, fax or email version of the survey. Over 450 people responded to the survey during the study period, over half of them via the Web but about 25% by mail and 20% by email. About a third of the people who filled out the survey also wrote comments – some of them very detailed – about their observations, issues, and frustrations. Tables showing descriptive statistics on survey respondents, and respondent concerns, are included in the report. (Chapter 2)

Interviews

Key informant interviews provided an opportunity to address issues that may not have been covered in hearings, focus groups or forums. InfoUse developed a list of key informants. SILC staff then reviewed the list and made additional recommendations. (Chapter 3)

Hearings and forums

Our hearings and forums invited the community in to talk to the SILC and the research team about their needs and concerns regarding independent living. Some of these meetings were targeted for specific groups: people who are blind and visually impaired, people who are Deaf and hard of hearing, and people with developmental disabilities. (Chapter 4) Other meetings were cross-disability. In each meeting, people were invited to share their experiences about barriers and successes.

Major Themes

Detailed information on the findings from these data collection activities is presented in Chapters 1-4 of this report. This introductory chapter includes results from all the methods. We have identified a number of major themes that emerged throughout the study and relate to community capacity to support independent living. In this section we introduce these themes and include illustrative issues and comments.

More detailed comments from each of the study components are then available in the methods chapters that follow.

- **Health care** from disability-aware health professionals, including Medi-Cal providers
- **Health insurance**, including provision for personal assistance services
- Accessible, affordable, safe **housing** located close to available transportation and services
- Help in understanding and supporting **disability rights and disability awareness**
- Accessible, available, reliable **transportation**
- **Emergency services** for medical emergencies and disasters
- Help in obtaining **assistive technology** and accessible **information technology**
- **Access to information and resources**: finding the resources needed to live in the community and securing financial and economic support
- **Employment** matching personal skills and interests
- **Isolation, self-esteem and the need for peers**, including recreation and social programs and choice of integrated programs or special programs with peers
- **Enforcing existing regulations** appropriately
- **Reaching out** beyond the traditional ILC community
- Serving **new immigrant communities** with new issues

Health care

Most participants in the written survey listed health care as a concern. Study participants addressed many specific health care issues.

- Community medical access for both physical and mental health services
- Accessible women's centers for mammography and other women's health services
- Access to health care for rural areas of California.
- Need for universal health care with a strong disability component
- Need for disability-aware health professionals, including Medi-Cal providers
- Need for more medical practitioners, including primary care physicians and specialists, that accept Medicare and Medi-Cal

- Need for interpreters for health care visits and a multilingual approach with material in print, disk, and Braille
- Wellness programs need interpreters and information on how to make wellness available to people with disabilities.
- Need to address recovery issues for people with disabilities who have a higher incidence of alcohol and drug abuse
- Need to link the medical system closely with community services, so that physicians and other medical professionals know what the possibilities are and what is available to support independent living
- Health insurance, including personal assistance services
- The need for health insurance and other resources that support life in the community, including the personal assistance services supported by California's In-Home Supportive Services (IHSS), was frequently mentioned in the study focus groups, hearings, forums and by most survey participants.
- Need for access to long-term care insurance
- Better personal assistance services and a community/home based care system, not nursing homes
- Expand the workforce for personal assistance services (through training, tax incentives, forgiving student loans, waivers, benefits, and better wages): *"If you can't sustain a workforce, you will not be able to have independent living."*
- People with disabilities need training on hiring personal assistance providers and becoming employers.
- Insurance coverage for special testing and treatment needed by people with chemical sensitivities
- Help in paying for medications: *"I live in severe pain, and I can't afford to buy some medications."*

Housing

Adequate, affordable, safe housing is a basic need for community living. Many respondents discussed the need for housing, especially housing located near transportation and services. The built environment, including the relationship between housing, community services, and transportation systems, can create barriers to independent living. One participant stated *"It is important that people, places, and all aspects of life be accessible to persons with disabilities."*

- More housing options, including multi-unit supported housing, quality group homes, housing for individuals with Multiple Chemical Sensitivity, and home purchase programs
- Housing unit size adequate to accommodate lifts, wheelchairs, and other equipment

- Housing rules to allow more mixed use of seniors and people with disabilities
- Improved accessibility in mobile home parks and modular homes, that are more affordable than other types of housing
- Waiting lists for affordable housing are too long.
- Need to expand the supply of affordable housing, and locate housing for people with disabilities near public transportation
- Use of universal design, including non-toxic building materials, in new construction
- Need to provide for visitability
- Location of housing near available transportation, shopping and services: “Housing needs to be near resources: transportation, grocery stores, pharmacies, shopping, recreation, ATMs, copy shops, etc.”
- Need for safe housing: *“Safe housing means housing in a safe well-lit location. Much affordable housing often is located in areas that are in transition, in unsafe areas of cities.”*

Disability rights and disability awareness

Disability rights issues were important to study participants, who mentioned the need for help in learning about and advocating for their rights. More than half of the survey respondents indicated a need for help on disability rights issues and almost half indicated the need for legal help.

- Need for expansion of disability awareness training in the community: *“It seems that we’re OK to stare at, but not to be taken seriously as productive members of society!”*
- Need to educate people with disabilities, and their families, about disability rights
- Need to establish disability and independent living sensitivity/awareness education and outreach in minority communities

Transportation

Many respondents mentioned the difficulties with access and reliability in the public transportation system, including special paratransit services. While there are difficulties in rural areas, people also mentioned scheduling, reliability and access difficulties in cities. Respondents emphasized that transportation support is vital to get to work, to doctors, other health care service needs, and to participate in other life activities. One participant defined accessible community transportation as *“being able to use the same transportation as anyone without a disability, not having to rely on paratransit or other isolated types of transportation.”*

- VERY limited hours and long delays between buses

- Lack of adequate signage, including better signage needed for pedestrian safety as well as for using the transportation system
- Need for better shelter at transportation stops and transfer points

Emergency services

Experiences with California fires, mudslides and earthquakes make it obvious that evacuation and emergency plans are needed for people with disabilities.

- Need for community emergency plans for people with disabilities
- Cross-train police, other law enforcement, firemen, service staff, and people with disabilities to establish an effective emergency approach.
- Expand the supply of emergency housing.
- Develop accessible emergency services, accessible homeless shelters and battered women shelters.
- Need for communication devices for disaster shelters
- Need for county notification systems to be compatible with TTYs to be able to alert people to emergencies

Assistive technology (AT) and accessible information technology (IT)

Technology can reduce barriers to independence and support community living and work. *“Without AT you aren’t going anywhere else...without a wheelchair, ramps, computers, etc. you can’t participate.”* Information technology and computer training and services are important so that people with disabilities have improved access, including access to the resources of the Internet and current software tools and skills. As information technology (IT) continues to improve, it is important that this technology is accessible and available to people with disabilities. Concerns included:

- Discounts on purchase of a vehicle with appropriate assistive technology adaptations
- In some areas, persons need or could use an electric scooter for transportation, but are not able to obtain them.
- Expanded sources for durable medical equipment that accept Medi-Cal
- Need for expanded insurance caps for power wheelchairs and other durable medical equipment that exceed current caps
- AT is a valuable ILC service. There is need for expanded funding for AT, including AT evaluations, training, and maintenance.
- Expand opportunities to access the Internet, including training and development of more public access locations

- Need for improved information on communication technology available from the phone company
- A way to get pagers such as Sidekick or Blackberry that are free or inexpensive
- Acrobat reader PDF files that have the ability to enlarge on screen AND to print in large print
- At-home entertainment access: reading, radio, television: *“The blind need additional support with talking books and Braille books; people who are Deaf need TV captioning.”*

Access to resources and information on available resources

While assistive technology and more inclusive regulations and laws make it more feasible to live independently in the community, many people with disabilities do not have the financial resources to do so. Many of the people in our focus group discussions mentioned reliance on public subsidy programs – for housing, health care, personal assistance services, transportation – and many others did not know of these programs or did not qualify. In the surveys, interviews, and focus groups, many of the most-mentioned concerns are familiar: adequate health care and health insurance, good housing, and adequate transportation scored high in both the focus group process and the survey. In the focus group, the most frequently mentioned concern was accessing resources. In the survey and in focus groups, participants mentioned the need for help in obtaining adequate and safe housing, reliable transportation, health care, prescription medications, and even adequate food. *“I am homeless and have no food or money.”* Areas of need for help in obtaining resources included:

- Access to loan programs to help with rental fees, security deposits, first and last months rent, etc.
- Need assistance in filling out forms for housing, benefits and services
- Discounted rates (including installation fees) for utilities, cable, etc.
- Services for abandoned older women
- Financial support and economic development programs to encourage independence from handouts and benefits
- Need a central resource center where families can access information - medical, housing, recreation, and benefits
- Improve programs in the schools K-12, in terms of attitudes of teachers and other students and in terms of better goal planning
- Need for ILCs either to set up interpreting agencies or keep a list of interpreter agencies
- Need for training on Independent Living Skills and advocacy

- Ways to give a person enough food to get them through the day and through the weekend
- Meals on Wheels, available to Seniors, needed by people with disabilities too
- Need for ILCs to collaborate with others who provide services to people with disabilities in their communities
- Need to develop an exchange about best practices in ILCs
- Need for more independent living skills/employment planning services for youth: IEP specialists, transition counselors, benefits advocates specifically geared toward youth
- Need for better communication access, including theater captioning, TTYs available in shopping malls, airports with alternative methods for announcing flight changes, fast-food service drive-through system ordering options, lack of TTYs in transportation and paratransit offices, accessible freeway call-boxes, and hospital emergency rooms without interpreters

Employment

Employment is an important goal, and a number of barriers to employment were mentioned, including employment disincentives. (The recent IHSS provisions allowing use of IHSS at work were not available at the time of the study data collection.) Concerns related to employment and to work-related services included:

- Difficulty of earning enough to pay for needed services, including housing, health care, and personal assistance
- Lack of available jobs
- Need for clear job descriptions and opportunities for career advancement
- Need for better information on self-employment
- Need for support in the rehabilitation process, so that delays in services or equipment don't result in failed employment
- Lack of preparation for job-related testing, including the opportunity to practice on Word, Excel, Powerpoint and other software that is frequently required at work: *"People seem to be thrown into their jobs without preparation, and that results in them not having the tools to do their jobs competently."*
- Need for programmatic supports for employment: assistance or training for developing resumes, interviewing skills, training, and job search skills: *"Most people don't understand my world. I have the education and skills base, but I don't know how I will be able to find a viable job."*
- More opportunities for telecommuting, to allow work from home (like what JetBlue Airlines has established for the reservations staff)

- Expanded resources for personal assistance services (PAS) so that family caregivers are not precluded from working
- Reliable work attendance depends on reliable transportation: people can't rely on paratransit to get to work
- Need training for people in Human Resources on how to see people with disabilities *"from an asset model rather than a deficit model"*

One respondent praised an ILC for help in returning to employment, and these comments illustrate the importance of employment services available at ILCs: *"... I have never found a better place to have my disability needs addressed on every level... They offer a number of workshops, training and other events that have been INVALUABLE to me and allowed me to believe that one day I might be able to function in the world of the employed again..."*

Isolation, self-esteem and the need for peers

Repeatedly, people participating in the study expressed frustration with isolation, community attitudes, and self-esteem. *"Too much isolation."* Some of the isolation is associated with transportation and program access issues. But it also was described as related either to an individual's own reluctance to participate or to the attitudes of others. *"People need someone willing to just talk to them."* Peer and support networks are important to successful independence. When ILCs were first founded, the programs relied heavily on peer counseling and a sense of peer community. There is a need for more peer support and mentoring.

- Need for expansion of networking opportunities, especially in peer-to-peer opportunities and in peer groups: *"I think the support or mere existence of a disability community is important to lessen the feelings of isolation and abandonment so common to those entrenched in or new to the disability lifestyle."*

While cross-disability inclusive programs are valuable, participants pointed out the need for specialized, targeted programs, schools, and services, needed particularly in the Deaf community, for people who are blind, for people with mental illness, and for people with developmental disabilities. Specific suggestions included:

- Day programs for people with mental illness, to provide counseling and activities, to help reduce depression and isolation
- Other disability-specific day programs, with good programs and employment possibilities, rather than *"glorified babysitting"*
- Individualized core services, specialized for blindness, are needed in three phases: adjustment, reinforcement, and lifelong supports: short-term residential programs teach what people have to learn in a visual world and how to do things another way
- Social, recreational, and cultural opportunities are important for independent living. Participants identified a need for more opportunities for cultural

events, recreation and social opportunities, including making parks and recreation programs more accessible.

Enforcing existing regulations appropriately

One of the frustrating issues that was repeated throughout the study was the difficulty encountered when existing regulations and legal requirements are not enforced. For instance, many participants commented on complaints regarding their paratransit systems, where the providers simply were not providing the services that were already arranged. Over half the survey respondents cited the need for accessible, available, reliable public transportation and 40% cited reliable paratransit that adheres to appointment schedules.

There are related complaints regarding community accessibility, including delays in removing barriers. *“On public streets, while out I’ve found curbs that I couldn’t go up or down... not being handicapped accessible.”* Another example of this issue is in access to movies for people who rely on captioned versions of the movie. Participants explained that movie theaters typically provide these alternative versions in the afternoon, rather than on Friday or Saturday nights so people who are Deaf can’t go to movies on the same schedule as the general public. Other issues relate to accessibility of office buildings providing disability services. Concerns included:

- Enforcement of existing public access laws
- Eliminate misuse of handicapped parking placards and the need for better police enforcement of parking regulations
- Better compliance with building code access requirements; more enforcement of access standards by local building officials and by state agencies
- Need to assure programmatic and physical accessibility of One-Stop employment offices, including signage, functioning elevators, doorways, interpreters, and alternative formats
- Need for improved access to public buildings, colleges, and other community resources
- Need for access to grocery stores and other stores, including help from staff in reaching items and carrying things

Reaching out beyond the traditional ILC community

The needs study was designed to reach out to underserved groups. While ILCs are visible in the established disability community in California, many people participating in the study did not know of, or use, ILCs. This includes people new to disability, either because of their own condition or because of a family member, as well as members of some minority and immigrant groups. Study participants contributed suggestions for expansion of services available from ILCs and other sources, to meet new needs, and to expand the visibility of ILCs. Study recommendations from the participants included:

- Expand targeted service groups, to include people with developmental disabilities, people with mental illness
- Need for better information for the general community, so that when a person or a family needs information on what to do in a new disability situation, whether temporary or chronic, the information is available and easy to find

Serving new immigrant communities with new issues

In several of the focus groups, we heard from many people with service issues related to language access, need for interpreters in languages other than English, need for culturally appropriate services, access to benefits, and questions of eligibility for benefits related to immigration status. Our outreach process did succeed in reaching a number of participants who had not used independent living centers before, and who do not use English at home.

Many people in the focus groups mentioned difficulties in obtaining needed services, because their immigration status, or the status of a family member, was a barrier. ILCs appeared to be the service center of last resort. As the population of California continues to change, ILCs will be challenged in meeting community needs.

Chapter 1: Focus Groups

During October and November 2003, the study team conducted 14 focus groups in communities throughout California. Demographic reports from the US census were used to identify “underserved” populations by age group, race/ethnicity, disability, education, employment, languages spoken at home and degree of fluency. Discussions with key staff of the SILC and Department of Rehabilitation provided additional information on areas targeted for additional outreach in the State Plan and other personal knowledge about underserved populations.

Ten Independent Living Centers participated in the focus group process. InfoUse worked with the participating centers to recruit individuals with disabilities who were unserved or underserved and to outreach into the community to include people who may not have used ILC services. Over 80 community organizations and individuals assisted in outreach. The participation was very diverse, and 43% of the 131 participants were not previous ILC users.

Participating ILCs and Areas of Focus

Center for Independent Living, Fresno and Merced. This Center hosted two focus groups. The Fresno group included participants of mixed ages and disabilities, included married couples and two youth in transition. The Merced participants were from the Hmong community, and used a translator from the community.

Communities Actively Living Independent and Free (CALIF), Los Angeles (Downtown). The participants of this focus group were Korean, Filipino and African American.

Community Rehabilitation Services (CRS), Los Angeles. The participants were Hispanic and Asian.

Central Coast Center for Independent Living, (CCCIL), Salinas. This Center hosted two focus groups. Salinas participants were Hispanic and former farm workers. Santa Cruz participants were persons with Traumatic Brain Injury.

Independent Living Resource Center (ILRC), San Francisco. The participants were a diverse group resulting from extensive community outreach to develop a new generation of advocates around disability issues.

Center for Independent Living (CIL), Berkeley. This Center hosted two focus groups. The Fruitvale group was conducted in Spanish and required a translator. The Berkeley participants were youth in transition ranging in age from 16 to 22.

Community Resources for Independence, (CRI), Santa Rosa - Ukiah branch. This Center did outreach to various tribes of Native Americans. Participants were from five different tribes. The hosted meeting was held at the Consolidated Tribal Health Project.

Community Access Center, (CAC), Riverside - Indio branch. The participants were persons who were Deaf, hard of hearing, and seniors. Sign language and Spanish translators were provided.

Dayle McIntosh Center for the Disabled, Garden Grove. This Center hosted two focus groups, one for Vietnamese with disabilities and another for people with sensory disabilities: blind, low vision, Deaf or hard of hearing. Sign language and Vietnamese translators were provided.

Resources for Independent Living, (RIL), Sacramento. The participants of this focus group were persons with mental health disabilities.

Characteristics of Participants

One hundred thirty individuals with disabilities were recruited by ILCs and participated in the focus group meetings. One additional participant was an agency representative. In addition to these individuals, one or more ILC staff and/or family members and friends of the participants also attended some meetings.

Twelve participants were under 21 years of age; 27 were from ages 21-35; 51 were age 36-50; 25 were 51-64; 6 were 65-75; and 9 were 76 or older.

Sixty-four participants were female; 67 were male.

Forty-eight were white/Caucasian; 36 were Hispanic, 11 were African American; 25 were Asian; and 11 were Native Americans.

Forty-nine participants had physical disabilities; 36 reported mental disabilities and/or traumatic brain injury. People with sensory disabilities were represented: 13 were blind; 9 were Deaf. Eight participants reported learning disabilities. Fifteen individuals described multiple disabilities.

Over half (75) of the participants had used ILC services; 56 (43%) had not used ILC services. Many service connections developed during the focus group process for those who previously had not used ILC services.

Focus Group Process

Each focus group discussion included from 6 to 14 people with disabilities. In some cases, a parent, family member or ILC staff also participated. InfoUse staff facilitated the groups and recorded the comments. In the focus groups, participants discussed their experiences in independent living, and barriers to successful community living. The focus group discussion questions were:

- What do you need more help with? What are the biggest problems you have to deal with, for living independently?

- How have you solved difficult problems? Where do you go for help when you need it? What are biggest obstacles to living independently?
- What has encouraged you to live independently?

Notetakers recorded the participant comments for each group and prepared electronic meeting records. These records were analyzed and coded, and the analysis was conducted using qualitative analysis software. Each individual comment in each group was coded according to the themes and issues discussed by the participant making the comment. The analysis results include a series of tables showing the frequency of comments related to specific themes. In addition, the analysis included reports of specific comments by theme as well as by focus group.

In addition to providing information from focus group participants, these groups provided each Center with an opportunity to meet individuals who previously had not used Center services.

Findings: Frequency of Concerns

Table 1.1 shows the number of issues recorded for each focus group coded by type of concern. Housing was frequently mentioned in the Sacramento and Salinas groups. Health Care was mentioned most frequently by the Sacramento, Salinas and Santa Cruz Groups. Education and Training was mentioned most frequently in focus groups where participants included youth in transition, persons with Traumatic Brain Injury (TBI) and those with sensory disabilities.

Table 1.1 Concerns by focus group

CONCERNS	Fresno	Merced	CALIF	CRS	Salinas	Santa Cruz	San Francisco
Housing	12	8	3	1	20	7	5
Transportation	2	2	4	12	4	8	1
Emergency Services	2	0	0	2	4	0	1
Health Care	10	12	3	9	22	23	4
Insurance	17	1	7	2	15	13	12
Personal Assistance Services	7	4	3	3	4	5	8
Employment	4	1	6	8	12	4	5
Disability Rights	10	0	4	19	19	10	5
Education and Training	15	0	9	11	1	20	11
Assistive Technology	5	3	3	3	1	3	9
Social Supports	5	4	7	2	8	15	8
Financial Supports	30	7	6	10	20	8	5
Record-Keeping	0	0	0	0	1	9	1
Communication	1	1	2	3	1	8	1
Accessing Resources	32	7	13	7	26	32	30
Accessibility and the Environment	1	0	0	21	7	1	3
Dignity and Self-esteem	7	3	8	8	5	5	7
Language and Culture	0	8	12	4	12	1	1
Depression	0	11	0	2	6	1	2

Table 1.1 (Continued). Concerns by focus group

CONCERNS	Fruitvale	Berkeley Trans	Ukiah	Indio	Dayle McIn 1	Dayle McIn 2	Sacra- mento
Housing	0	1	4	5	3	1	40
Transportation	0	6	4	6	10	3	11
Emergency Services	0	1	0	5	0	0	0
Health Care	7	3	7	12	1	11	33
Insurance	5	2	11	12	2	5	4
Personal Assistance Services	2	3	0	1	5	9	2
Employment	0	2	5	2	7	1	6
Disability Rights	4	1	0	13	0	3	1
Education and Training	2	17	1	21	5	8	0
Assistive Technology	2	5	5	5	5	16	0
Social Supports	4	0	4	7	4	2	9
Financial Supports	1	0	15	5	5	0	5
Record-Keeping	0	0	0	1	2	0	2
Communication	0	0	0	14	0	7	1
Accessing Resources	9	11	16	22	7	10	25
Accessibility and the Environment	2	8	0	7	0	1	0
Dignity and Self- esteem	2	3	5	12	4	2	10
Language and Culture	5	0	6	0	3	0	0
Depression	0	0	0	1	0	3	10

We examined the difference in comments made by male and female participants in the focus groups. (Table 1.2) Comments related to accessing resources were the most frequent for both males (139 comments) and females (109). For the men who participated, housing (69 comments), financial supports (67), and education (64) frequently mentioned concerns, while for women, health care was the area most mentioned (91), followed by education and training (57).

Table 1.2 Concerns by gender

CONCERNS	Male	Female
Accessing Resources	139	109
Housing	69	43
Financial Supports	67	50
Education and Training	64	57
Health Care	62	96
Insurance	58	50
Employment	42	21
Dignity and Self-esteem	42	40
Social Supports	39	41
Disability Rights	36	54
Transportation	35	38
Assistive Technology	33	33
Personal Assistance Services	30	28
Language and Culture	29	23
Accessibility and the Environment	24	27
Depression	19	17
Communication	17	22
Record-Keeping	10	7
Emergency Services	8	7

Whether a participant was associated with an ILC or not, concern with accessing resources and health care were most frequently mentioned. For those who had not participated with ILCs, housing was the next most frequent concern.

Table 1.3 Concerns by connection with Independent Living Centers (ILCs)

CONCERNS	Connection with ILC	
	Yes	No
Accessing Resources	140	108
Health Care	77	80
Financial Supports	64	53
Insurance	63	45
Education and Training	63	56
Disability Rights	51	38
Social Supports	49	30
Employment	47	16
Housing	46	64
Transportation	43	29
Dignity and Self-esteem	42	39
Personal Assistance Services	41	15
Assistive Technology	37	29
Accessibility and the Environment	34	17
Language and Culture	32	20
Communication	19	20
Depression	13	24
Record-Keeping	10	6
Emergency Services	8	7

Findings: Detailed Focus Group Comments

In the focus groups, people discussed available resources and resource needs for independent living. The people who attended these focus groups are living in the community, but many experience significant barriers to full community participation. This section includes selected comments from the groups, organized by theme. Direct quotes from participants are in *italics*.

Health care and health insurance

There were a variety of issues with health care: general practitioners who did not understand the affect of a disability on certain health conditions; having to go to the primary care doctor to get a referral that can take up to 3 months to get the referral authorized; lack of accessible testing equipment. Several participants commented on problems with medication - there are long delays before purchases, or before one gets approvals or gets reimbursed. Medical service providers do not always have interpreters available.

"Medical offices, by law, must provide health care interpreters, family cannot translate for family...violates privacy. Can't ask children to be their interpreter. Communication is not clear."

Another participant stated *"The Medi-Cal formulary is always changing. Bottles of pills come in 100's - I take 3 pills a day and only get 90 pills - so I have to pay more, Medi-Cal doesn't cover the extra 10 pills."*

"Medicare won't pay for supplies. I can't get Medi-Cal because my wife works. I need things for my wheelchair and medications such as catheters and lubricants."

Participants described a range of needs for assistance from personal assistance services and/or from family members, in performing daily activities: cooking and shopping, dressing, bathing, bathroom/personal hygiene, reading, interpreting, typing, laundry, filling out forms and applications, and driving.

Personal assistance is the key to independent living for many people with severe disabilities. *"I used to live alone and the attendant came once a week. But now I can't live without an attendant...I don't have the level of independence I used to have."*

While some participants said it is relatively easy to find attendants (*"There is not much of a problem getting attendants."*), others report more difficulty. *"We get very few hours of in-home support services...attendants don't want to work for a few hours, so we can't find an attendant."*

In the situation where resources for personal assistance are not available, family members often provide the services. *"... cannot get a full-time job because of taking care of mother."*

Some participants discussed long delays in qualifying for, or in obtaining, needed personal assistants. *"IHSS is a problem. It took 4 or 5 months to get a response. I came here to CIL for them to help call. IHSS decided to respond."*

"When he was sick, he didn't speak the language. He needed help or services to interpret." One participant mentioned that, *"People in the Hispanic community need more Spanish speaking doctors."* This need is certainly true for other populations with language barriers as well. *"We have to bring someone to translate. The doctors tell us that we need to be the ones who are responsible for bringing a translator."*

Several problems with medical translators were mentioned. It was reported that all translators are not competent to do translations in medical situations; some have left in the middle of appointments to avoid making mistakes for which they might be liable.

Housing

Many participants mentioned Section 8 housing. Section 8 has provided opportunities for living independently, but participants mentioned several concerns related to Section 8. Waiting times experienced by some were very long. *"It takes 2 or 3 years to get in."* Participants mentioned inadequate sizes of the living units, and difficulty finding 2- or 3-bedroom units for larger families.

Participants described that HUD housing for seniors and people with disabilities usually are small studio or one-bedroom units inadequate to house people with disabilities who use lifts, large wheelchairs, and other larger assistive technologies. *"Biggest problem is like I'm living in a storage room, it's not even a 1 bedroom, it's a studio, cannot have medical equipment, school equip, dining room, bedroom etc. all in one room with a 5 foot square closet sticking into the room."* One participant explained that the size limitations are different than in his country of origin: *"This country is not like our country, can only have 3 people in 2 bedroom, 5 in 3 bedroom."*

Without Section 8 or other housing subsidy, people described high rents and lack of accessible housing stock. *"I'm fortunate, because I have my own home, but I remember how difficult it was to find an accessible apartment...there's a real need to look at housing, at how to identify places that are accessible...For people in wheelchairs, finding housing is a real challenge."*

For participants in the mental health focus group who had been in jail, housing was a particular problem. *"A lot of people don't have a place to go when you get out of jail." "I've been in prison most of my life. I just want a place by myself." "I've been on the SRO list for 4 months, it's not moving."*

"I own a condo and when I go to the homeowner's meetings I'd like to have an interpreter. They say I have to pay, but I can't pay, so I don't go to the meetings anymore."

Transportation

Many of the people who participated in the focus groups rely on public transportation, especially buses and paratransit, and describe transportation as one of the biggest problems in living independently, or the single biggest problem. *"Sometimes I have to miss appointments because the transportation doesn't show."* Long lead times for scheduling, combined with lack of reliability on pick-ups, were mentioned by many participants. Many people complained of being late for appointments, school, and work because the paratransit and buses were late and unreliable. Participants reported that public transit buses often passed them up; that drivers of even new buses would say the lift doesn't work. Transportation *"requires*

special scheduling ahead of time, more planning. As a result I must miss too many classes.”
“I am always delayed.”

Paratransit promises flexibility but is needed because more mainstream transportation options (private automobile, regular bus) are not available to many focus group participants.

Some described physical difficulties operating a vehicle: *“I try to drive but I’m not strong enough.”* *“I can’t drive anymore.”* Others described the expense of owning, operating and maintaining a car or van, or obtaining needed modifications.

Relying on regular bus service for transportation is not always feasible, and participants discussed difficulties with limited schedules, need for many transfers, lack of adequate bus stops, and lack of bus stop shelters that are needed in bad weather.

Other transportation issues included help with car or van repairs, assistance in obtaining a car or van, and getting modifications for car or van so the person with a disability can drive himself.

Access

Access to sidewalks is a major problem in many communities. The following issues were described: sidewalks blocked by debris, including materials from adjacent construction sites; sidewalks filled with cars; lack of sidewalks in some communities; sidewalks with cracks; sidewalks with no curb cuts; curb cuts and ramps built with “lips” that can flip a wheelchair over; and curb cuts but not located at the crosswalks. Access to sidewalks is better in newer communities, but retrofit of older sidewalks has not been completed. *“It is impossible to fix them all.”* Some participants noted that people in wheelchairs have to go into the streets in traffic when sidewalks are blocked; they are not easily seen by motorists and accidents have happened.

In addition to this widespread concern with sidewalks, many other access issues mentioned are specifically related to wheelchair use. This includes access in the individual’s own home and access to stores and shopping. *“The expensive stores are accessible and the cheaper ones aren’t.”* *“When I can’t get in, I go home or I go to another store.”* Participants who use wheelchairs pointed out that people who don’t use chairs themselves can’t know the problems of people who do use chairs. *“I have friends that care about me, but they are not in chairs so they don’t know the problems.”*

Access to grocery stores, including help from grocery store staff in reading labels, reaching for items, and carrying things, was a repeating theme. *“I wish grocery store people would take me around to help me.”* Others have found ways to obtain this help, such as going early in the morning so that the store is not busy, and asking the manager for assistance.

Access to information and resources

Participants discussed difficulties in finding the right information in a timely manner and in finding help in obtaining benefits or in carrying out everyday tasks. Some participants stressed the need for legal assistance and advocacy in securing benefits, saying that the rules are not easy to understand.

Many of the participants either receive benefits from Social Security and Section 8 housing, or have tried to qualify unsuccessfully for these benefits. For many of the recent immigrants and their families participating in this study described confusion about whether particular benefits are available, and what the requirements would be. Some participants cited high rejection rates for Social Security benefits.

Many participants discussed the difficulties of living on SSI and the consequences when one works: *"If they want us to work and be independent they shouldn't take away the money; we are living below poverty."* *"They keep you on such a short leash that you can't get ahead. I'm on the special part of the program where I can work, but I can make up to \$800 before I lose my benefits. It would be a good idea if they would increase it. To \$1000-1200 a month."*

Some participants, especially participants with brain injury and learning disabilities, described the paperwork required by the different agencies - Social Security, SSI, Housing and others - as a tremendous burden. *"Organizing all of that is a nightmare. I have stacks and stacks of paper that pile up."* *"Everything that comes at you is too much."*

In addition, participants pointed out that forms that were translated into other languages were not good translations, did not make sense, and were difficult to understand and complete.

Language is a barrier in finding services, especially for those who do not speak or read English. *"If he doesn't know the language, how can they help him?"* Without using English, many cannot access services or find out about benefits. *"Because we are unable to express ourselves we are not getting adequate services... There needs to be informational meetings of people with disabilities who speak the same language."*

Many participants discussed where one could obtain assistance for food: food banks, Salvation Army, Catholic Charities and other places that give away government surplus food to qualified recipients.

School

Some participants, drawing on their own experiences, discussed shortages of classes, trained teachers, assistants, and lack of computers in the schools. Participants described the value of having teachers that understand and recognize disability, especially hidden disability.

Participants stressed the value of legal assistance and advocacy in achieving educational goals.

Some participants stated that teachers in some school districts are against mainstreaming and don't want to deal with it. In some instances children were forgotten while others went to assemblies, left alone in fire drills, or left to sit in the playground by themselves. Some schools have let nurses go for budgetary reasons.

More than one participant mentioned a significant gap between the services available in special education services or in special children's programs (such as Shriner's Hospital) and services available to adults. One participant noted that one day you have the services, then you have a birthday that puts you over the age limit, you still need the services but are no longer eligible. *"The children's services are good for people under 21, but when you're over 21, it gets harder."*

Employment

Several participants mentioned long waits – six months to a year – to receive authorized computers and other equipment through the Department of Rehabilitation resulting in lost jobs or not getting jobs because of delays in getting needed equipment. One participant stated, *"I can't be out 8 hours a day to go to school, why can't I have a computer in my home and one that is adapted. Rehab requires a number of credits or hours per day. I need a computer adapted for my vision problem."*

Participants also described mixed experiences in finding opportunities for higher education or in convincing rehabilitation counselors and others that educational goals are valid and attainable.

Communicating about disability

Participants stressed the value of being able to talk about their disabilities and explain needs, especially with health care workers and service providers but also with friends and others. *"It doesn't seem to sink in with sighted people that we cannot see, even people we've met many times."* *"Police, fire, grocery stores, doctors – they are all very rude to the Deaf..."* *"Unfortunately, because of my disability, I am limited in my ability to speak."* Participants discussed ways to improve communication, and how both people with disabilities and people in the community need more training to avoid breakdowns in communication. Persons who are Deaf reported that more training about disabilities, especially deafness, are needed for police, paramedic and fire personnel. One reported being picked up for being drunk before the police realized he was Deaf. *"We have to inform people of our needs."*

Participants mentioned difficulty in communicating about disability to people who are not disabled or who do not share the same disability.

One participant stated, *"Disability is kind of taboo in Native American culture. It's more difficult to access resources. Even wondering what resources are out there."*

Resources available for meeting independent living needs

Focus group participants mentioned many resources, including service organizations, which have been essential in addressing specific needs. A partial list of resources includes: California Department of Rehabilitation, Meals on Wheels, Braille Institute, Lighthouse for the Blind, Shriners' Hospital, Orientation Center for the Blind, Guide Dogs, Brain Injury Support Group, independent living centers (ILCs), friends, and family members. Usually, people rely on several resources:

"Thanks to my brother and the city I am now going to college and understand others with disabilities... I got support from school, from family, through education, CIL and the Church."

For many, it is the Independent Living Center that has provided links to other services and resources:

"I am grateful to CIL... I was able to get what I need and a personal assistant that helps."

"I have learned a lot from CIL and from others who come here; that's why I have different goals."

"I'm thankful to the CIL because I've changed. They've helped me a lot. The way (others) view me now has changed because I have people from the CIL backing me up."

"What made me feel better was talking to people at the CIL. I'm getting things off my chest with someone who has a disability, people who understand. If I talk to people who don't have a disability, they can't relate, they don't understand."

Chapter 2: Independent Living Needs Survey

The Needs Survey was conducted in early 2004. Surveys could be completed in English or Spanish via email, standard mail, or online. The results presented in this report are based on 453 surveys received through April 2004. Needs categories for the survey were developed from findings of an earlier SILC needs study and from input in public hearings conducted in California in 2003 as part of this study. Major categories (e.g., housing, transportation, and health care) were further defined in terms of specific concerns. The survey asked respondents to check all that applied. The survey collected some descriptive information about county of residence, type(s) of disabilities, gender, age, ethnicity, and California county. We also invited written comment, and over one-third of the respondents chose to respond with comments. The survey was completely voluntary. People who live in California and either have a disability or a family member with a disability were invited to respond and to advise the SILC and the Department of Rehabilitation about their needs and concerns.

This section describes the characteristics of the survey respondents and describes the relative importance of the concerns for those who completed the survey and differences by gender, age, disability and ethnicity.

For those familiar with previous disability studies in California, the major themes will be familiar. Concerns with housing, health care, health insurance, and transportation continue. A concern of lack of benefits and financial resources was also common. Many commented on isolation and lack of understanding by others in the community. Independent Living Centers were recognized, both individual centers and ILCs as a group, and there were suggestions for how Centers might expand services.

Characteristics of Survey Respondents

Respondents could check one or more disability categories. The most frequent disability reported was physical disability (61.1% of respondents), followed by vision (24.3%), other (22.1%), and hearing (20.3%), cognitive (15.0%), mental (15.0%), learning disability (12.8%), brain injury (11.5%), and developmental disability (9.1%). "Other" was indicated by 22.1% of respondents.

Responses included more females (54.5%) than males (45.5%).

Over two thirds of survey respondents were white (68.0%), followed by Hispanic/Latino respondents (11.7%). African-American respondents (7.1%), Asian/Pacific Islanders (3.1%), and Native Americans (2.2%).

The majority of respondents were between the ages 41 and 64 (58.5%). Nearly one quarter of respondents were between the ages 21 and 40. Adults 65 years and older comprised 7.9% of the survey respondents. Less than 5% were 20 or younger.

Process

A majority of survey respondents used the web to respond to the survey (58.1%). Nearly one third of surveys (30.2%) were sent in by regular mail. We anticipated a higher response by using the Internet as the major vehicle for the survey. Some Independent Living Centers and other service organizations sent packets of surveys or downloaded surveys for clients. Use of email was lower (11.7%).

Twenty of the 453 surveys processed used the Spanish language version provided in the survey. Of these Spanish language surveys, 90.0% were sent via regular mail. Two (10.0%) were transmitted via the web, and none were sent via email.

The first returns were from the online survey. Independent Living Centers throughout California assisted in promoting the survey through email and with hard copies of the survey. By the end of the survey period, hard copy returns accounted for approximately one third of the surveys. A public television and radio promotion of the survey, by California Connected, on April 9, 2004, resulted in an increase in returns from Southern California. As many as 71 new surveys can be attributed to the broadcast. Of these, 24% arrived in the mail, 20% were sent by email, and the remaining 56% were sent in using the website

Findings

Table 2.1 shows the major categories of need and the response rates ordered by frequency of category selection for all survey respondents. Health care (93.2%) and health insurance (92.1%), housing (89.6%), disability rights (88.3%), and transportation (88.1%) were the most frequently areas. For details on the specific need areas within each category, see Table 2.2.

Table 2.1 Major categories of need ordered by frequency of survey response

Category of Need (n=453)	Frequency	Percent Response
Health Care	422	93.2%
Health Insurance	417	92.1%
Housing	406	89.6%
Disability Rights	400	88.3%
Transportation	399	88.1%
Emergency Services	375	82.8%
Assistive Technology	350	77.3%
Access to Information and Resources	350	77.3%
Employment	335	74.0%

Financial-Economic Support	332	73.3%
Accessibility	331	73.1%
Education and Training	320	70.6%
Communication Needs	288	63.6%
Personal Assistance Services	276	60.9%
Recreation and Social Access	265	58.5%
Record-keeping	215	47.5%

Table 2.2 SILC survey major categories of need, items of need, and response rates (part 1 of 3)

Category of Need	Need Item	Frequency	Percent Response
Health Care	Disability aware health care professionals	291	64.2%
	Health care professionals who take Medi-Cal	216	47.7%
	Timely access to health care	149	32.9%
	Nutrition services: beneficial nutrition, diet, weight control	142	31.3%
Health Insurance	Coverage that meets health care needs / access to specialists	307	67.8%
	Coverage that provides equipment or other assistive devices	247	54.5%
	Availability of dental insurance	197	43.5%
Housing	Affordable housing in a safe location	286	63.1%
	Accessible housing or housing appropriate for my disability	191	42.2%
	Home modifications	147	32.5%
Disability Rights	People to help and support me on disability rights issues	248	54.7%
	Legal help	218	48.1%
	Programs and information about my rights	213	47.0%

Table 2.2 (continued) SILC survey major categories of need, items of need, and response rates (part 2 of 3)

Category of Need	Need Item	Frequency	Percent Response
Transportation	Accessible, available, reliable public transportation	254	56.1%
	Reliable paratransit that adheres to appointment schedule	182	40.2%
	Help in obtaining an accessible car or van	122	26.9%
Emergency Services	Available, accessible services for medical emergencies and disasters	260	57.4%
	Available program for emergency personal assistant services	200	44.2%
	Help with abusive situations	68	15.0%
Assistive Technology	Help in obtaining assistive technology, supports, devices	243	53.6%
	Maintenance and repair services	195	43.0%
	Training in assistive technology	160	35.3%
Access to Information and Resources	Resources to live independently: rent, furnishings, supplies, etc.	217	47.9%
	Counseling with peers and support groups	175	38.6%
	Access to information about independent living in my community	148	32.7%
	Independent Living Skills Training	126	27.8%
Employment	Employment that matches my interests and skills	256	56.5%
	Appropriate on the job training	146	32.2%
	Job search programs/resources: resume writing, interviewing, etc.	124	27.4%
Financial-Economic Support	Help with obtaining benefits	214	47.2%
	Service to determine benefit eligibility: SSI/SSDI/Medi-Cal/Other	197	43.5%
	Timely eligibility process	178	39.3%

Table 2.2 (continued) SILC survey major categories of need, items of need, and response rates (part 3 of 3)

Category of Need	Need Item	Frequency	Percent Response
Accessibility	Accessibility in public places	266	58.7%
	Accessibility in private businesses	220	48.6%
	Accessibility in government services	204	45.0%
	Accessibility in offices	183	40.4%
Education and Training	Help with education and training issues	182	40.2%
	Classroom accommodations, assistive devices, note takers, test time	151	33.3%
	Career planning	139	30.7%
	School to work services	120	26.5%
Communication Needs	Internet access	185	40.8%
	Alternate formats	118	26.0%
	Access to interpreters, TTY	85	18.8%
Personal Assistance Services	Finding, training and keeping a reliable personal assistant	239	52.8%
	Personal assistance services at job	80	17.7%
Recreation and Social Access	Participation in recreation, religious and social activities	265	58.5%
Record-keeping	Assistance with personal business, bill paying, budgeting, etc.	178	39.3%
	Assistance with payroll taxes, etc.	92	20.3%

All people 20 or younger responding to the survey selected education and training, and also selected health care, health insurance and housing as most important. For people 21 to 40, and for those 41 to 64, health care was the most frequently selected, and other major needs were health insurance, housing, and disability rights. For people 65 and older, the need for transportation was selected at the same rate as health care and health insurance.

Table 2.3 Categories of Need by Age Group

Category of Need	Frequency (and Percentage) of Age Group			
	20 or younger (n=21)	21 to 40 (n=112)	41 to 64 (n=265)	65 or older (n=36)
Health Care	20 (95.2%)	106 (94.6%)	246 (92.8%)	34 (94.4%)
Health Insurance	20 (95.2%)	100 (89.3%)	248 (93.6%)	34 (94.4%)
Housing	20 (95.2%)	100 (89.3%)	240 (90.6%)	31 (86.1%)
Disability Rights	17 (81.0%)	99 (88.4%)	240 (90.6%)	31 (86.1%)
Transportation	19 (90.5%)	97 (86.6%)	232 (87.5%)	34 (94.4%)
Emergency Services	17 (81.0%)	92 (82.1%)	223 (84.2%)	28 (77.8%)
Assistive Technology	19 (90.5%)	84 (75.0%)	205 (77.4%)	27 (75.0%)
Access to Information and Resources	18 (85.7%)	90 (80.4%)	205 (77.4%)	24 (66.7%)
Employment	18 (85.7%)	94 (83.9%)	196 (74.0%)	14 (38.9%)
Financial-Economic Support	16 (76.2%)	81 (72.3%)	196 (74.0%)	28 (77.8%)
Accessibility	12 (57.1%)	87 (77.7%)	200 (75.5%)	19 (52.8%)
Education and Training	21 (100.0%)	92 (82.1%)	179 (67.5%)	16 (44.4%)
Communication Needs	16 (76.2%)	74 (66.1%)	165 (62.3%)	21 (58.3%)
Personal Assistance Services	16 (76.2%)	74 (66.1%)	157 (59.2%)	19 (52.8%)
Recreation and Social Access	13 (61.9%)	74 (66.1%)	152 (57.4%)	17 (47.2%)
Record-keeping	12 (57.1%)	61 (54.5%)	116 (43.8%)	13 (36.1%)

Table 2.4 shows how females and males participating in the survey selected areas of concern. The table shows little difference in the ways that females and males responded: health care and health insurance are most the most frequent concerns for both, followed by housing, disability rights, transportation, and emergency services. There is a small difference in how the areas are prioritized. For men, housing and transportation were more important, while women selected housing and disability rights.

Table 2.4 Categories of Need by Gender

Needs Category	Frequency (and Percentage) of Gender	
	Female (n=244)	Male (n=204)
Health Care	227 (93.0%)	192 (94.1%)
Health Insurance	224 (91.8%)	188 (92.2%)
Housing	215 (88.1%)	186 (91.2%)
Disability Rights	218 (89.3%)	178 (87.3%)
Transportation	211 (86.5%)	184 (90.2%)
Emergency Services	202 (82.8%)	169 (82.8%)
Assistive Technology	192 (78.7%)	153 (75.0%)
Access to Information/Resources	194 (79.5%)	152 (74.5%)
Employment	177 (72.5%)	153 (75.0%)
Financial-Economic Support	181 (74.2%)	147 (72.1%)
Accessibility	184 (75.4%)	143 (70.1%)
Education and Training	176 (72.1%)	141 (69.1%)
Communication Needs	157 (64.3%)	128 (62.7%)
Personal Assistance Services	151 (61.9%)	123 (60.3%)
Recreation and Social Access	135 (55.3%)	128 (62.7%)
Record-keeping	115 (47.1%)	96 (47.1%)

Health care and health insurance rank among the top need categories for all disability groups, followed by housing, disability rights, and transportation. (Table 2.5) Nearly all (94.8%) of respondents reporting a learning disability, 91.2% of those with a mental disability, and 90.4% of those with a brain injury selected access to information and resources as a need.

About 70% of those with a learning disability (72.4%), developmental disability (70.7%), and physical disability (70.4%) indicated a need related to personal assistance services.

Table 2.5 Categories of need by disability type (part 1 of 3)

Category of Need	Frequency (and Percentage) of Disability Type		
	Brain Injury(n=68)	Cognitive (n=68)	Developmental (n=41)
Health Care	51 (98.1%)	66 (97.1%)	39 (95.1%)
Health Insurance	51 (98.1%)	66 (97.1%)	39 (95.1%)
Housing	50 (96.2%)	62 (91.2%)	35 (85.4%)
Disability Rights	50 (96.2%)	61 (89.7%)	33 (80.5%)
Transportation	48 (92.3%)	62 (91.2%)	37 (90.2%)
Emergency Services	46 (88.5%)	56 (82.4%)	35 (85.4%)
Assistive Technology	41 (78.8%)	54 (79.4%)	28 (68.3%)
Access to Information/ Resources	47 (90.4%)	58 (85.3%)	34 (82.9%)
Employment	42 (80.8%)	54 (79.4%)	31 (75.6%)
Financial-Economic Support	41 (78.8%)	52 (76.5%)	32 (78.0%)
Accessibility	36 (69.2%)	49 (72.1%)	29 (70.7%)
Education and Training	43 (82.7%)	53 (77.9%)	33 (80.5%)
Communication Needs	33 (63.5%)	44 (64.7%)	28 (68.3%)
Personal Assistance Services	32 (61.5%)	45 (66.2%)	29 (70.7%)
Recreation and Social Access	33 (63.5%)	43 (63.2%)	30 (73.2%)
Record-keeping	31 (59.6%)	35 (51.5%)	24 (58.5%)

Table 2.5 (continued) Categories of Need by Disability type (part 2 of 3)

Category of Need	Frequency (and Percentage) of Disability Type		
	Hearing (n=92)	Learning (n=58)	Mental (n=68)
Health Care	85 (92.4%)	54 (93.1%)	68 (100.0%)
Health Insurance	82 (89.1%)	53 (91.4%)	66 (97.1%)
Housing	76 (82.6%)	50 (86.2%)	64 (94.1%)
Disability Rights	81 (88.0%)	51 (87.9%)	62 (91.2%)
Transportation	76 (82.6%)	51 (87.9%)	61 (89.7%)
Emergency Services	76 (82.6%)	46 (79.3%)	59 (86.8%)
Assistive Technology	72 (78.3%)	49 (84.5%)	54 (79.4%)
Access to Information/ Resources	64 (69.6%)	55 (94.8%)	62 (91.2%)
Employment	71 (77.2%)	44 (75.9%)	52 (76.5%)
Financial-Economic Support	68 (73.9%)	47 (81.0%)	58 (85.3%)
Accessibility	72 (78.3%)	48 (82.8%)	50 (73.5%)
Education and Training	69 (75.0%)	50 (86.2%)	52 (76.5%)
Communication Needs	72 (78.3%)	47 (81.0%)	46 (67.6%)
Personal Assistance Services	45 (48.9%)	42 (72.4%)	45 (66.2%)
Recreation and Social Access	54 (58.7%)	38 (65.5%)	43 (63.2%)
Record-keeping	41 (44.6%)	40 (69.0%)	39 (57.4%)

Table 2.5 (continued) Categories of need by disability type (part 3 of 3)

Category of Need	Frequency (and Percentage) of Disability Type		
	Other (n=100)	Physical (n=277)	Vision (n=110)
Health Care	96 (96.0%)	261 (94.2%)	102 (92.7%)
Health Insurance	93 (93.0%)	260 (93.9%)	99 (90.0%)
Housing	90 (90.0%)	259 (93.5%)	93 (84.5%)
Disability Rights	90 (90.0%)	251 (90.6%)	96 (87.3%)
Transportation	89 (89.0%)	250 (90.3%)	100 (90.9%)
Emergency Services	85 (85.0%)	236 (85.2%)	84 (76.4%)
Assistive Technology	77 (77.0%)	226 (81.6%)	86 (78.2%)
Access to Information and Resources	85 (85.0%)	215 (77.6%)	86 (78.2%)
Employment	66 (66.0%)	210 (75.8%)	78 (70.9%)
Financial-Economic Support	75 (75.0%)	209 (75.5%)	83 (75.5%)
Accessibility	68 (68.0%)	219 (79.1%)	74 (67.3%)
Education and Training	71 (71.0%)	189 (68.2%)	79 (71.8%)
Communication Needs	69 (69.0%)	170 (61.4%)	76 (69.1%)
Personal Assistance Services	63 (63.0%)	195 (70.4%)	60 (54.5%)
Recreation and Social Access	63 (63.0%)	169 (61.0%)	64 (58.2%)
Record-keeping	52 (52.0%)	121 (43.7%)	63 (57.3%)

People in all ethnic groups selected health care and health insurance in high frequencies. There are some interesting differences the way people in different groups ranked the areas of concern. We summarize the most frequently selected areas for each group, here. Table 2.6 shows the frequency by ethnic group for each of the survey's concern areas.

For African-American respondents, health care was the most frequently selected, followed by housing, disability rights, and access to information. For Asian/Pacific Islanders, all selected health insurance, transportation, and emergency services, then health care, housing, and disability rights. For Hispanic people, health care and disability rights were most frequently selected, then health insurance and housing. All participating Native American respondents selected employment and transportation as well as health care, health insurance, housing, and emergency services. For white respondents, the most frequent categories were health care and housing, followed by disability rights and transportation.

Table 2.6 Categories of need by ethnicity

Category of Need	Frequency (and Percentage) of Ethnic Group				
	African-American (n=32)	Asian/Pacific Islander (n=14)	Hispanic /Latino (n=53)	Native American (n=10)	White (n=308)
Health Care	31 (96.9%)	13 (92.9%)	50 (94.3%)	10 (100.0%)	288 (93.5%)
Health Insurance	28 (87.5%)	14 (100.0%)	46 (86.8%)	10 (100.0%)	287 (93.2%)
Housing	30 (93.8%)	13 (92.9%)	46 (86.8%)	10 (100.0%)	277 (89.9%)
Disability Rights	30 (93.8%)	13 (92.9%)	49 (92.5%)	9 (90.0%)	268 (87.0%)
Transportation	29 (90.6%)	14 (100.0%)	43 (81.1%)	10 (100.0%)	270 (87.7%)
Emergency Services	27 (84.4%)	14 (100.0%)	36 (67.9%)	10 (100.0%)	257 (83.4%)
Assistive Technology	27 (84.4%)	11 (78.6%)	38 (71.7%)	8 (80.0%)	237 (76.9%)
Access to Information/ Resources	30 (93.8%)	12 (85.7%)	40 (75.5%)	7 (70.0%)	230 (74.7%)
Employment	26 (81.3%)	12 (85.7%)	39 (73.6%)	10 (100.0%)	221 (71.8%)
Financial-Economic Support	25 (78.1%)	11 (78.6%)	43 (81.1%)	7 (70.0%)	219 (71.1%)
Accessibility	26 (81.3%)	11 (78.6%)	39 (73.6%)	9 (90.0%)	216 (70.1%)
Education and Training	23 (71.9%)	12 (85.7%)	40 (75.5%)	9 (90.0%)	209 (67.9%)
Communication Needs	21 (65.6%)	11 (78.6%)	40 (75.5%)	7 (70.0%)	185 (60.1%)
Personal Assistance Services	25 (78.1%)	10 (71.4%)	31 (58.5%)	7 (70.0%)	182 (59.1%)
Recreation and Social Access	18 (56.3%)	12 (85.7%)	30 (56.6%)	7 (70.0%)	181 (58.8%)
Record-keeping	11 (34.4%)	8 (57.1%)	32 (60.4%)	8 (80.0%)	135 (43.8%)

Summary of Survey Comments

In the survey, InfoUse encouraged people with disabilities in California to express their comments. Of the 453 surveys returned, 170 (37.5%) people responded with written comment in addition to completing the questionnaire. In this section we have selected comments that show the range of issues identified and the recommendations to the SILC and the state of California. These comments all were volunteered, and many introduce needs and issues that were not specifically addressed in the survey questions. Many respondents included “thank you” for the opportunity to provide information.

We have extracted respondent comments from the comment text file, removed personal identifiers, and organized comments by theme.

Health care and health insurance

Health care and health insurance were the most frequently identified areas of concern in the surveys. Survey participants expanded on the concern for health-related services:

- Need for universal (better) health care, with a strong disability component
- Women's centers for mammography and other women's health services are practically non-existent.
- Need for dental insurance and access to dental care: *“regular teeth cleanings and dental check-ups are crucial and I have not been able to afford them”*
- Need for access to medical specialists, especially providers who accept Medi-Cal
- Access to long term care insurance.
- Durable medical equipment and resources that accept Medi-Cal: *“Insurance coverage regularly follows rigid Medicare guidelines for DME [durable medical equipment], etc. I am seeing a \$2,000 annual cap; on DME coverage -- what will I do when I need a new \$12,000 power wheelchair?”*
- Need for insurance coverage for testing and treatment need by people with the chemical sensitivity

Need for personal assistance services

Many survey respondents mentioned the need for retaining and expanding personal assistance services, especially services provided by the In-Home Supportive Services (IHSS) program. *“We need to ensure that people with disabilities, seniors and children have access to In-Home-Support.” “IHSS is very vital support service for the disabled.”* One participant stated need for *“better attendant services and community/homebased care, NOT NURSING HOMES!”* arguing that nursing homes are *“way too expensive and only*

about 5% of the population needs this whereas probably 75% of the elderly need it, as do many people with disabilities.” Ideas related to personal assistance services and IHSS included

- A redesigned IHSS residual program that includes advance pay, also provider, and parent provider; food accommodation for motel, hotel residents
- Training those providing assistance to the disabled, to be sensitive to those they serve
- Eliminate poverty of all people and give IHSS workers a living wage with healthcare!
- Don't cut use of family members for IHSS
- In-Home Operations Program, a federal nursing home waiver program, to at least quadruple the number of slots for maintenance care to be provided by nurse's aides or CNAs
- Marketing plan to enlist interest in home care in high schools, junior colleges through graduate schools, nursing schools, and welfare recipients with tax incentives or forgiving student loans for work performed

Importance of housing choice

Housing continues to be an important area of need. There are many aspects of housing need, including need for affordable housing, housing located in safe neighborhoods, housing accessible for people with disabilities, and a variety of housing choices to respond to the variety of needs in terms of size of the household, proximity to transportation, and other needs. *“We need to do more Direct Housing Advocacy.” “We are NOT doing enough to have affordable housing”* Ideas included:

- Group homes: Need for quality group homes, for small groups, for multi-living homes *“for older disabled whose parents have died, and they need company & social events”*
- Non-toxic housing accessible for people with Multiple Chemical Sensitivity (MCS)
- Need for more affordable housing
- Need for assistance in home purchasing

Transportation

In addition to concerns about reliability and frequency of public transportation, survey respondents mentioned sidewalk access, signage, and other aspects of transportation in the community. Concerns include city curb cuts, comfort of transportation vehicles, access to sidewalks, and other issues. Additional

transportation concerns are listed in the area of enforcement. *“Accessible Disabled Services would be nice.”* Transportation comments included:

- Some curbs are still inaccessible
- Some sidewalks are blocked, making them inaccessible for wheelchair users
- In rural areas, public transportation has very limited hours and long delays between buses
- Noise and bad shock absorbers on buses make them too difficult to ride. Jerky stops are hard on the back.
- Improved signage to help in using transportation: *“At my last job, the only way I could figure out which BART exit to use was because there was a huge advertising sign right near the exit I needed...with cognitive challenges, looking at a small sign way up on top of a door simply doesn’t register...That advertising space right near the BART exit could simply be used to identify the exit rather than sell a product”.*

Employment

Ideas for expanding employment opportunity included:

- On-going supported employment would be helpful -- volunteer or paid
- Need for more jobs availability to all Deaf & hard-of-hearing communities without any barrier and discrimination
- Information and access to self-employment training and opportunities
- Department of Rehab to work closer with businesses and non-profits to develop a "worksite" for disabled people
- Special Assistive Technologists at "one stop shopping" locations where individuals with disabilities could work together and receive the special assistance they need
- Assistance in preparing for employment tests, including tests requiring software such as Word, Excel, etc.
- Need Job Sampling for career choice
- Need clear job descriptions before starting job
- Need opportunities for career advancement.
- Additional information and assistance with work related issue of reasonable accommodation: what is allowable and what is not given
- Telecommuting jobs for people to able to work from home –for example, Jet Blue airlines reservation staff who work from their own homes

Need for public awareness of disability and disability rights

Survey respondents identified a number of needs related to public knowledge about disability. Ideas for improvement included:

- Leadership Training for people with disabilities as disability advocates - ADA, press release writing, Debating skills
- Better training for people working in independent living and advocacy positions, including accurate knowledge of the laws providing access protections: *" they don't seem to know as much as I do let alone be able to effectively advocate for me."*
- More education of architects and contractors re access requirements
- Public awareness of what services and accommodations are offered or available
- Disability sensitivity training for public employees and officials, especially police, fire, judges, public attorney
- Public education regarding indoor pollution (toxic buildings, perfumes and scented products, etc.)

Need for financial resources

Recommendations regarding access to financial resources included the need for loan programs, need for resources to support independent living for individuals and for families, economic development programs, special programs serving people with disabilities, and for services for disabled women:

- Access to loan programs to help with rental fees, security deposits, 1st and last month's rent, etc. *"Many of us are very low income and cannot afford moving fees"*
- Offering discounted rates (including installation fees) to low-income/disabled individuals
- Consistent funding for all independent living services
- Preserve current level of Regional Center Services
- Economic development programs to encourage independence from handouts/benefits
- Expanded services for disabled and abandoned former housewives whether or not they get alimony
- Services for abandoned older women (without children) are sadly lacking, especially health services
- Financial assistance for caregivers, housings

- Offering discounted rates (including installation fees) to low-income/disabled individuals

Need to enforce existing rights and access requirements

Survey comments related to the need to enforce existing requirements included:

- Cities to enforce existing public access laws
- The misuse of handicapped parking placards
- Enforcement of already existing laws -- building codes, etc.
- Legal Information and support when public agencies are abusing their power
- Safe Housing - Enforcement of existing rules and creation of new laws to provide such housing
- Need better police enforcement of folks parking in the van accessible parking access aisle. Need medical providers to severely limit how many temporary handicapped parking placards they sign for!
- Better compliance with building access codes by Architects, building Inspectors, etc.
- More buy in by the State and Federal government of the ADA and other laws to do with access
- More enforcement by local building officials of access standards
- More enforcement by state agencies of access standards

Accessibility of the built environment

Many people commented on access to public places, as well as access in and around the home: *“It is important to me that people, places, and all aspects of life be accessible to persons with disabilities.”*

- Accessibility in Educational facilities such as colleges
- Universal Design is very important: *“Roll-in showers are not as readily available as I’d like.”*
- Better Ventilation/ Air Exchange in Public Buildings
- Houses and public buildings without toxic materials: *“Why can’t government offices and public meetings, at least, be fragrance and chemical-free? There are many nontoxic alternatives to pesticides and caustic cleaning products.”*

Importance of the disability community and peer support

One participant who completed the survey mentioned *“Too much isolation”* and lack of social opportunities. *“I think the support or mere existence of a disability community is*

important to lessen the feelings of isolation and abandonment so common to those entrenched in or new to the disability lifestyle.” Related comments submitted by participants included:

- *“Being with TBI folks is the most incredible and helpful thing I can do. We all learn so much from one another. Am thankful for both programs.”*
- *“Working link of California disability and senior networks and coalitions to be effective”*
- *“One on one mentoring with person of similar disability various sorts”*
- *“Terrific need to network people with disabilities and cast aside egos, titles and just deal as people to put together a working document that can be provided to governor and state and federal legislators as one voice of those things which we demand and those things that we aspire to such as California Olmstead Planning.”*

ILCs

Several respondents praised their ILC, mentioning how much help they received: *“I have never found a better place to have my disability needs addressed on every level...They offer a number of workshops, trainings and other events that have been INVALUABLE to me and allowed me to believe that one day I might be able to function in the world of the employed again”* *“The local Independent Living Center is a great resource, but more outreach to individuals with development disabilities needs to happen.”* *“Well tied into our independent living center - a great help”* and *“I appreciate independent living centers and the services they provide.”* Respondents contributed ideas for expanding and improving ILC services:

- Expand services for Deaf and hard of hearing in ILCs as most of the focus is on physical disability
- Include disability in diversity training and policies
- More ILC outreach to individuals with development disabilities
- More Legal Services, and better information about various resources
- ILC Boards need to be trained so not to forget why they exist and what consumer control is.
- More emphasis and resources toward community advocacy and systems change rather than one to one direct services
- Educate people with disabilities about the need to volunteer and vote.
- All ILC staff trained in proper documentation, advocacy methods, customer service (especially courtesy and active listening), and working with people with disabilities

Suggestions for new or expanded ILC services

Participants suggested a range of new services or resources that could be developed by ILCs or others:

- Sensitivity / awareness forums in minority community
- Conduct outreach forums to ethnic minorities who are not familiar with Independent Living.
- Central 800 number and one central office where anyone can call to get disability information: *"We need a central resource center where families can access information they need for whatever problems they have - medical housing, recreational, whatever."*
- Volunteer services for home organizing, filing etc.
- Improved day programs with *"more employment and less glorified babysitting"* for people with medical needs; for people with mental illness; and others. *"A program that provides stimulation and counseling. This helps to reduce depression and loneliness..." "I feel the day programs are too few in this county. Many consumers in this [county] are have no programming"*
- Assistance with DMV issues.
- Assistance and funding in getting Service Dog - including how to handle landlords
- Cultural events for people with disabilities
- *Qigong and Tai Chi classes*
- An accessible "tool library" where disabled people could check out a tool or piece of equipment for a day or two, to get to some home maintenance projects
- Need for better information on access to benefits

Chapter 3: Key Informant Interviews

Key informant interviews provided an opportunity to address issues that may not have been covered in hearings, focus groups or forums or to enrich the information.

A list of key informants was developed by InfoUse and reviewed by SILC staff, who made additional recommendations. The 28 people included CIL directors, state and local government employees, Commission members in key positions related to disability services, non-profit agency people who serve people with disabilities and their families, persons with disabilities, and persons in education and research institutions. In phone interviews, these people discussed key issues affecting people with disabilities in California.

Interviews

- Ralph Acuna, Program Coordinator for Information and Referral for people with disabilities, City of Los Angeles
- Fran Bates, Executive Director, Rolling Start, San Bernardino ILC
- Charles Calavan, Executive Director, Public Authority for IHSS for Alameda County
- John L. Darby, Executive Director Emeritus, Hearing Society for the Bay Area; founding member, California Communications Access Foundation
- Nancy Dolton, Chair, California Commission on Aging
- Juno Duenas, Executive Director, Support for Families with Children with Disabilities
- Janet Eaton, Planning and Program Specialist, State Council on Developmental Disability
- Idabelle Fosse, Health Access
- Laurie Frank, re chemical and electrical sensitivity
- Louis Frick, Executive Director, The Access Center of San Diego
- Nancy Gardner, Executive Director, North Bay Regional Center
- Ann Guerra, Executive Director, Foundation of Resources for Equality and Employment of the Disabled (FREED), an ILC in Grass Valley
- Benjamin Harville, Chief, IL Section, Department of Rehabilitation
- Mary Lamar-Wiley, California Department of Health Services, Medi-Cal Division
- Herb Levine, Executive Director, ILRCSF – San Francisco
- Michael Mankin, Office of Universal Design, Division of State Architect

- Tink Miller, Executive Director, Placer Independent Resource Service, Auburn
- Christina Mills, Access Center of San Diego
- Tom Montasanti, Area I Developmental Disabilities Board
- Dan Passini, investment consultant, re electrical sensitivity
- Richard Patterson, Clinical Support Program Coordinator, Santa Clara Valley Medical Center
- Brenda Premo, Director, Center for Disability Issues and the Health Professions, Western University of Health Sciences
- Teddie-Joy Remhild, Community Liaison Coordinator, Personal Assistance Services Council of Los Angeles County
- Liz Rottger, Division on Aging, Department of Health Services, Marin County
- Dan Sorensen, formerly with the California Department of Mental Health, with the California Coalition on Crime against people with disabilities, represents ARC-CA, and Action Team on Crime and California Disability Advocacy Network
- Tanya Temkin, Disability Statistics Center, University of California, San Francisco
- Anthony Tusler, Appointee, advisor and/or volunteer, State Rehabilitation Council, WID, Disability Associates
- Patricia Yeager, Executive Director, California Foundation for Independent Living Centers

Interview Process

Phone interviews with 28 respondents were conducted following a discussion guide.

- What services or supports are needed to support independent living?
- What parts of the system are working well to support independent living?
- What do you see as barriers to independent living for people with disabilities?
- What do you see as gaps in service or support for people with disabilities to live independently?

Responses to these questions are summarized below in topical or thematic categories.

Findings

Most of the interview participants made it clear that independent living needs, barriers to independent living, and gaps in service were different for each individual

or different disability. The same need, barrier or gap could exist in urban or rural settings with a different solution needed in each case. Throughout the interviews, people stressed the importance of disability rights and advocacy.

Health care

Health care and health care benefits were of prime importance. As one disability leader and researcher stated, *“My career is managing my health care.”*

- Many interview participants viewed State proposed budget cuts to IHSS and Medi-Cal as the worst thing that could happen to people with disabilities who live independently and as threats to independence.
- Without adequate health care, independence is very difficult. Participants identified as a most critical need a community system that provides quality coordinated health care: primary and specialty care: access to appropriately trained health care specialists and generalists.
- The medical care system needs to be linked closely into community services. Physicians need to know more about what is available.
- There are access issues regarding health providers: health conditions can be exacerbated. For instance, communities lack accessible exam tables or other accessible equipment for certain tests (accessible mammograms were mentioned specifically). Access to needed health care is particularly difficult in rural areas that don't have specialists and don't have Medi-Cal transit providers. Just getting basic health care is difficult, as there are few providers that take Medi-Cal. It was also pointed out that a person with a developmental disability who lives in the community should be able to access Medi-Cal reimbursable health care specialists at Developmental Centers. Another interview participant suggested that Medi-Cal should fund more such as oxygen, basic health services, optometry and dental care.
- A large segment of the population does not have health care insurance. *“Look in any emergency room, its not always younger people with babies; often there are seniors and disabled people.”*
- Several participants supported universal health care.
- Another gap is strong long-term care services (not necessarily institutional services)– services that only seniors get, but people with severe disability need as matter of function, not age.
- A participant stated that *“The length of stay in hospitals and rehabilitation facilities for newly injured persons is too short. Neither patients nor families are ready to deal with issues of disability in such a short period of time.”*
- Another identified barrier is getting waivers to provide services at home instead of out of the home in institutional settings. *“The Medi-Cal bias to fund nursing home care rather than community care is a major barrier. There is a remaining institutional bias in favor of nursing homes for people with disabilities and the funding bias supports it.”*

- Access to medical care is problematic for people who are chemically or electrically sensitive. Medical expenses for chemical sensitivity are high. Doctors have to have avoidance management (air, water filters, organic food, etc.) If persons are house bound, they are out of medical loop as almost no doctors make home visits. Clinics that are mandated to serve low income won't make home visits. Mobile units that provide dental/ medical care aren't safe and are inaccessible to people with EI/MCS and ES. Many professionals don't understand EIMCS or ES and view reactions as psychiatric. A resource pool is needed of workers who are chemically clean enough to work with people with this disability.
- Almost anything wellness-related is not available to people with disabilities. For instance, one local TV wellness program had no interpreter or suggestions on how to make wellness available to people with disabilities.
- Health care in rural areas is a huge program gap. Federal Medicare regulations for HMOs require that a person must be within a 30 mile radius to be part of an HMO. People are forced to use the fee for service system that has very few doctors and few specialists. People often have to travel 100 to 300 miles round trip to see the specialist.
- *"The system works in unexpected places, some nurses, even doctors sometimes do a good job. However, all professions need education about IL. People with disabilities need everyone to be an ally and to support them in making informed choices."*

Some good models are developing. For instance, one interview participant described the Inland Empire Health Plan multilingual approach with material in print, disk, and Braille, and a range of disability services.

Personal assistance services

Personal assistance services were identified as vital to independent living. Participants identified several areas for potential changes:

- Expand the current IHSS program so the services are relevant to people cognitive disabilities.
- Home care, chore services, and personal care services need to be affordable.
- Most interview participants stated that human resources are a huge gap - not having an adequate, trained workforce, to provide quality services for people who can use them.
- Other needs include: good training for personal care assistants; adequate wages and benefits are needed for IHSS workers to increase the pool of people who will do home care, whether they are certified or uncertified.
- Reimbursement rates need to be adequate to allow dedicated professionals to work in the field providing services; many are leaving the field, as they cannot afford to stay in the system.

- In-home supportive services won't do in-hospital assessments before a person goes home. The person won't get service dollars until the IHSS assessment is done and the person often goes into a facility rather than home.
- IHSS people need to talk to organizations that serve people who are blind, Deaf, and developmentally disabled to make them aware of IHSS services.
- People with disabilities need training on hiring attendants and becoming employers.

Most interview participants said that California's In-Home Supportive Services (IHSS) works well because of consumer directed service, that IHSS is good for the majority of people who need the service, emergency worker services, if available, and registry services help to make Independent Living easier for people with disabilities. One participant commented that *"If people get assistive technology and IHSS, independent living is well supported."* Interview participants stated that compared to where the IHSS system was a couple of years ago, the Public Authorities are making the system more effective for people who use them, and making the system more user friendly. The Public Authorities have helped to stabilize the workforce and manage the paper work, screening, and hiring for the person with a disability. Public authorities are ranked high on the *"working well"* list for advocating for people with disabilities and providing an urgent care program. Public Authorities improved the ability to recruit and retain workers who provide personal assistant services.

Housing and "safe housing"

"Housing is so critical. A person has to have a place to live," "Even to get someone out of a nursing home, the person needs an apartment and someone to help them." Interview participants were quick to point out that there is no adequate stock of affordable housing in California either for the individual with a disability or the service provider (personal assistants). *"If you can't sustain a workforce, you will not be able to have independent living."* It was reported that most service and time-consuming effort is placed in finding and maintaining housing, which is compounded by a lack of accessible places for people with physical disabilities and landlord attitudes. *"The whole housing issue is a barrier: the lack of safe, accessible, affordable housing that is within walking distance to services – grocery stores, doctors, other services, movies, parks, etc.- is a barrier."* Concerns related to housing included:

- Housing needs to be near resources: transportation, grocery stores, pharmacies, shopping, recreation, ATMs, copy shops, etc. Safe housing means housing in safe well-lit locations. Much affordable housing often is located in areas that are in transition, in unsafe areas of cities.
- Access to and in the home is important. If a person becomes disabled, he or she needs to have funds to make home modifications, build ramps, etc. to get in and out of the home.
- Safety in the home is important. People are living longer and need support at bath, floors that enable them to move wheelchairs, accessible cupboards, and

other kitchen appliances. Someone should figure out how to make adjustments in homes.

- The interview participants indicated need for a range of housing programs and solutions to the crisis.
- The high cost of housing is forcing people to move into mobile home parks. These and modular homes need to be accessible.
- One participant reported that most housing being built are monster houses. *“Why won’t the community work to integrate everyone in moderate housing? Expensive assisted living facilities have been built that are not accessible then they charge extra (hundreds of dollars) for putting in grab bars or ramps.”*
- Housing needs to be of adequate size to accommodate lifts, wheelchairs and other equipment.
- Housing rules need to permit more mixed use of seniors and people with disabilities.
- *“There still are instances where a landlord raises the rent when a wheelchair makes marks going down steps or they have other ways of preventing people from staying independent.”*
- For persons with chemical or electrical sensitivity safe housing means housing made of materials that are less toxic, untreated wood, plaster on walls, floors that meet less toxic standards. For those with electrical sensitivity, some housing should not be near power lines, cell towers, and other electrical sources. ...Housing can’t be near polluted downtown urban areas. Some housing needs to be in suburban and rural areas so there are choices for varying degrees of sensitivity
- There is not enough Section 8 housing. The system isn’t funding enough in tight housing markets...programs have to grow. *“There are no aftercare certificates or Section 8 in this community.”*
- Housing assistance is needed: filling applications, negotiating with landlords for access issues around service animals, accessible parking, access to recreation in large complexes, issues around neighbors. A person initially may not be in an accessible unit, but if function declines the person needs additional access and needs assistance in arranging it.
- People with disabilities need to advocate with the federal government and local planning bodies for more housing and housing assistance, including funding for home modifications. Universal design in new construction needs to be advocated.

Transportation

To many, accessible community transportation means *“being able to use the same transportation as anyone without a disability, not having to rely on paratransit or other isolated types of transportation.”* Participants stated that transportation is critical in all its aspects as a needed support for independent living. They addressed public,

community-based transportation, paratransit systems and mobility issues. There are transportation problems in cities, in suburbs, and in rural areas. There is need for better accessible, available, reliable public transportation. Some said transportation is inadequate; others stated that transportation is a disaster. Transportation barriers include: lack of public transportation in rural areas, lack of centralized regional trip planning in rural areas, and lack of reciprocity among counties and between transportation systems.

- For people with disabilities who want to go to work transportation is inadequate. Participants iterated that transportation support is vital to get to work, to doctors, other health care service needs, and to participate in other life activities. In areas where transportation is bad, some provision should be made to go to the home.
- Some rural areas have no public transportation. In rural areas where there is public transportation, buses can't or don't run on schedules when seniors or people with disabilities need buses. These systems often operate on commute hour schedules. One interview participant reported that theirs is a big county and buses and trams are often a distance away from where people live. Some form of transportation is needed to get people to the Independent Living Center or other needed services.
- Paratransit services can be inadequate, and need to be better, more reliable, more responsive, and adhering to appointment and work schedules. Participants pointed out that each county has a paratransit committee, but that there is not much representation of people with disabilities on the committees and suggested that California ILCs should take an active, assertive role in advocating for appropriate paratransit services.
- In some areas, persons need or could use an electric scooter for transportation. However, they are not able to obtain them.
- Gaps in service depend on where you live. Rural areas need more attention than they are given. Rural interview participants indicated that when people retire they often move from the city to their more rural or mountain dream home. Then something happens and they can't drive to needed services. *"We need to do a better job educating people before retirement, so they make good decisions."*

Emergency services

- Participants recognized the importance that the state take the lead in developing concrete evacuation plans for people with disabilities in disaster situations such as fire storms, floods, mud slides and earthquakes.
- Homeless and battered women shelters are not accessible for people with disabilities, especially women who are Deaf.

Employment

Interview participants stated that many people with disabilities would like to work and need employment. *“Independent Living can be set up around Social Security, Supplemental Security Income, etc, but good jobs are a better basis for independence.”*

- The workplace is getting more rigid in how it accommodates and supports people with disabilities and human resource people are looking at people with disabilities from a deficit model rather than an asset model and need education to change this trend.
- Participants noted a need for effective pre-employment, pre-vocational and vocational services, including assistance or training for developing resumes, interviewing skills, training, and job search skills.
- One-Stops don't out reach to people with disabilities and they often don't meet code requirements for access, have inadequate signs or elevators that aren't working.
- When a person gets a job and the Department of Rehabilitation provides assistive technology (AT) or other supports, the process take may take too long. Sometimes jobs are lost.
- One of the early barriers to employment was the loss of Medicaid and Medicare services. One participant described the current California Medicaid Infrastructure Grant activities to expand personal assistance services into the workplace as a valuable resource.

Assistive technology/special supports/devices

Most interview participants strongly supported all types of assistive technology (AT). *“Without AT you aren't going anywhere else...without a wheelchair, ramps, computers, et cetera, ... you can't participate”.*

- *“We need to be AT advocates, to provide AT; AT needs a funding stream. We need some broad-based campaigns to let people know where to get information about disabilities. An advertising campaign about where services are available.”*
- Several expressed concern that the State budget crisis would put AT *“on the chopping block.”* Most stated that AT needs to be kept at least at current levels; that AT is a great addition to Independent Living services and should become a core service.
- Funding for AT and AT evaluations, training, and maintenance are needed. Technology is affordable; it works well, and ties into economic independence.
- Most people don't know there are specialized phones through the phone company, a free program, that can provide a cordless phone for those who have a mobility impairment, or phones with a loud ringer, TTD, or visual flashing ringers.

- Some participants identified a need for education of people with disabilities on disability rights, to learn how to advocate for themselves and request reasonable accommodations wherever they go.

Recreation and social access

Social and recreational opportunities should be available to everyone. Park and recreation programs need to be accessible. Other important activities were identified:

- At-home entertainment is needed: reading, radio, TV. *“The blind need additional support with talking books and Braille books, the Deaf need TV captioning.”*
- Several identified socializing as important to successful independence. *“People need someone willing to just talk to them.”* Interview participants identified peer and support networks as important to prevent isolation. However, they felt that peer support has become a lower priority.
- Community colleges often offer good programs and effective supports. Some local colleges have a person who works with individuals in small groups to help them to have life enhancing programs and programs for skills-development.
- Some community – based services such as Parks and Recreation programs are offering programs that are accessible to people with disabilities.
- Services for Seniors are available through the Older Americans Act Area Agencies on Aging.

Communication

Identified communication needs included accessible, affordable, sign interpreters and language interpreters, access to AT and information, and Internet access.

- People who are Deaf or hard of hearing need interpreters in the community – places, agencies, organizations and services don’t provide interpreters.
- All kinds of interpreters are needed-- sign and languages other than English. Interpreter services particularly are needed for medical appointments and for medical services. TDD or speech relay is also needed. There have been some problems accessing 911.
- Many people with disabilities have limited access to the Internet and really try to get to the independent Living Center to access the Internet.

Access

Access to everything is important: not just mobility, but self-care, communications and carrying out day to day activities such as using an ATM, making a photocopy of a record, going to the corner grocery store or laundromat, or accessing community services.

- Lack of unity in the disabled community is a barrier to resolving disability issues. Tensions between the disability community and the aging community were cited as one cause of fragmentation and lack of coordination.
- The state system and health care has no uniform point of entry or assessment; people receive various services, have a myriad of case managers, and it's not coordinated. *"I would like to see providers in the county work together...it will reduce duplication of services and conserve resources."* While there has been moderate success in providing information in some areas, there is no central clearinghouse – each part of the system is working in itself, but they don't collaborate or interconnect.
- The lack of policy expertise in government regarding the continuum of services has people making decisions based on stereotypes – care based on what they think people can do or need, not what people can do or what the person really needs.
- Planners and public policymakers need to be aware to make communities livable for people with disabilities. *"County plans are not that bad, but the information is not getting back to the legislators. The state level needs to begin to learn how to make compliance documents more useful." "Roles need to be defined to establish who is responsible for what phases in creating accessible housing. A systems approach is needed to make sure plan reviewers review and enforce what is enforceable. There are problems in construction because everybody thinks someone else is paying attention to universal design and related accessibility issues."*
- *"People can go to school and get an education now. The world is so much larger for people with disabilities."*

Need for adequate resources

Lack of sufficient resources was identified as a major barrier. *"As a society we don't have the commitment at any level of government to support community living – put our money where our mouth is."*

- Funds are needed to help people in a rental crisis, to make ends meet for rent, for PG&E, and for food. There is never enough money to help people for food, clothes, medical equipment, and other necessities.
- One interview participant explained that his organization developed a revolving fund, *"I would like to see the revolving fund grow so that people can borrow from it and pay back when they can. This helps with the moving process, first and last month rent, etc. This kind of non-governmental face-to-face support can help make or break independence."*
- Meals on Wheels, available to seniors, are needed by people with disabilities, too, so that people have enough food.
- *"People living on disability benefits are losing buying power. They can't get what they got a couple of years ago as rents and transportation costs go up."*

- The entitlement program limited to a developmental disabilities, under the Lanterman Act, could be broadened to cover all disabilities.
- Many people don't pay attention to being disabled until they become disabled. So people don't know what services are available or how to find the services. People need to know how to navigate the maze and get the information needed to live independently with the disability. Families need resources and information to understand issues regarding the disability of a family member
- The ability to access information and resources varies greatly from area to area. There is a communication gap, procedural or process gap between people who have resources and the people who need them, with no over all quality control. People who provide services need to be adequately trained on what the needs are and what services meet those needs.
- Access to information must be timely. People need information about their options, how to access services, who's got the services they need, and they need the information at the right time. People who are injured or go on state disability who will have a permanent or long term disability may not be informed early enough about the deadline date for applying for long term or permanent disability benefits. When informed too close to the deadline there is inadequate time left to apply for benefits and people lose out and go long periods without services and assistance.

Attitudinal barriers

Attitudes on the part of the public and professionals can create barriers. This is difficult because you have to change human behavior. Interview participants echoed focus group comments that prejudice and fear of disability runs so deep and is so pervasive that there is a lot of work to be done in changing attitudes. It was suggested that a great deal could be learned from the diversity community in order to make attitudinal changes. Other interview observations included:

- Many people think of individuals in wheelchairs as "the disabled", but there are people with other disabilities, including hidden disabilities .
- Many Seniors don't like to consider themselves disabled and this is a major obstacle as there are issues that ILCs and seniors can get together to advocate for.
- *"Marketing is a problem with adult day health care programs. Older people don't want to go there, but they like it when they do go. These programs need another name, perhaps call them day outpatient clinic. Because of this bias on the part of seniors, these programs are struggling."*
- Attitudinal barriers make access to housing and employment very difficult. This is especially true for people coming from institutions who are living in the community for the first time as a person with a disability.
- To avoid developing additional systems barriers, the service system must adapt to changing demographics, including the aging of the baby-boomers,

the increase in autism, the changing ethnic makeup of California and the number of individuals who do not speak English.

- *“When I look at other systems like environmental efforts to conserve resources such as waste management programs that have a short term price for long term gain, people are voluntarily into it. This same effect has not been seen in disability. People resent doing something for a group that has special needs. This failing combined with a lack of partnership with service providers to generate buying power or market niche exacerbates the attitudinal barrier.”*
- *“People are defined by diagnosis or medical reason. It is impossible to get out of the cycle. If a person becomes successful, the disability doesn’t go away, but the supports that enable the person to become successful are taken away.”*
- Another issue is that insufficient attention is paid to diversity. A program may serve blind only, but may have biases by age, gender, race, cultural issues, sexual orientation or other factors.
- Schools need to find a way to negotiate access for kids with disabilities; attitudes of teachers and other kids toward people with disabilities need work. It was suggested that disability should be part of diversity discussions. One participant made a strong statement about Post Secondary programs, *“Burn the programs down and start over. Disability programs need to act like diversity programs – they need to provide both service and diversity. People with disabilities need to be working in these programs.”*
- Some felt that there need to be legal sanctions to actively prohibit discrimination.

ILCs

The ILC system in California is tied together through a strong state organization. The California Foundation of ILCs, and the Department of Rehabilitation’s Independent Living Section that works as in partnership, not just in administering funds, but in implementing and making possible community living. Some ILC’s are very strong. Information flows well. Some ILCs are doing systems change and AT well. Some ILCs are doing a good job at putting together a good array of services to help people make the transitions. CFILC and the ILC system have created an awareness of people with disabilities being in the community. Opportunities for peer support through ILCs and other organizations bring people with disabilities together.

- The systems change network is getting consumers involved in creating change, e.g., universal design is now in the affordable housing plan in one area.
- Statewide, the network is getting information out on legislation that affects people with disabilities.
- The Department of Rehabilitation’s Independent Living Section is educating centers on an ongoing basis about what is needed to fulfill state requirements.

- The Department of Rehabilitation has improved with client focus rather than program focus.
- Teleconferences among the ILCs invite allies to participate in meetings.
- Support groups for people with spinal cord and brain injury, where they exist
- Some supported living programs are better than others. The good ones help people keep clean, keep homes clean, provide financial tracking, nutritional tracking, and other support services.
- Advocacy – individual advocacy, self-advocacy and system advocacy are working well; they could be better, but they are working.
- Some less-populated rural areas work better because they are more collaborative and have more access to the local power base and people are willing to help.
- The level of access to the physical environment that we have in this state.
- Senior Centers provide meal sites and offer a whole range of programs such as health, wellness, computers, and other activities, etc.
- Some Information and referral systems are working. Also, Center listservs
- *“There is better telecommunication through the Internet. This is very positive for people with disabilities to feel fulfilled, to get information, and to make their ideas and opinions known. This needs to be stimulated and made more available. An example of how it could be done is surcharges on phone bills.”*

Interview participants identified a number of gaps in services. Some of the gaps also were considered as barriers to independent living. Following are those gaps mentioned by a number of the participants.

- Disability groups try to work collaboratively, but there is no structure or financing to encourage collaboration. The Department of Rehabilitation should take a lead role in encouraging collaboration among agencies and organizations.
- Services that people need to have to live independently are not being provided; services often aren't available or there is a lack of funding for existing services.
- First responders: emergency medical technicians, police, law enforcement, firemen, and Regional Center and Mental Health staff, and consumers with disabilities need cross training so they get to meet each other and understand different disabilities.
- Better markings are needed for pedestrian safety; people with disabilities often can't make it across the street before lights change.
- Some ILCs focus on service without a corresponding commitment to policy change that could effectively inform the development of their services.

- Need for more Independent Living skills training by ILCs and other community organizations. There are resources in the community besides ILCs that provide skills training such as menu planning, budgeting, etc.
- In general, demand for ILC services has outstripped the supply. There are waiting lists for meals and other services. Since ILCs and Area Agencies on Aging are not top heavy with administrative overhead, there is little room for cuts.
- ILC service system needs to develop consistent, quality training for employees, develop people to go into other jobs in the system. Basic training is needed to learn what does and doesn't work so people don't have to start from scratch.
- Lack of Independent living skills training or advocacy in skills are identified as barriers to independence.
- Many ILC employees need to know IL history, philosophy, and policy. Staff persons should be trained to know when to refer a client over to another person who may have more expertise to serve the client.
- Centers need to have a consistent quality of information.
- Staff of ILCs should include people with disabilities, but the variety of disabilities and culture of the community often are not represented.
- There is a lack of consistency of services from center to center. Some centers offer transportation, some don't; some centers offer employment some don't.
- Staff need to be able to look at all different the services available to a person with a disability. Generally, staff is trained to give different specific information; so one counselor may be able to give more thorough information than another sitting at the next desk. Thus, the training to know when to refer a client to another staff person is essential.
- Communication between ILCs, the SILC and CFILC needs to be improved.
- ILCs were set up to be disability community-based, grass roots, organizations. Centers need to go back to local community collaborations, working with other groups, and complement each other.
- There needs to be more ongoing training for staff on current services of the ILCs and new and emerging issues.
- All ILCs should learn about environmental illness, chemical and electrical sensitivities and train staff and clients about keeping the organization accessible to these folks.
- ILCs need to look at recovery issues for people with disabilities who have a higher incidence of alcohol and drug abuse. Significant support for drug and alcohol abuse is needed. Someone who recognizes substance abuse and knows how to deal with it is needed.
- ILCs need to advocate with mental health services to get accessibility in substance abuse programs or offer it as a component.

- Services as well as support need to coincide with the cost of living in the area. ILC staff cannot live on their own unless they have subsidized or low-income housing, or share housing.
- Services that ILCs provide are based on expertise with a disability, but other agencies may not have that expertise and they tend to tell the client what they think the client should do or need, which often is demeaning to the client.
- *“ILC’s are doing some good programs, but are problematic; they used to be only game in town, but they don’t know how to collaborate with others who provide services to people with disabilities. ILCs need to work on outreach on an ongoing basis – to city officials, new, local and historical agencies that provide services to everyone, and to community groups and projects. Open communication will result in proper referrals and information among agencies.”*
- ILCs need to work on the way they present their services so they appear attractive, something that will capture the consumer to want to come to the ILC to learn what independent living is.
- An array of community services are needed from wheelchair maintenance to a friendly visitor program, home delivered meals, etc.
- There is a need for a greater number of staff members familiar with the IL philosophy who have experience with disabilities – personally or having experience working with people with disabilities.
- ILCs need to develop an exchange about best practices.
- Seniors and people with disabilities need to speak with a louder voice to builders, contractors, and architects to use universal design in new building and to modify structures to accommodate aging population.

Regional Centers and services for developmental disability

- The self-determination pilots in the DD system are working. They put the individual at the center of the system. There are 3 official pilots and 3 regional centers are doing it without state funding. The consumer, and, if appropriate, the family, get to say what services are important to them. The purpose is to facilitate consumer and family control of public funds for services in the IPP. Services are designed for the individual rather than the individual molded to the services.
- From the DD perspective, the early start 0 to 3 population program is more supportive than adversarial than the rest of the system.
- As there is more movement into supported living and independent living some people with DD or cognitive disabilities want friends and are more vulnerable, more subject to predators. They fall prey to things that people worry about with their children. *“People with DD get their checks at the beginning of the month, predators come around and entice them through drugs and alcohol, then the person with the disability is broke rest of month.”*
- Those who are eligible for Regional Center services can get help.

Olmstead and transition to the community

There needs to be somebody responsible for issues of transition from skilled nursing facilities; that it is much more difficult to get someone out of a nursing home once they are in one. In one to two weeks a person can be demoralized. In 2 out of 3 cases people are afraid to return home; afraid they could not get through the night alone.

- Different services and supports are required at multiple stages. Services and supports are needed for people who are transitioning into independent living.
- *“Olmstead is an unfunded mandate. There is no money, housing, no money to fund transition.”*

Youth services

There needs to be a broader range of services available – more youth services, e.g., IEP specialists, transitioning counselors, and benefits advocates specifically geared toward youth.

- Policy makers need to understand that cuts to one part of the system hurts other sections that support people. There does not seem to be an understanding of the interconnection of services. Reducing pay for home care to minimum wage and with no benefits will make it harder for people to live independently. IHSS is a basic safety net program. Cuts will cause the most severely disabled to have to go into board and care or other institutional settings.
- Another level of services needed is for young people transitioning from their parents’ home to independence. They have to learn to be employers at an early age, learn IL skills, etc.
- Questions were raised about why young people are not connecting with ILCs. Is it because they are mainstreamed, or that transition programs aren’t giving all the information that would include ILCs?
- Young people with disabilities are being groomed in small numbers to be future leaders.

Chapter 4: Hearings, Forums and Meetings

The Needs Assessment hearings and forums provided an opportunity for people with disabilities to express their needs and concerns and to identify barriers to independent living. Meetings with the SILC during the project provided the opportunity to discuss study findings during the SILC planning process.

Hearings, forums and meetings were conducted during the Needs Assessment project to gather general information on independent living needs and barriers to independent living, and to present and discuss interim findings of the needs assessment.

4/30/03, San Rafael, California. Four forum discussions - transportation, housing, developmental disabilities and moving people out of nursing homes - were facilitated as a part of the 4th Annual Independence Forum of Marin County Unity: Celebrating Life with a Disability.

5/1/03, Oakland California. This hearing was coordinated with the SILC Northern California Public Hearing Regarding Proposed Amendments to the 2002-2004 State Plan for Independent Living and the northern California premiere showing of the video: *The Power of Independence*.

5/5/03, Woodland Hills, California. This hearing was coordinated with the SILC Southern California Public Hearing Regarding Proposed Amendments to the 2002-2004 State Plan for Independent Living and the southern California premiere showing of the video: *The Power of Independence*.

2/5/04 Sacramento, California. Public Hearing and Forum regarding Independent Living Needs of Individuals who are blind or have visual impairments. Conducted jointly by the SILC and InfoUse.

4/1/04 Los Angeles, California. Forum for people who are Deaf or hard of hearing. Conducted jointly by the SILC and InfoUse.

4/9/04 Riverside, California. Forum for people who are Deaf or hard of hearing. Conducted jointly by the SILC and InfoUse.

In addition, we attended four meetings with the SILC in Northern and Southern California, and presented interim study findings during the SILC planning process. Detailed comments and suggestions from the public meetings and forums follow. For each forum or meeting, the report includes a meeting summary of the discussion topics and presentations.

San Rafael - Marin Independence Forum April 30, 2003

Transportation

This forum break-out session was concerned with local Marin County and Golden Gate Bridge Transit District service information and the need to cut \$20 million of district operating expenses. The District developed 3 different scenarios: Inter-county emphasis, ferry emphasis and Marin mobility. "Lifeline" issues included persons with disabilities.

As a result of community outreach meetings, comments were received and narrowed down to one scenario with modifications. The scenario involves more segments covering existing service areas. Features are some hourly routes and some half-hourly routes, more transfer points. Are there shelters at new transfer points?

The population in wheelchairs who are going to be in San Francisco and can't get back to Marin after 10:00 p.m. needs to be addressed.

There are not enough bus routes and schedules are limited to certain hours: it can take all day to go to College of Marin to take one class.

Housing

This group discussed housing issues for people with disabilities. Concerns included:

- Find a way to increase units available for certification/vouchers throughout community.
- Open dialogue and problem solving for increasing diversity of disabled/elder populations mixed in same locales or communities
- Need for more available advocacy/communication/workers as differing "barriered" populations live together in same communities, while maintaining confidentiality/privacy concerns in appropriate manner
- Expand shelter-plus types of programs (shelter plus services). There is a growing need.
- Broad-based community input/idea development for more adequate low-income housing
- How to handle "NIMBY" more effectively?
- Solicit more citizen participation in planning issues – from both for profit and public interest arenas.
- Arrange for people on both/opposite sides of housing/development issues to meet and find out about each other.

- Define what “workforce” populations are in our communities and what the housing related issues are as they define them: financing/buying, availability, locations, etc.

Needs of people with developmental disabilities

This forum breakout session was one of the largest with over thirty people with developmental disabilities and their advocates. The following needs were identified:

- Need help in finding an affordable place to live
- The high cost of living and high cost of housing makes people with disabilities poor.
- Opportunity for home ownership should be available.
- Wants a respectful roommate
- Board and care home is noisy and loud
- Paratransit schedules endanger people with developmental disabilities who are vulnerable (they come early or late, putting people at risk). Drivers treat everyone as equals; staff needs education about the vulnerability of people with developmental disabilities. Advocacy and education on these issues are needed.
- Access to medical care: there are very few Medi-Cal providers because the rates are too low; those who are there aren't great; without advocates people don't get services. The quality of medical providers available suffers because of low rates. Need Universal Health Care.
- Impact of the relationship between Health Care Licensing and Intermediate Care Facilities because unavailability of health care providers (facilities get cited, but are given no assistance in solving systemic problems); why doesn't everyone get together to solve the problem?
- Dental care is an issue. If one is on Medi-Cal there are long waits for appointments.
- Sometimes it is difficult to get prescriptions for custom chairs approved.
- It's a struggle for people with disabilities to advocate and get respectful treatment and to get assistance with dignity.
- Concern about proposed cuts in budget and the loss of day and work program services that enable independent living
- The living wage in Marin County is about \$21/hour. Rates in DD system make it possible to pay \$9-10. Employees end up working several jobs – this impacts quality of care.
- Health Care Licensing fines ICFs for not having physicians and other health providers. Fines do not change the situation of lack of availability of Medi-Cal providers.

- SSA: *"SSA is not customer friendly"*. There are problems with mistakes. Too bureaucratized. Uses too many resources to fix minor problems (\$2 overpayment generates a six-page letter that is hard to understand.) Need to foster better relationship between SSA and consumer. Issues of reporting and adjustments make it hard for people to know how much money they can count on from month to month. Delays in adjustments on SSA payments affect people's ability to budget. Must make copies of everything you send to anyone. They lose papers. Work impacts benefits and errors in overpayment are too complicated and bureaucratic for people to handle alone. SSA should have a point person for the community who understands disabilities and can assist with benefits.
- Access to emergency wheelchair maintenance on weekends. Repairs take time and affect ability to work.

Getting people out of nursing homes

This forum break out session resulted in the following points:

- *"Keep people OUT of nursing homes in the first place! Talk to people who are IN institutions (not just professionals.)"*
- Get to know Skilled Nursing Facility (SNF) staff; build relationships. Local CILs may provide services/housing for SNF residents. CIL will publish *"How to Survive in a SNF..."* on the rights of SNF residents.
- Do better assessments – people lose courage to live alone and people feel safe in nursing homes.
- Challenge is to put in place long term more national efforts that will equal independent living training or role models.
- Public Awareness – Engage the media, tell the story, do media training, and use the editorial pages to ratchet up the media exposure.
- Nobody wants to go into a SNF, but assisted living is *"different."*
- Where is the advocacy for *"supported living"*? Are CILs out there advocating?
- *"I don't want to go into a nursing home. I need people who care, who know who I am."*
- Community living advocates need to be put in place – to help people STAY independent.
- Need adequate personal assistants who are responsible and reliable.
- Expand IHSS to make it relevant for people with cognitive disabilities. Expand IHSS hours – as a funding issue – redirect money to community care.
- Need public education on sub-standard care in SNFs
- The ability to visit housing is critical.
- Architectural barriers are problems and Universal Design is needed.

- Create a culture of independent living. Disability is feared and unacceptable. People feel a loss of dignity.
- Empower persons to be independent.

Oakland Hearing - May 1, 2003

Housing

- Both people with disabilities and their employees need affordable housing.
- CILs need to be able to provide more info concerning housing or perhaps can provide technology to community to assist with finding affordable housing.
- Personal safety issues were also discussed. Many of the areas where people with disabilities can afford to live are not safe.
- Would like a "How to Guide" on certain issues such as how to get the building to install bars to help with safer bathing

Transportation

- Public transportation is not reliable. There are no benches or shelters for bad weather and the bus is often 20 or more minutes late.
- There is need for more hours of scheduled service / nighttime service for those who work late.
- Paratransit service often arrives too late or too early and the service is inconsistent. Paratransit must be scheduled ahead, trips not planned well.
- Need more access to other forms of community transportation

Health care

- Mental Health Care Services: Often mental health care and counseling is not given unless the person has become suicidal.
- More preventative care is needed and sensitivity training given to hospitals and organizations concerning depression and disability
- Services are too expensive, the average price for sliding scale is now \$50.00; this is too much for those living on fixed or small incomes. The \$5 to \$10 dollar range would be much more affordable.

Employment

- More education is needed for employers, since many are uncomfortable with hiring people with disabilities. The primary goals of the education would be to show the value and stability that employees with disabilities offer.

- Employers also take long amounts of time installing any assistive devices or software that employees may need.
- Employers concerned with compatibility issues of assistive software with current software.
- Also the employment process for people with disabilities is lengthy compared to the process for non-disabled candidates.
- There is a great need for ILC counselors to prepare persons with disabilities to be in the workforce.
- Once employees are trained there is not enough money to hire them, not even part time.
- Career days are needed for children with special needs.

Education and training

- Outreach programs need to attempt contact with youth with disabilities and their families far earlier in the education cycle.
- Most outreach is done in High school. It should be ages 0-21 instead starting at age 16.
- Peer counseling and mentoring from similar age/background/disabilities wanted (would like CIL as well as other organizations to provide)
- More assistive technology is needed in schools.

Access to information and resources

- Need internet access to assist with searches for jobs and housing
- Also there is more need for alternate formats and large print.
- Currently you can go through the DOR for some technology resources but the process is lengthy and funds are limited.
- Need more access to technology and those trained to help people use it

Financial support

- How can I get more money from the federal government?
- Payments from SSI /SSDI are small...and working reduces them further.
- Medication, AT and PAS funds are coming out of my pocket ...where can I get assistance?

Communication needs

- People need appropriate language services, including English.

- People with cultural or language barriers need translators, assistance in getting IHSS and filling out forms.

Disability rights

- People with disabilities who are victims of crimes need legal assistance.
- Legal assistance in general not affordable or available to people with disabilities.

Equipment and assistive technology

- Need places where wheelchairs can get charged near home and work.

Legal issues

- The legal system in general is not accessible because it does not accommodate for disability throughout the process.
- There are regulatory barriers that prevent people with disabilities from learning how to take and monitor medications on their own.

Deaf/hard of hearing

- Deaf and hard of hearing-would like to see more topics concerning their issues (legal issues, access to alt formats).

Spanish language services

- Language access at the CILs is limited; there is need for more interpreters.

Immigrants

- Many immigrants who have lived in the U.S for 15-20 years working on a permit cannot apply for benefits because of citizenship status.
- Many members of Asian communities still need outreach. The families and the individuals react to disability with "shame" and won't seek help from CILs on their own .

TBI or cognitive disability

- People with developmental disabilities and those with cognitive disabilities would like to see more topics for their concerns.
- People with cognitive disabilities cannot take the citizenship tests successfully.

Woodland Hills Hearing - May 5, 2003

Housing

- Need cities to provide land to build new housing

Transportation

- Improve the provision of non-emergency transportation to reduce fears of being abandoned at the door of a facility.
- Reduce segregation in the transportation system (paratransit being the transportation for a person with a disability)
- Make paratransit less discriminate and more helpful.
- Make general transportation more fully accessible.

Education

- Provide effective communications access for deaf and hard of hearing students in educational settings.

Domestic Violence

- Need a support system for victims of abuse by family or caregiver. Need somewhere to go or to call in case a disabled individual is in a helpless situation or in case a family member or assistant becomes violent.
- Prepare school systems to deal with abuse of children with disabilities. Make sure that children with disabilities have a voice and are treated the same as non-disabled peers in cases where abuse may have occurred.

Personal assistance

- Need to see IHSS brought up to date, especially in regards to emergency services and respite services.
- Provide funds to implement respite services.
- Require background check for all individuals in the field of interpreting, personal assistance, guiding, or assisting of any kind.
- For IHSS, provide background checks even if a PA is selected who is not on the regular list.
- Make PAS an occupation that has value rather than a low-income unimportant job; use political pressure for higher pay and/or certification and training.
- Establish minimum standards and licensure for interpreters.

Employment

- DOR needs to more consistently provide assistive equipment to the individual with disabilities at work to ensure that employees start working as soon as possible.
- Implement state laws about employment discrimination.
- Businesses may see hiring a deaf individual as expensive and bothersome due to the assistance required. A communication barrier exists. Many individuals would rather stay on SSI because trying to find a job is discouraging.
- More accessible opportunities and training skills are needed.

Rights

- Adjust the CAP system to provide a true method for people with disabilities to make a complaint about services without fear of retribution (like loss of services) as it is a conflict of interest to have the CAP program and who was being complained about in the same agency.

Emergency services

- Red Cross emergency shelters need to be accessible.
- Need better and more consistent captioning services for television, especially for emergency situations.

Communications

- New 211 phone line needs to be accessible and use existing experiences (Are they going to have a TTY? Are they prepared for people with cognitive disabilities?).
- Awareness training for telephone operators is needed (211 and otherwise).

Recreation

- Recreational options need to be broadened and made accessible (e.g., having one event once a year for kids is not enough, need to have accessible trails, need to have effective communication access).

Information

- Disseminate public information about how to keep Medi-Cal if earning up to 250% of poverty level.
- There is need for more up-to-date resources for parents with disabilities.

Sacramento Public Forum: Issues of Concern to People who are Blind or Visually Impaired - February 25, 2004

This forum was conducted in conjunction with the SILC hearing on plan sections related to blindness. Participants made the following points.

- There are three phases of blindness that must be supported: the adjustment phase, reinforcement phase and lifelong supports. For example, if you move you may need a mobility instructor to acclimate you to the new area. There is no set program for this. There needs to be an individualized sensitivity to meet needs at a given point in time. Current services are one size fits all and that doesn't work.
- Core Services are needed for people who are blind or who have impaired vision. Participants assumed that core services were in place or should be available to every Californian who needs them. But services are slanted toward persons who have means (financial). And unless one speaks English or is computer literate it is hard to get services that are available. Even if you live where there are services, you don't have the self-confidence to speak for yourself. There needs to be mentors/advocates to help navigate the system.
- Medi-Cal doesn't cover testing strips for people who are not insulin-dependent to prevent neuropathy – diabetic retinopathy.
- There need to be more youth programs like those of the Foundation for the Junior Blind. This is a non-public special education school. It takes as many as 20 teenagers on outward bound experiences, dog sledding in Minnesota. It contracts with a dozen school districts for its services. It is critical that kids feel okay about themselves. Youth programs provide this. Families are very protective of children and don't let children do much for themselves. One service has a three week program for youth 16-21. Children need social skills: appropriate interaction with sight-oriented peers, (dating, etc.) Children describe negative, discriminatory public school experiences: canes are stolen from them; they are teased.
- ILCs do Independent Living skills training, mentoring and peer counseling. Organizations that serve the blind do this, but there is not enough. Whoever does these services have to understand blindness. AT training is specialized for the blind, ILCs may not have these skills.
- We don't have family resource programs for the older population that is blind.
- Residential programs enable you to become part of the blind culture. These programs teach what people have to learn to live in a visual world. These programs teach how to do things another way and provide an opportunity to talk with others and get ideas. Short-term residential programs are good for the newly blind. Residential settings are not good, though, for the frail elderly; they need training in their own homes. Learning how to allocate energy is a problem.

- Issues: How do you keep people who are blind out of nursing homes? How much do cultural issues affect non-participation? For example, in ten years, a service two blocks from Chinatown served one person who was Chinese and blind. Blindness may be considered an imperfection to remain hidden in some cultures. Another person reported that their recreation staff is Hispanic so there is a natural connection.
- Everything you do is complex. For example, public transportation: ride BART every day, but it is easier to ride a bus. You have to figure out how to use BART without the benefit of sight. Complexity can be simplified if you develop routines. This also saves energy.
- Education needs to include knowledge of career options, what is expected in a work setting and expectations about jobs need to be addressed. Not *"Tell me jobs blind people will be hired for."* (Like stuffing envelopes) but: *"What are your dreams and aspirations?"*
- Things that are working well include free talking books from the Library of Congress can be obtained through the mail, NFB (National Federation of the Blind) telephone newspaper, and accessing newspapers online.
- Work has improved due to access to computer applications and the Internet. For example, 15 years ago 1-2 hours of secretarial support a day was needed, now it is about 1 hour per week. Increased availability of Braille helps by printer in the office. As much as possible is done by e-mail. Very few seniors are on the Internet – about 20%; this will change with the baby boomers.

Los Angeles and Riverside Forums on Deafness - April 1 and April 9, 2004

Needs and suggested solutions

During the forum, it became clear that finding locations providing services and acquiring information about these services was a need in the Deaf community. Some may not know how to go about acquiring benefits such as Medi-Cal and Supplemental Security Income (SSI), and if there are services available to help deal with the paperwork and processing of related forms. Reference was made to the Website www.disabilitites101.org, which was created by the World Institute on Disability (WID) and may assist with some of these needs. Other services such as adequate childcare is lacked for both children who are Deaf and for hearing children who have parents who are Deaf.

A need for more information regarding interpreters was also expressed throughout the forums. One person felt that it would be helpful if Independent Living Centers (ILCs) were to set up interpreting service agencies or at least keep a list of interpreting service agencies. It was also mentioned that One-Stop Centers should provide sign language interpreters and social service agencies should hire their own

interpreters rather than contracting with outside agencies. (One person felt that One-Stop Centers are improving but are still inaccessible to people with certain types of disabilities). Interpreters in the schools were sometimes denied to students with hearing disabilities due to funding costs or lack of resources (some felt that it also may be due to bias). The Center on Deafness Inland Empire (CODIE) was mentioned as a potentially helpful resource for dealing with interpreter issues. The Regional Center also was mentioned as a future resource as they are currently in the process of creating a Website that will provide information that will make lists of interpreters available.

Others voiced concern about vocational rehabilitation services: there was a sense that the counselors do not seem to be on the client's side. Individuals felt that they have to fight for every service that they are already supposed to be receiving. When violations of the Americans with Disabilities Act (ADA) are recognized, it was not known where one could go to register complaints.

A need also was expressed for better social outreach. Finding local support or information on STI, STD, cervical cancer, teen pregnancy, HIV and AIDS for people who are Deaf was mentioned as a great need as conventional methods for disseminating this information were not reaching the Deaf community. It also was suggested that there is a great need to have trained counselors who are available to work with individuals who are Deaf in mental health and substance abuse programs (perhaps more scholarships should be made available to encourage more people to enter this field specifically). Other possible sources of help with these issues may include CODIE, the Community Access Center, Department of Rehabilitation (DR), ILCs, and the Greater Los Angeles Association of the Deaf (GLAD).

Concern about the educational training for interpreters

There was a request for the Department of Rehabilitation to teach communication skills in adult education settings so that they learn American Sign Language (ASL) well enough to get further training. It also was mentioned that training in sign language should be available at an early age (e.g., Head Start programs) and continued throughout the series of school years.

There was a concern about the AB-2912 bill requiring certification to all interpreters: those that are qualified (but not certified) would be eliminated as a resource all together. It was felt that *experience* (and not necessarily certification) was the key factor in being a successful interpreter. It was mentioned that the Coordinator Advisory Network (CAN) is having a meeting to discuss issues related to the AB-2912 bill on May 7, 2004.

Access to technology

Access to technology varies in the Deaf community due to a number of different factors. Many cannot afford paging technology devices such as "Sidekick" and "Blackberry" that allow the user to send typed messages over a wireless network.

DSL links to the Internet are also expensive, but offer many possibilities for assistive technology within the Deaf community, such as video relay and third-party interpreters. The California Telephone Assistance Program (CTAP) offers some telephone services free to those who are Deaf, hard of hearing, have low vision, or qualify due to other kinds of disabilities. Rolling Start also helps people with disabilities get connected to technology and also may be a useful resource.

Others were concerned about determining which technology best met the needs of the individual. For example, some people may not have verbal skills; others may not have typing skills, while some may only require amplification. One person mentioned specifically that they would like better communication with Social Security using a Video Relay Service (VRS) rather than typing back and forth as not everyone has this skill. Some people with cognitive disabilities also may not be able to use the TTY; so video relay would be better in this case (if it is made affordable). Others voiced frustration with TTY relay systems like 711 where often there are hang-ups. Relay systems sometimes take long periods of time to communicate between two people, often resulting in frustration from either party. Even systems like "Sidekick" and "Blackberry" were criticized for long relay times and do not have any option for speaking orally, which would be desirable for some. A representative from the California Association for the Deaf (CAD) brought up a newer technology called "speech to speech" which is a different kind of relay system. With all of these kinds of technology available, it is sometimes confusing determining which system works best and meets the needs of each individual within certain financial and physical constraints.

Employment and other financial concerns

Although employment was not discussed extensively at the forums, one person did mention that they felt that employers did not want to pay for accommodations for people with hearing losses. It was suggested that employers would be more willing to provide accommodations to people with disabilities if they had access to federal incentives such as tax write-offs. The Job Accommodation Network (JAN) website specific to job accommodations was mentioned as a possible resource.

Two other financial concerns were voiced during the forums. One was related mainly to finding funding for communication devices for people who are Deaf and hard of hearing (see the section "Access to Technology" above). The other was related to health care and the ever-rising costs of items like hearing aids (SSI may assist in these cases).

Communication issues (accessibility)

A number of frustrations were voiced about access to information in society as a whole. Shopping malls generally do not have TTYs available. Airports do not have adequate alternate methods of alerting people to important information such as flight changes; trains do not have screens to explain the source of a delay. Fast-food drive-through systems also do not have ordering options for people who are Deaf.

Transportation and paratransit services staff do not know how to use TTYs and sometimes require their clients to use the relay system.

There also was mention of difficulties with various captioning systems. Movie theaters often do not have captioning available, or if they do, it is at an inconvenient time (causing social isolation). Sometimes the technology used in the theater to allow captioning only for the individual makes it difficult to see the screen properly. Although not all of these issues were addressed, the Website www.insightcinema.org was mentioned as a resource that lists captioned movies by geographic location. News broadcasts sometimes have two conflicting captioning systems that block each other and make the broadcast confusing. One person suggested that it might be better if the captioning was on the side, or ideally it would be helpful to have a separate screen with an interpreter. It also was noted that captions are not helpful to non-native English speakers.

In emergency situations, these kinds of communication and accessibility issues also are extremely important. Freeway call boxes are not accessible to people who are Deaf or hard of hearing. (Here a VRS system would be more helpful). Disaster shelters also need communication devices for those with a hearing disability, and county notification systems need to be compatible with TTYs so they can adequately alert more people in case of an evacuation. Hospital emergency rooms should always have an interpreter available to assist in communication with doctors or other health service providers.

It also was suggested that, in general, healthcare providers and doctors need to be better informed by the California Medical Association and the Medical Board of their legal responsibilities. Better education and training should be provided so that the Deaf community can have access to coherent health education.

Useful resources mentioned at these two forums

California Association for the Deaf (CAD): CAD has a newer kind of relay service called "speech to speech". (It is different from TTY).

California Telephone Assistance Program (CTAP): Free phone headsets and other telephone equipment are available to anyone that qualifies currently for a TTY: Provides repair services, and will replace broken equipment. CTAP is well funded, and from time to time will hire people with disabilities to attend meetings. Some pay as much as \$300/day.

Center on Deafness Inland Empire (CODIE): A non-profit offering resources and support services, established in 54 California counties, which provides interpreters and works with Vocational Rehabilitation and some employment services.

Community Access Center works with the needs of Deaf/hard of hearing individuals. The Community Access Center is trying to influence the California Medical Association and the Medical Board to provide education and training

information to their members. They are also trying to provide effective communication and access to their offices and services.

Coordinator Advisory Network (CAN) will discuss the AB-2912 bill that, if passed, will require certification for all interpreters.

Department of Rehabilitation (DR) provides Deaf services and deals with employment issues, funding people in school and helping people get assistive technology.

Independent Living Centers (29 in CA) provide information and referral services for any type of disabilities

Greater Los Angeles Association of the Deaf (GLAD) provides outreach to the Deaf community in the greater Los Angeles area.

Job Accommodation Network (JAN) Website about accommodation in the workplace

Media Access Office is a branch of the California governor's office, and one of their goals is to educate filmmakers and their production companies about people with disabilities.

One-stop Centers have improved, but are still not all accessible to people with certain types of disabilities.

Supplemental Security Income (SSI) qualifies a person for Medi-Cal.

Rolling Start helps people with disabilities get connected to technology.

"**The Regional Center**" is currently trying to produce an informational Website for people with disabilities. For example, they would like to have a list of interpreters, agencies, skills and instruction for people who are Deaf, and agencies that hire people who are Deaf.

Video Relay Services (VRS). With a high-speed Internet connection, real-time interpreting is now available.

World Institute on Disability (WID) has created an informational website: disabilitybenefits101.org, which has information on California benefits and services

Conclusion

Our study was underway during a difficult time in our state – the funding for California’s In Home Support Services (IHSS) was threatened as the new Governor and legislators attempted to solve the state deficit problems. Many participants mentioned the importance of IHSS to the ability to live independently in California. Section 8 Housing, a resource for many people with disabilities, has also been threatened with a reduction in available units. For many people who provided information in this study, reductions in basic services would create great hardship. It is not surprising that news of potential program cuts influenced the discussions and the comments on personal and family needs.

By using several methods for gathering information from the community, this study has identified key themes for the SILC and DOR to consider. During the study, we made interim findings available as the SILC planning process progressed. The issues and concerns contributed by study participants provide many ideas for continuing improvement of the capacity for independent living in California.

The Introduction chapter includes the study’s major cross-cutting themes. These major themes are useful for policymaking and planning. In addition to the major themes in the Introduction to this report, Chapters 1-4 include detailed comments and ideas from each of the information collection activities; these detailed comments will be useful for planning programs. In particular there are many suggestions for Independent Living Center services and programs, as well as for improvement in community infrastructure, services and resources.

The focus group process of the study, in particular, was valuable in providing a rich source of information and introduced participating centers to new service needs and unserved or underserved people. We encourage the SILC and the ILCs to establish additional focus groups as a continuing process of exploring the changing needs for independent living services in California.

This Statewide Independent Living Needs Assessment provides the SILC with information on the basic independent living needs of people with disabilities, the barriers to independence and the gaps in services and supports in California. This study provides information to assist the SILC in fulfilling its mission “to promote appropriate policies, programs and activities that maximize options for independence for Californians with disabilities” and ultimately to reach the SILC’s vision of society where people with disabilities have the choice to live without barriers and to participate fully in all aspects of the community.

Appendix A: Californians with Disability: 2003 American Community Survey

Information published by the Census Bureau shows the extent of disability in California. The following tables are based on the 2003 American Community Survey, and show that 12.9% of California's 32 million people (4,152,000) report some disability. Of these, 783,000 (2.4% of Californians) report that they need help from others for self-care. The table also shows the number of people with sensory, mobility, and cognitive disabilities, and people who have difficulty leaving home, or difficulty working, because of a disability. The American Community Survey provides better estimates of disability than were available from the Census 2000. These Census resources make disability data available locally and should be very valuable for Independent Living Centers.

The Census information provides information on the extent of disability, and more severe ("self-care") disability. Because Census 2000 and American Community Survey information is for local areas, such as counties, these data are useful for planning. The census information also helps in identifying areas of the state where the community has unique needs, such as using languages other than English or having higher rates of poverty or unemployment. This study's preliminary report submitted to the SILC includes county tables from Census 2000 that were used in identifying sites for the study focus groups. In addition to the Census materials, the study team reviewed reports from major California government agencies including the Departments of Developmental Disabilities, Education, Health, Mental Health, Rehabilitation, Aging, and Finance, and other data, also summarized in the preliminary report.

Table A-1: California population 5 and over: Prevalence of disability and self-care disability, 2003

	Population (000s)	Without a disability		With a disability (000s)		With a self-care difficulty (000s)	
Total in California (ages 5 and over)	32,107	27,955	87.1%	4,152	12.9%	783	2.4%
Disability type							
Sensory				1,142	3.6%	235	0.7%
Mobility				2,524	7.9%	696	2.2%
Cognitive				1,501	4.7%	446	1.4%
Self-care				783	2.4%	783	2.4%
Leaving the home				1,194	3.7%	587	1.8%
Work disability				2,242	7.0%	645	2.0%

Source: Calculated from ACS estimates from the Center on Personal Assistance (www.pascenter.org)

Table A-2: California population 5 and over: Gender, family income, living arrangement, OASDI/SSI for people with and without disability and self-care disability, 2003

	Population (000s)	Without a disability (000s) (n=27,995)	With a disability (000s) (n=4,152)	With a self-care difficulty (000s) (n=783)			
Gender							
Male	15,876	13,948	49.9%	1,928	46.4%	320	40.9%
Female	16,232	14,008	50.1%	2,224	53.6%	463	59.1%
			100.0%		100.0%		100.0%
Family income							
In poverty	4,145	3,428	12.3%	717	17.3%	150	19.2%
Above poverty	27,864	24,435	87.4%	3,429	82.6%	631	80.6%
			99.7%		99.9%		99.7%
Living arrangement							
Lives alone	3,037	2,219	7.9%	818	19.7%	149	19.0%
Lives with others	29,070	25,737	92.1%	3,333	80.3%	633	80.8%
			100.0%		100.0%		99.9%
Benefit reciprocity							
Social Security (OASDI)	3,817	2,116	7.6%	1,701	41.0%	395	50.4%
Supplemental Security Income	669	35	0.1%	634	15.3%	205	26.2%

Source: Calculated from ACS estimates from the Center on Personal Assistance (www.pascenter.org)

Note: Gender, family income and living arrangement may not total to 100% due to missing values and rounding.

Table A-3: California population 5 and over: Employment rates for people ages 18-64 with and without disability and self-care disability, 2003 (Continued)

	Population ages 18-64 (000s) (n=21,716)	Without a disability (000s) (n=19,460)	With a disability (000s) (n=2,256)	With a self-care difficulty (000s) (n=365)			
Employment (Ages 18-64 only)							
Employed	14,995	14,182	72.9%	813	36.0%	51	14.0%
Unemployed (in labor force)	1,355	1,200	6.2%	155	6.9%	10	2.7%
Not in labor force	5,281	3,993	20.5%	1,288	57.1%	305	83.6%
			99.6%		100.0%		100.3%

Source: Calculated from ACS estimates from the Center on Personal Assistance (www.pascenter.org)

Note: May not total to 100% due to missing values and rounding.

Appendix B: Outreach by Community Organizations

Independent Living Centers hosted all focus groups. The Centers were asked to do an extensive outreach to recruit focus group participants who were unserved or underserved and who were not Center users. Forty-three percent of the participants were not users of ILC services. Following is a list of 87 groups or individuals that were contacted by the Centers to recruit participants. The outreach included individuals with disabilities, teachers and other professionals.

- Alameda County Network for Mental Health
- Arriba Juntos
- Asian Resources
- BORP - Bay Area Outreach and Recreation Program
- Braille Institute
- California State Employment Development Department
- California State Student Association
- Charles A. Jones Skill Center
- Chinatown/North Beach Mental Health
- Chinatown Neighborhood Resource Center
- Chinese Family for the Disabled
- Chinese NewComer Services
- City of Palm Springs
- Community Employment Services
- Community Health Services - Chinese Community
- Community Mental Health Services
- Community Youth Center
- Consolidated Tribal Health Project
- Consultants on disability issues - various, e.g., accessibility - 2
- County Mental Health
- County of Riverside Mental Health
- Creativity Explored
- DCARA
- Department of Rehabilitation
- Desert Hot Springs Family Resource Center

- Drug prevention program for disabled girls
- Familia Unida - Living with Multiple Sclerosis
- Families with Disabilities
- Glide Memorial
- Gum Moon Asian Women's Resource Center
- Healing Adventures
- Healing Waters
- ILC Advisory Board
- ILC staff outreach - parents, teachers, various professionals - 5
- In and Out Mobility of Palm Desert
- Indian Senior Center
- Korean Disability Association
- La Raza
- Little Jesus Family
- Lyric
- Mayor's Office on Disability
- Mental Health Advisory Boards
- Mental Health Associates
- Mental Health Association
- Mental Health Board
- Merced Lao Family Community, Inc.
- Mission Family Center
- Mission Neighborhood Resource Center
- Native American Clinics of Riverside and San Bernardino Counties
- Neighborhood Resource Center
- Office of Self Help
- Operation Access
- Paratransit
- Parent Resource Center
- Personal Assistance Services Council
- Pinoleville Indian Reservation Vocational Rehabilitation Program
- Planning for Elders in the Central City

- Pleasant Care Nursing Home TBI Support Group
- Precious Blood Catholic Church
- Protection and Advocacy
- Public Authority
- RCH
- RCH - Brainstorm
- Regional Center
- San Francisco Vocational Services
- SBC employee
- Spirit Menders
- Sutter Hospital TBI Support Group
- Tenant's Association
- The ARC
- The Dancing Boat, Creativity Explored
- Toolworks
- Transitional Living and Community Support
- Vietnamese Handicapped Support Group
- Vietnamese League
- Vocational Services
- Whirlwind Women
- Youth Empowerment Center
- YWCA - Center for People with Disabilities