



# SIILC

STATE INDEPENDENT LIVING COUNCIL

**NEEDS ASSESSMENT FOR  
PEOPLE LIVING WITH DISABILITIES**



# Table of Contents

<b>Acknowledgements</b> .....	<b>1</b>
<b>Executive Summary</b> .....	<b>2</b>
<b>Geographic Distribution of Unmet Needs</b> .....	<b>3</b>
<b>Minority, Ethnic and Disability Groups</b> .....	<b>4</b>
<b>Unmet Service Needs</b> .....	<b>5</b>
<b>Developing and Strengthening the Independent Living Network</b> .....	<b>6</b>
<b>Areas for Further Investigation</b> .....	<b>7</b>
<b>Cross-Cutting Needs and Conclusions</b> .....	<b>9</b>
<b>State Independent Living Council 2009 Statewide Needs Assessment Report</b> .....	<b>11</b>
<b>Methods</b> .....	<b>11</b>
Table 1: Documents and Reports Used in the Study .....	13
<b>Organization of This Report</b> .....	<b>15</b>
<b>Geographical Considerations</b> .....	<b>15</b>
Social Security Data .....	16
Comparison with Consumers Served Nationwide .....	17
Penetration Rate .....	17
Nursing Home Residents .....	18
Parolees .....	20
Table 2: Summary of County-Level Calculations .....	22
Summary .....	27
Areas for Further Investigation .....	28

**Minority, Ethnic, and Disability Groups .....29**

- Demographic Trends.....29
- Culturally Appropriate Outreach and Service Strategies .....30
- Disability Groups.....34
- Summary .....36
- Areas for Further Investigation.....36

**Unmet Service Needs .....37**

- Summary.....41
- Areas for Further Investigation.....42

**Developing and Strengthening the  
Independent Living Network .....43**

**Cross-Cutting Needs And Conclusions.....45**

**APPENDIX A: Catalog of Documents.....48**

- Regional Disability Task Force Reports .....48
- Reports from Ex-Officio State Agencies and Other State  
Agencies and their Contractors.....48
- Area Agencies on Aging: Needs Assessment Studies .....49
- Independent Living Centers: Needs Assessment Studies.....50
- Independent Living Centers:  
704 Annual Performance Reports (2008).....51
- Statistical Databases .....54

<b>APPENDIX B: Requests for Information .....</b>	<b>55</b>
Initial Request for Information.....	55
Request for Ideas Regarding Developing and Strengthening the Independent Living Network .....	57
<b>APPENDIX C: Supplemental Tables .....</b>	<b>59</b>
<b>Table C-1: Calculation of Penetration Rates (Screen reader accessible) .....</b>	<b>59</b>
<b>Table C-2: Inundation Potential (screen-reader accessible) .....</b>	<b>68</b>

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## Executive Summary

Every three years the State Independent Living Council (SILC) conducts a statewide needs assessment study to inform the development of the triennial State Plan for Independent Living (SPIL) required under Title 34 of the Code of Federal Regulation, Part 364.42. The 2011-2013 SPIL will be a road map detailing how California will develop and strengthen Independent Living (IL) services and allocate federal funds for that purpose. The SILC contracted with the Center for Applied Local Research (C.A.L. Research) to review data previously collected by

SILC staff and submit a report synthesizing statewide needs to the SILC.

The key research questions addressed by this needs assessment study are:

- What geographic regions are most in need of additional IL services?
- What underserved ethnic and disability minority communities are most in need of IL services?
- What are the most important unmet service needs for Californians with disabilities living independently?
- What are the most important needs that the SILC should address in developing and strengthening California's independent living network (that is, programs providing independent living services and independent living centers [ILCs]); and other programs providing services for individuals with disabilities?

Previous statewide needs assessments have relied on a variety of data collection and analytic methods, including statewide surveys of consumers with disabilities and community forums to collect the testimony of consumers, experts, and service providers. This year (2009), the SILC needs assessment report is based on a review of quantitative and qualitative data originally collected by different members of the independent living network in California.

## **GEOGRAPHIC DISTRIBUTION OF UNMET NEEDS**

We relied on two studies recently conducted by the California State Department of Rehabilitation (DOR) – one comparing California service recipients with nationwide Social Security beneficiaries, and the other comparing the same service recipients with vocational rehabilitation consumers served across the nation. We added three additional analyses in which

we have compared the reported population served by the California ILC network with 1) the most recent census estimates of the population with disabilities in each county, 2) nursing home residents voicing a preference for returning to their communities, and 3) the geographical distribution of parolees with disabilities. While each of these approaches provides only a rough indicator of current or potentially unmet needs, taken together they provide a fairly clear and consistent assessment:

- The region served by Rolling Start (**San Bernardino, Inyo, and Mono Counties**) is identified by all five assessment methods used as having high needs;
- The regions served by Community Access Center (**Riverside County**) and by the CA Association of the Physically Handicapped (**Fresno, Kings, Madera, Merced, and Tulare**)

**Counties**) are identified as having high needs by three of the methods; and

- The regions served by Resources for Independent Living (**Sacramento and Yolo Counties**) and by Disability Resources Agency for Independent Living (**Amador, Calaveras, Mariposa, San Joaquin, Stanislaus, and Tuolumne Counties**) are identified as having high needs by two methods and above-average needs by two other methods.

These regions all contain large, formerly rural areas that have undergone rapid population growth and urbanization over the past 20 years. That growth has outpaced the expansion not only of IL services but human services of all kinds, particularly throughout the Central Valley and Inland Empire regions.

## **MINORITY, ETHNIC AND DISABILITY GROUPS**

We reviewed a variety of documents for the purpose of determining which ethnic groups and disability groups are most in need of IL services. Our sources – which include qualitative and quantitative data from ILCs, Area Agencies on Aging, partnering state agencies and various DOR reports – yield consistent conclusions:

- Latinos, Asian Americans, and Native Americans are the most frequently mentioned ethnic minority populations in need of IL services;



- Proportionally, Asian Americans and Latinos are underrepresented in the DOR and ILC service rates;
- ILCs are actively developing culturally appropriate outreach and service delivery strategies to meet the needs of these groups and are organizing efforts to reach out to the growing population of Latinos and other ethnic groups with disabilities;
- Older adults with disabilities in rural areas are underserved, and people with disabilities who have aged, have different needs than older adults whose disability is associated with aging;
- People with Traumatic Brain Injury (TBI) throughout the state need individually tailored services such as peer support, housing, and non-emergency medical transportation; and

- Deaf and/or hard-of-hearing individuals are underserved in several Los Angeles areas and in rural Northern California.

## UNMET SERVICE NEEDS

The results clearly show that people with disabilities are severely impacted by economic circumstances. As the economy has soured and state budget cuts have been made, the following unmet needs have become exacerbated, affecting older adults, working-aged people with disabilities, and children with disabilities:

- **Housing** has become less affordable, especially near locations where IL services are available;
- **Public and other forms of transportation** have become more costly and less accessible due to eligibility restrictions;

- **Health care** co-pay and premium costs have increased and the availability of providers accepting Medi-Cal and Medicare has decreased; and
- **Other unmet needs** persist, such as the need for personal assistance services; information and referral; peer support; employment; and legal advocacy for children with multiple disabilities in the schools, the mental health system and the Medi-Cal payment system.

## **DEVELOPING AND STRENGTHENING THE INDEPENDENT LIVING NETWORK**

The independent living network is defined as 1) centers for independent living; 2) programs providing independent living services; and 3) programs providing services for individuals with disabilities. Ideas for developing and strengthening

the network submitted by network participants include:

- Encourage collaboration between different parts of the network such as: 1) ILCs and AAAs in communities of color,
- 2) TBI advocates and medical rehabilitation providers and professionals,
- 3) those focused on cross-disability and those focused on a single disability, and
- 4) advocates and service providers;
- Advocacy for increased basic funding could shore-up the capacity of the ILCs to provide services to more individuals with disabilities;

- Develop stronger standards and indicators than those specified in the Rehabilitation Act. Use additional funds to support board recruitment, development, and strong management. Assure smooth transitions in leadership when turnover occurs;
- Strengthen the infrastructure by 1) upgrading the technology used to support communications among the ILCs including conference calls, web conferences, training and a training library to maintain these upgraded communications; and 2) providing an environment that encourages members of the network to communicate freely with each other;
- Develop stronger standards and indicators for ILCs, beginning with improved standards for ILC boards of directors and management staff;
- Develop a comprehensive centralized data collection and reporting system for the SILC; and
- Hire a SILC staff member dedicated solely to tracking and analyzing legislation and regulatory changes, providing testimony at hearings, and engaging in negotiations when required.

### **AREAS FOR FURTHER INVESTIGATION**

This study provides a rich and representative picture of the unmet needs of people with disabilities across different regions of California and among minority, ethnic and disabilities groups. However, several opportunities to learn more about those needs and how the IL network might address them could be pursued. These areas for further investigation are:

- To better understand how the ILCs can support Olmstead transition candidates, we

recommend 1) studying a sample of nursing home residents who want to move out of their group facilities, and inquiring where they would want to live and why, and 2) asking a sample of consumers currently served by the IL network about where they previously lived, why they moved, and where they would like to live if services were available. Taken together, results from these two surveys would substantially enhance our understanding of the geographical distribution of the need for IL services.

- We recommend local studies in both rural and urban areas to better understand the similarities and differences in service needs between older adults who acquired their disability prior to becoming a senior citizen versus those whose disabilities are linked to aging. These studies should focus on how the former group experienced

the system of care targeting older adults, how the latter experiences the ILC service system, and how the different systems of care have responded to these groups?

- We also suggest that the SILC encourage examination of how veterans with disabilities find their way to ILCs for services and advocacy, asking such questions about 1) outreach activities that have been initiated to help them gain access; 2) current service needs; and 3) gaps existing between services provided by Veterans Affairs and those provided by ILCs.
- We recommend periodic identification of trends in how people with disabilities rank-order their unmet service needs at the local (ILC) level using a standardized survey instrument.

## CROSS CUTTING NEEDS AND CONCLUSIONS

The study period for this report, 2007 to 2009, has been characterized by shrinking federal resources, severe state budget cuts, and further threats to cut major programs for people with disabilities such as In-Home Supportive Services. This gloomy context heightens awareness of the needs of the 2.3 million Californians with disabilities caught in the oppressive circle of poverty, unemployment, and widespread lack of housing and transportation. Major cross-cutting themes are:

- Geographically, people with disabilities in the Inland Empire and Central Valley are the most in need of services from ILCs, and that ILCs in the Central Valley are the most impacted by the gap between need and services. Underserved minority and ethnic groups include Latinos, Native Americans, Asian Americans,

and older adults with disabilities.

- Few ethnic groups have gone completely ignored as network providers strive to address the needs of all people in their catchment areas. ILC, AAAs and other network providers have improved their ability to provide culturally appropriate services and have plans to increase capacity to do so. Underserved disability groups include people with traumatic brain injuries and hard-of-hearing or deaf individuals, especially those individuals in the Los Angeles area and in rural northern California. Unmet services needs begin with housing, transportation and health care, each stemming from poverty and scarcity of these services.
- Services gaps in the Central Valley may be strongly affected by the influx of Latinos and Asian

Americans. In “service-poor” rural areas, ILCs are more likely to serve older adults than their counterparts in “service-rich” urban areas.

- Responding to the needs described above would go a long way in strengthening the Independent Living Network. These efforts may be enhanced by supporting ideas for enhancing the network itself. This includes encouraging projects that involve the cooperation of ILCs with other providers such as AAAs and senior centers, employment and

training programs, and children’s services, as well as joint efforts to advocate for affordable housing, greater transportation capacity, and increased access to affordable health care. The network may also be enhanced by building the capacity of its members to communicate with each other.

# State Independent Living Council 2009 Statewide Needs Assessment Report

Every three years the State Independent Living Council (SILC) conducts a statewide needs assessment study to inform the development of the triennial State Plan for Independent Living (SPIL) required under 34 CFR 364.42. The 2011-2013 SPIL will be a road map outlining how California will develop and strengthen independent living services and allocate federal funds for that purpose. To inform the development of the new SPIL, the SILC contracted with the Center for Applied Local Research (C.A.L. Research) to review and synthesize data collected by SILC staff and submit a needs assessment report.

The key research questions to be addressed by this needs assessment study are:

- What geographic regions are most in need of additional IL services?
- What underserved ethnic and disability minority communities are most in need of IL services?
- What are the most important unmet service needs for Californians with disabilities living independently?
- What are the most important needs that the SILC should address in developing and strengthening California's independent living network, that is, the network of federally-funded independent living centers, the SILC itself, and other organizations involved in the independent living field?

## Methods

Previous statewide needs assessments have relied on a variety of data collection and analytic methods, including statewide surveys of

consumers with disabilities and community forums to collect the testimony of consumers, experts, and service providers. This year (2009), the SILC needs assessment report is based on a review of quantitative and qualitative data originally collected by different members of the independent living network in California. Overall, SILC staff requested needs assessment data from 136 members of the independent living network (See Appendix B).

Data submitted by the federally funded independent living centers (ILCs) included their 2008 Section 704 Annual Performance Reports submitted to the SILC and the federal government, and/or the results of several recently completed local needs assessment studies. Data were also gleaned from special studies conducted by local disability-oriented task forces, as well as from mandated needs assessment studies

conducted by several Area Agencies on Aging. Additional qualitative and quantitative data included reports from several state agencies such as the Governor's Committee on the Employment of People with Disabilities, the disability technical assistance consultant to the state Alcohol and Drug Programs, and Disability Rights California. C.A.L. Research also reviewed statistical data provided by the California Department of Rehabilitation, the Department of Corrections Division of Adult Parole Operations and the U.S. Center for Medicare and Medicaid Services. These documents are cataloged in Appendix A and summarized in Table 1, below. Finally, at the request of the SILC's Communications and Collaboration Committee, SILC staff emailed the 136 independent living network sources requesting their ideas for developing and strengthening the independent living network (Appendix B).

## LEGEND

Table 1: Documents and Reports Used in the Study consists of four columns. The first column, “Type of Agency/ Document,” identifies which of the five major types of agency or organization submitted a document to the SILC for this needs assessment report.

The second column, “Number Received,” identifies the

number of documents submitted by the agency.

The third column, “Target Group/Topic,” identifies the target group or topic covered in the documents submitted.

The fourth column, “Data Collection Strategies,” lists the major methods used to collect data in the documents submitted by each type of agency.

**Table 1: Documents and Reports Used in the Study**

Type of Agency/ Document	Number Received	Target Group/Topic	Data Collection Strategies
Regional disability task force reports	1	Housing Parents with disabilities	Forums Task Forces Expert surveys
Reports from Ex-Officio State agencies and other state agencies and their contractors	9	Transportation Employment Parolees Substance abusers Rehabilitation Legal advocacy	Service utilization data Demographic data Census data Staff analysis

*Table 1 Continued...*

Type of Agency/ Document	Number Received	Target Group/Topic	Data Collection Strategies
Area Agency on Aging: Needs Assessment studies	8	Older adults	Surveys Focus Groups Stakeholder Interviews
Independent Living Centers: Needs Assessment Studies	7	All disabilities	Staff observation Surveys Forums Service utilization data
Independent Living Centers: 704 Annual Performance Reports (2008)	22 (plus reports from satellite offices)	All disabilities	Self study Service utilization data Staff observation
Statistical databases	3	Parolees Nursing home residents ILC service utilization and Census disability data	Statistical

Once these documents were assembled, C.A.L. Research catalogued and reviewed the materials, identified common themes and priorities, and produced this summary needs assessment report for the SILC. A draft of this report was reviewed by the SILC at its quarterly meeting in Bakersfield on December 1, 2009.

## Organization of This Report

The report begins by looking at the geographic distribution of unmet needs by county and region, largely based on statistical data. This is followed by a discussion about underrepresented minority, ethnic and disability



groups as identified by the ILCs and other members of the independent living network. Next, we analyze how members of the independent living network prioritized unmet services such as housing, transportation and specialized services provided by ILCs and other organizations serving consumers with disabilities. We follow these analyses of need with a discussion of ideas for developing and strengthening the independent living network in California.

## Geographical Considerations

In this section, we summarize several approaches to identifying geographical regions in greatest need of expanding existing services in support of independent living. We relied on two studies recently conducted by the California State Department of Rehabilitation (DOR) – one comparing DOR service recipients with Social Security

beneficiaries, and the other comparing the same service recipients with vocational rehabilitation consumers served across the nation. We added three additional comparisons in which we have compared the reported population served by the ILC network – first, with the census estimates of the population with disabilities in each county, then with nursing home residents voicing a preference for returning to their communities, and finally with the geographical distribution of parolees with disabilities. Detailed data are provided in Appendix C (Table C-1: Calculation of Penetration Rates and Table C-2: Calculation of Inundation Potential) and summarized in Table 2, below. At the conclusion of this section, we describe some findings which are generally consistent across these various approaches.

## **SOCIAL SECURITY DATA**

In its *2010 State Plan Update*, DOR summarizes the results of a county-by-county comparison between OASDI (Old Age, Survivors, and Disability Insurance) beneficiaries and DOR service recipients (which includes ILC consumers as well as those who receive other DOR services). The results of that study showed that in most California counties, DOR serves fewer people than are currently eligible because they already receive OASDI benefits. While the *Update* does not include the underlying data adjusted by age or employment status, it does identify six counties as potentially the most underserved: Sacramento, San Bernardino, San Joaquin, Fresno, Stanislaus, and Kern.

## **COMPARISON WITH CONSUMERS SERVED NATIONWIDE**

DOR's *2010 State Plan Update* also compared DOR and vocational rehabilitation consumers nationwide across five major impairment groups (visual, communicative, physical, cognitive, and psychological). This study identified three impairment groups for which California was below parity with national figures – communicative, physical, and psychological impairments – and went on to identify seven California counties where the percentage of service recipients fell below national rates in those categories – Contra Costa,



Los Angeles, Monterey, Sacramento, San Bernardino, San Francisco, and Solano Counties. These results suggest that people with communicative, physical, and psychological disabilities may be underserved in these seven counties.

## **PENETRATION RATE**

Another way to gauge needs for additional services is to estimate the percentage of the disability population that is served by each ILC. For ILCs that serve the entirety of one or more counties, the calculation is simple: Divide the total number of consumers served in a recent year by the estimated size of the disability population in the county or counties served by the ILC, including satellite offices. For Los Angeles County (7 ILCs) and Alameda County (2 ILCs), we combined the consumers served across the entire county and divided those totals by the estimated disability population for each county respectively.

These calculations show that while the California ILC system serves more than 20,000 consumers each year, the disability population is far greater than the number served – indeed, about 175 times greater on a statewide average. Put another way, the ILCs collectively reach and serve just three quarters of one percent of the estimated population with disabilities.

As meager as this coverage is, it varies widely across ILC catchment areas. For example, the Center for Independent Living in Fresno, which serves Fresno, Kings, Madera, Merced, and Tulare Counties, reports serving just over two tenths of one percent (0.2%) of the roughly 245,000 people with disabilities who live in its five counties. At the other end of the spectrum, FREED Center for Independent Living, which serves Colusa, Nevada, Sierra, Sutter, and Yuba Counties, reports serving slightly more than 2.5 percent

of the nearly 45,000 people with disabilities in its five counties, a “penetration rate” that is more than ten times that of the Fresno ILC.

These data suggest that the disability population in the five counties served by the Fresno ILC is in much greater need of expanded services than are their counterparts in the five counties served by FREED. Other regions with extremely low penetration rates are Riverside County (served by Community Access Center) and San Bernardino, Mono, and Inyo Counties (served by Rolling Start). Penetration rates for all regions (with Los Angeles and Alameda Counties treated as single regions) are shown in Table 2: Summary of County-Level Calculations.

### **NURSING HOME RESIDENTS**

We also considered the potential impact on the independent living network of the unfunded federal mandate to serve “Olmstead

transition candidates,” that is, nursing home residents and other institutionalized persons who wish to return to the community. Center for Medicare and Medicaid Services data from the third quarter of 2009 suggest that slightly more than 25,000 Californians who are currently in nursing homes would like to be back in their respective communities. As it happens, that number is very close to the total number of consumers currently served each year by the entire ILC system. Were all 25,000 to move out of their nursing homes and to seek ILC services to enable them to do so, they would more than double the statewide consumer population currently served by ILCs – effectively inundating the service delivery system.

We explored how this potential for inundation varies across regions, dividing the number of institutionalized adults expressing a desire to return to their communities by the

current number of consumers served by the local ILC. This “inundation index” suggests that some ILCs would be totally overwhelmed by a wave of new consumers, while others would perhaps be able to stretch their services to fit a new and only somewhat larger service population. At the most extreme, the Center for Independent Living in Fresno would be faced with a 213 percent increase in its consumer population, more than tripling the number of people whom it serves. Similarly, Community Access Center in Riverside County would see a 199 percent increase in its consumer population, and Rolling Start (serving Inyo, Mono, and San Bernardino Counties) would have 149 percent more consumers to serve. At the other extreme, FREED Center for Independent Living (serving Colusa, Nevada, Sierra, Sutter, and Yuba Counties) would find its consumer population

increasing by only about 18 percent, difficult but not impossible to absorb.

These data again suggest that the regions served by the Fresno ILC, Community Access Center, and Rolling Start are in considerably greater need for expanded services than are other regions of the State. They also suggest the region served by FREED has much less need to expand services. Inundation index figures for all service regions are shown in Table 2.

## **PAROLEES**

The Department of Corrections and Rehabilitation operates a Disability Placement Program for parolees with disabilities. As of the end of fiscal year 2009, there were 3,334 adult parolees with disabilities, a number that represents only the smallest fraction of the disabled population but is a group for which the State actively seeks services. Statistics reported

by the Division of Adult Parole Operations show the geographical distribution of these parolees by region – Northern California and Central Valley, Bay Area and Central Coast, Los Angeles County, and Southern California (excluding Los Angeles County). We compared the number of parolees with disabilities with the number of consumers served by the ILC network in each of these four regions, and found that serving this special group might have the greatest impact on ILCs in the Southern California region (excluding LA County), where they would add as much as 13.7 percent to the ILC consumer population. In contrast, parolees with disabilities might only add about 6.2 percent to the consumer population served by ILCs in the Bay Area and Central Coast Region.

## LEGEND

Table 2: Summary of County-Level Calculations is a data table comprised of five columns.

The first column, “Service Provider,” identifies the name of each of the 29 ILCs in California.

Column two, “Counties Served,” lists the counties served by the ILC named in column one. Some ILCs serve multiple counties, and Los Angeles and Alameda counties are served by multiple ILCs.

Column three, “Disability Population,” is a number estimation, based on 2007 Census data, of the number of non-institutionalized persons age 5 and over residing in the county or counties listed in column two.

Column four, “Penetration Rate,” is an estimate of the percentage of the Disability Population (column three) served by the ILC listed in column one. Estimates

followed by one asterisk denote above-average need and those with no asterisk denote below average need.

Column five, “Inundation Rate,” is an estimate of the percentage increase in a “ILC’s” 2007 caseload, were it to provide transitional and other services to all the individuals residing in nursing homes who indicated that they would like to return to their communities. As in column four, estimates followed by an asterisk indicate above the average statewide need.

The last row in the table indicate statewides totals for Disability Population, Penetration Rate and Inundation Rate.

**Table 2: Summary of County-Level Calculations**

Service Provider	Counties Served	Disability Population	Penetration Rate	Inundation Potential
Center for Independent Living Fresno	Fresno, Kings, Madera, Merced, Tulare	245,306	0.228%*	213%**
Community Access Center	Riverside	230,662	0.269%*	199%**
Rolling Start	Inyo, Mono, San Bernardino	245,754	0.303%*	149%**
Resources for Independent Living	Sacramento, Yolo	221,300	0.395%*	115%**
Central Coast Center for Independent Living	Monterey, San Benito, Santa Cruz	76,844	0.488%*	122%**
The Access Center of San Diego	Imperial, San Diego	336,659	0.496%*	139%**
Independent Living Resource Center	San Francisco	99,333	0.528%*	105%**
Silicon Valley Independent Living Center	Santa Clara	160,620	0.533%*	123%**

\*Indicates below average statewide | \*\*Indicates above-average need

*Table 2 Continued...*

Service Provider	Counties Served	Disability Population	Penetration Rate	Inundation Potential
Center for Independence of the Disabled	San Mateo	70,793	0.545%*	103%**
Disability Resource Agency for Independent Living	Amador, Calaveras, Mariposa, San Joaquin, Stanislaus, Tuolumne	195,232	0.571%*	114%**
Independent Living Services of Northern California	Butte, Glenn, Lassen, Modoc, Plumas, Shasta, Siskiyou, Tehama	119,331	0.591%*	97%**
Independent Living Resource of Contra Costa County	Contra Costa, Solano	172,942	0.596%*	85%**
Independent Living Center of Kern County	Kern	109,689	0.637%*	43%

\*Indicates below average statewide | \*\*Indicates above-average need

**Table 2 Continued...**

<b>Service Provider</b>	<b>Counties Served</b>	<b>Disability Population</b>	<b>Penetration Rate</b>	<b>Inundation Potential</b>
Placer Independent Resource Services	Alpine, El Dorado, Placer	42,979	0.675%*	125%**
Independent Living Resource Center	San Luis Obispo, Santa Barbara, Ventura	171,898	0.950%	51%

**\*Indicates below average statewide | \*\*Indicates above-average need**

*Table 2 Continued...*

Service Provider	Counties Served	Disability Population	Penetration Rate	Inundation Potential
Community Rehabilitation Services	Los Angeles	1,112,923	0.965%	69%
Community Actively Living Independent and Free	Los Angeles			
Disabled Resource Center	Los Angeles			
Independent Living Center of Southern California	Los Angeles			
Service Center for Independent Living	Los Angeles			
Southern California Rehabilitation Services	Los Angeles			
Westside Center for Independent Living	Los Angeles			

\*Indicates below average statewide | \*\*Indicates above-average need

*Table 2 Continued...*

Service Provider	Counties Served	Disability Population	Penetration Rate	Inundation Potential
Tri-County Independent Living	Del Norte, Humboldt, Trinity	32,288	0.969%	42%
Dayle McIntosh Center	Orange	262,011	1.219%	53%
Disability Services and Legal Center	Lake, Mendocino, Napa, Sonoma	101,425	1.739%	30%
Center for Independent Living	Alameda	169,022	1.920%	36%
Community Resources for Independent Living	Alameda			
FREED	Colusa, Nevada, Sierra, Sutter, Yuba	44,749	2.548%	18%
Marin Center for Independent Living	Marin	27,049	2007 data not available	2007 data not available
	Statewide Totals	4,271,321	0.760%	77%

\*Indicates below average statewide | \*\*Indicates above-average need

## SUMMARY

Each of the five approaches used to assess which geographic areas are most in need of additional services provides only a rough indicator of current or potentially unmet needs, but taken together they provide a fairly clear and consistent assessment:

- The region served by Rolling Start (**San Bernardino, Inyo, and Mono Counties**) is identified by all five methods method as having high needs;
- The regions served by Community Access Center (**Riverside County**) and by the CA Association of the Physically Handicapped (**Fresno, Kings, Madera, Merced, and Tulare Counties**) are identified as having high needs by three of the methods;
- The regions served by Resources for Independent Living (**Sacramento and Yolo Counties**) and

by Disability Resources Agency for Independent Living (**Amador, Calaveras, Mariposa, San Joaquin, Stanislaus, and Tuolumne Counties**) are identified as having high needs by two methods and above-average needs by two other methods.

These regions all contain large, formerly rural areas that have undergone rapid population growth and urbanization over the past 20 years. That growth has outpaced the expansion of human services of all kinds throughout the Central Valley and Inland Empire regions. It should not be surprising that these same regions are in greatest need for expanded services to facilitate independent living by people with disabilities.

## AREAS FOR FURTHER INVESTIGATION

To draw additional conclusions we need more information about why people with disabilities choose to live where they do, and about what factors help condition their choice of communities. For example, services for people with disabilities should ideally be located in (or at least near) the communities where they want to live. But it is possibly more likely that once services are established in particular communities, people who want or need those services will begin to relocate to be nearer to the service locations.

Yet we know that other factors are important. For example, in a recent survey of nursing home residents in Monterey County, respondents who said that they would like to return to the community were asked which community they would prefer and why. A surprising majority selected communities other than those where their

nursing home was located. And the most frequently cited reason for their choice of a particular community was their perception of which communities are safest.

We recommend two statewide surveys. One, replicating the Monterey County study, would query a sample of nursing home residents who want to be moved out of their group facilities about where they would want to live and why. The second survey would ask a sample of consumers currently served by the IL network about where they previously lived, why they moved, and where they would like to live if services were available. Taken together, results from these two surveys would substantially enhance our understanding of the geographical distribution of the need for IL services.

## Minority, Ethnic, and Disability Groups

This examination of the needs of populations within the disability community acknowledges the inclusion of all races and ethnicities within the IL network. While each ILC reports on its capacity to serve the specific needs and populations within its own catchment area, generalizations can be drawn that are relevant to ILCs across California. Sub-populations within the disability community are identified across the ILC needs assessment studies, the Section 704 reports, demographic data provided by the California Department of Rehabilitation, and documents submitted by the SILC's ex-officio partners and other state agencies.

### DEMOGRAPHIC TRENDS

Hispanic/Latinos, Asian Americans (including Chinese, Korean, Cantonese, Filipino,

Asian/Pacific Islanders, Vietnamese), and Native Americans were the three minority or ethnic populations identified as being underserved across all of the ILC needs assessments studies and Section 704 reports. Many reports cited a need for greater outreach and culturally relevant services for these groups. Several sub-populations were identified in many of the needs assessments which cut across all ethnic groups: seniors, children/youth, and young adults were mentioned as particularly in need or at risk. Our sources also identified veterans, homeless individuals, and the Lesbian, Gay, Bisexual, and Transgender (LGBT) community as requiring culturally relevant outreach and services.

In its *2010 State Plan Update*, DOR provides demographic estimates for their caseload in fiscal year 2007-08. African Americans (18.6 percent), Whites (47.9 percent), and

Pacific Islanders (1 percent) accessed DOR's services at rates that are higher than their representation in the general population of California. Asian Americans (4.3 percent) and Hispanics/Latinos (25.3 percent) were underrepresented in the DOR 2008 caseload, gaining access to DOR services at rates significantly below their proportions in the general population. DOR notes that methodological flaws may have led to under-representation in its Hispanic/Latino rate. Native Americans and multi-racial populations accessed the DOR at rates nearly identical to their population proportion. While DOR does not look at possible reasons leading to under-representation of Asian Americans and Hispanics/Latinos in their consumer caseload, several ILC studies have cited societal and cultural barriers.

## **CULTURALLY APPROPRIATE OUTREACH AND SERVICE STRATEGIES**

ILCs indicate they are very aware that many potential consumers do not access their services due to cultural barriers, and that some potential consumers see ILCs as outside of their own culture and opt not to engage due to mistrust of service providers. Other potential consumers are simply unaware of their local ILCs and the services that they provide. Area Agencies on Aging share a similar view. As exemplified by the El Dorado County Area Agency on Aging



in its survey of older Latino adults, “lack of finances, insufficient knowledge and community education regarding available services, and lack of trust in service providers” were the most oft-cited barriers to access.

Sonoma County’s Area Agency on Aging cited “linguistic isolation” as one of the major barriers to access for some older members of ethnic communities. The United States Census Bureau defines linguistic isolation as a household where no person over the age of 14 speaks English and no person over age 14 who speaks a language other than English speaks it very well. For individuals with disabilities, living in a linguistically isolated household may make it especially difficult for them to be aware of and to gain access to services. It is important that the ILCs make special attempts to reach these individuals since printed

literature may not be effective.

The various reports in our possession collectively supported the imperative that ILCs reach out to those who may not otherwise be informed of their services. Outreach activities that target ethnic communities were reported as especially effective in maintaining a consumer caseload that is a representative of the ILC’s catchment area. Many ILCs reported that they send outreach workers into their community to do footwork in locations where minority populations are most concentrated. The ideal outreach worker is not only fluent in the language of the community, but is also a trusted and representative member of the target community. A few centers mentioned that forging referral networks with other service providers has also helped broaden their caseload. Some ILCs reported that forming

alliances with neighboring community organizations that specialize in working with seniors or specific minority populations was especially helpful. All of these steps helped ILCs get the word out to local minority populations that may otherwise go unaware and underserved.

Many Section 704 Reports outreach plans recognized that ILCs must foster culturally and linguistically relevant and inclusive services. Specific strategies included 1) hiring and training employees that are representative and sensitive to the ethnic diversity in their community, 2) offering materials and services in the languages of the community, and 3) locating ILC offices along easily accessible public transportation routes or within minority communities. Many centers, while citing budget constraints, wanted to open local offices within ethnic enclaves like Chinatown in San Francisco. A few

ILCs conducted in-service educational days on topics relevant to the community's diverse populations. These activities go a long way toward promoting a safe and relevant environment for community members of all ethnicities.

Some ILCs and AAAs mentioned service needs specific to the minority groups in their area. Access to professional caregivers can be a problem for consumers who do not speak English. The Independent Living Center of Southern California cited the lack of bilingual personal assistants as a barrier for some minority persons with disabilities in their community. The Riverside County Area Agency on Aging listed the need to “educate cultures that it is acceptable to receive services” in their needs assessment; recognizing that asking for assistance is perceived as shameful within some cultures. Other centers mentioned the need

for family-centric programs to mesh with the cultures of their diverse consumers. Unlike U.S. Caucasians, who embrace an individualistic culture, many Latinos and other consumers come from countries where the family unit is integral to the individual's identity. Any service provider working with ethnic populations must be aware of this cultural difference and seek alliances with not only the consumer but with their families as well.

As several of our sources have observed, most consumers, especially those with fixed incomes, have been hit hard by the downturn in the United States economy. According to many ILCs this has been especially true for nonwhite consumers. Communities Actively Living Independent and Free of Los Angeles repeatedly called for "the need for real alternatives to poverty" and cited discrimination as a significant problem for consumers in their region.

Poverty limits access to health care, personal assistants, housing, transportation, and food. These are all services essential to an individual's basic quality of life and her or his ability to live independently.

Looking to the future, it is clear that the population of California will not only increase in size but will become more diverse. Many of the needs assessment studies and Section 704 reports mentioned the continued growth of the Latino population and other ethnic groups across California. This trend is expected to continue through the next few decades. As Sonoma County's Area Agencies on Aging report noted, "relatively more of California's Latinos are recent immigrants, non-citizens, and of Mexican or Central American descent compared with Latinos in the rest of the United States." This leaves California's independent living network with the unique challenge of developing a culturally and

linguistically responsive service infrastructure. According to the many studies and reports we have received, most participants in the independent living network have anticipated these trends and will continue to find ways to provide greater access to ethnic minorities in California.

## **DISABILITY GROUPS**

Information regarding underserved disability groups was based mostly on ILC needs assessment studies and 2008 Section 704 Reports, and from state agencies and statewide advocacy organizations. The required format of the Area Agency on Aging needs assessment studies did not facilitate the identification of specific groups of older adults with disabilities. Our sources identified a range of disability groups in their respective locations that warranted more services than currently provided. In their Section 704 Report

narratives, ILCs are required to describe their cross-disability strategies in order to ensure they are serving people with a range of disabilities. About two-thirds of the ILCs identified specific disabilities or disability-related groups in this section of the report. By far, the most often mentioned group were older adults with disabilities, i.e., both people with disabilities who have aged and older adults whose disability is associated with aging. People with traumatic brain injuries were singled out by several ILCs throughout the state as needing individually tailored services, especially peer support, housing, and non-emergency medical transportation.

Deaf and/or hard-of-hearing consumers were perceived as underserved in several Los Angeles area ILCs and in two rural ILCs in northern California, often in the context of needing assistive technology to gain access to

services provided by ILCs, and generally to reduce the isolation they experience in everyday life. A Bay Area task force attended by parents with disabilities and their service providers and advocates singled out deaf parents of non-hearing impaired children as a group especially needing integrated support. Some ILCs also identified blind and visually impaired individuals as needing greater access to services.

Although several ILCs identified children and youth with disabilities and some ILCs wrote about youth with developmental disabilities, both physical and intellectual, it is not clear whether these are two different groups. In its strategic planning process, Disability Rights California heard from many parents and family members of children and adults with developmental disabilities.

Some ILCs reported that they want to improve outreach to people with mental health issues, not with the intent of providing therapeutic services, but for the purpose of providing peer support, peer advocacy, and help with transportation and housing and personal care. Often, when writing about directing outreach efforts at individuals with multiple disabilities, ILCs included mental illness as a coexisting disability. Other disability groups mentioned by our sources included people with HIV/AIDS, women with breast cancer, the “newly disabled,” including veterans and residents of nursing homes, group homes, and psychiatric facilities.



## SUMMARY

We used a variety of documents for the purpose of determining the ethnic groups and disability groups most in need of services provided by the independent living network. Our sources, whether based on demographic data provided by DOR or on qualitative data based on perceived need and submitted by ILCs and other entities, are very consistent:

- Latinos, Asian Americans, and Native Americans are the most frequently mentioned ethnic minority populations.
- Asian Americans and Latinos are underrepresented in the DOR and ILC access rates.
- Participants in the independent living network are actively developing culturally appropriate outreach and service delivery strategies to meet the needs of these groups and are organizing even greater efforts to reach out

in particular to the growing population of Latinos with disabilities.

- People with disabilities who have become older adults may have different needs than older adults who acquire a disability later in life.
- People with traumatic brain injury throughout the state need individually tailored services such as peer support, housing, and non-emergency medical transportation.
- Deaf and/or hard-of-hearing individuals are underserved in several Los Angeles areas and in rural northern California.

## AREAS FOR FURTHER INVESTIGATION

Little is known about the similarities and differences in service needs between older adults who acquired their disability prior to becoming a senior citizen versus those

people whose disabilities are linked to aging. How does the former group experience the system of care targeting older adults, and how does the latter experience the ILC service system originally designed for younger people with disabilities? How have the different systems of care responded to these groups?

The data are vague about the specific unmet needs of children and youth with different types of disabilities. Additional clarification is needed to identify the specific unmet service needs of youth with disabilities.

How often do veterans find their way to ILCs for services and advocacy? What outreach activities have been initiated to help them gain access? What services do they need and receive? What gaps exist between the services that Veterans Affairs provide and those provided by ILCs to this population?

## Unmet Service Needs

The SILC received eight local Area Agency on Aging (AAA) needs assessment studies representing urban and rural areas in Northern and Southern California, with the southern part of the state more heavily represented. These studies relied on federal, state, and county-level demographic data, analysis of service utilization data, and consumer surveys of person aged 50 and older in the service area. Some of these surveys used randomized samples. At the top of the list of greatest unmet service needs are 1) health care, particularly access to affordable dental care and medical prescriptions (perhaps affected by the Medicare bubble); 2) transportation, both public and non-emergency medical transportation; 3) housing costs in urban areas and home repair needs in rural areas; and 4) social and

recreational opportunities to alleviate loneliness and isolation. Older adults also identified needs for caregivers, mental health care, end-of-life planning, information and referral, and adult day health care.

In the past, statewide surveys of consumers reached through ILC mailing and telephone lists have shown that the greatest unmet needs tend to be housing, transportation, public benefits, personal assistance services, health care, assistive technology, peer support, and advocacy. However, the Section 704 Reports contained very limited information that could be used to prioritize unmet service needs for Californians with disabilities. Data from the seven ILCs that provided needs assessments studies, the eight Area Agencies on Aging, and several statewide reports were consistent with these past results and provided further elaboration of the nature of

these unmet service needs. The information provided in these documents reflected widespread awareness of the difficulties facing people with disabilities in an era of economic downturn and cuts in public benefits.

The top issue, **housing** was often tied to public benefits in that the lack of housing vouchers, e.g., Section 8 vouchers and other rent subsidies, combined with low vacancy rates, meant that many consumers could not afford housing or faced financial hardships in other areas in order to pay for housing. Housing and transportation were intertwined because affordable housing was often located far from independent living services and other resources offered in urban centers. For some, a key housing concern was the lack of universal design, which in some respects resonates with the frequently expressed need for home repairs among

older adults as they become increasingly frail and encounter trouble living in their standard-designed homes. The lack of accessible and affordable housing limited some ILCs from acting aggressively in transitioning nursing home residents and others into the community.

A consortium of community-based organizations in Monterey County, led by the local ILC, conducted a community survey focused on housing issues facing people with disabilities and found that 46 percent of all respondents spend about one-third of their income on housing, and another 35 percent spend half of their monthly income on housing. Almost seven of ten people said they could only afford \$500 or less per month for housing. Almost 35 percent found themselves having to go without basic needs such as childcare, health care, or food in order to pay the rent or mortgage.

The second most unmet service need was **transportation**. Like housing, unmet transportation needs are exacerbated by financial hardship largely caused by the rising cost of fixed-route public transportation and paratransit services; eligibility for, and the cost and lack of availability of, non-emergency medical transportation; and everyday problems like carriers' lack of punctuality and reliability. The report, entitled *Assessing Human Services Transportation Coordination in California: An Analysis of Legal and Regulatory Obstacles* by the California Department of Transportation, confirmed many of these problems and attributed them to Medi-Cal, insurance companies, and state and federal transportation regulations as well as to county and provider eligibility restrictions. For example, this report contains the following troubling vignette:

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*“In rural areas where paratransit services are provided, it may be more practical to take a client to a doctor or hospital across a state or county line... In Modoc County... it is sometimes necessary to take clients to a doctor’s appointment in Reno, Nevada or in Oregon. Nevertheless, this is made difficult by restrictions imposed by insurance companies, and state and federal regulations.”*

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The third most discussed unmet service need was **health care**, despite the fact that most people with significant disabilities and adults age 65 and older are eligible for Medi-Cal or Medicare. Unmet health care needs were also associated with financial hardships as our sources identified rapidly increasing costs of health care, premiums, and co-pays in Medicare.

Another reason may be restricted access to specialists as fewer physicians agree to the low reimbursement rates paid by Medi-Cal and Medicare, which may mean that consumers have to travel further for appropriate care. Many of these same problems were also identified by older adult respondents in the consumer surveys conducted by the Area Agencies on Aging.

A pilot survey of 10 disability access programs provided by 28 California health care plans indicated that only about half of these programs reported having 1) specific individuals, departments or official programs to develop and oversee services for people with disabilities; 2) written procedures to inform members with disabilities of their rights; 3) formal training programs for providers and office staff regarding members’ rights to request disability accommodations; and

4) a process to track requests for disability accommodations.

**Other unmet needs** included the lack of availability of personal assistance services, especially through the In-Home Supportive Services program, followed by employment, information and referral, peer support, and independent living skills.

While lack of housing, transportation, and health care (intensified by poverty) dominated perceived needs among people with disabilities and older adults, a somewhat different picture emerges from the needs assessment studies and strategic planning documents submitted by specialized state agencies and task forces. Legal advocacy was, of course, the central concern expressed in the public forums conducted by Disability Rights California (DRC). According to DRC, parents of children with multiple disabilities wanted help advocating for their

children and for themselves in the school, mental health, in-home support services systems, as well as Medi-Cal and Medicare programs. A task force of parents and experts working to identify the needs of parents with disabilities and deaf parents echoed many of the same unmet advocacy needs found in the DRC report.

## **SUMMARY**

We reviewed the available sources to determine the most important unmet services of people with disabilities in California. The results clearly show that people with disabilities are severely impacted by economic circumstance. As the economy has soured and state budget cuts have been made, older adults, working-aged people with disabilities, and children with disabilities are experiencing increasing needs in the following areas:

- **Housing** has become less affordable, especially near locations where services are available;
- Public and other forms of **transportation** have become more costly and less accessible due to Medi-Cal eligibility restrictions;
- **Health care** costs, increased co-pays and premiums and the lack of availability of providers accepting Medi-Cal and Medicare; and
- Other unmet needs persist, such as personal assistance services, information and referral, peer support, employment, legal advocacy for schoolchildren with multiple disabilities in the school and mental health systems, and in the Medi-Cal and Medicare programs.

## AREAS FOR FURTHER INVESTIGATION

Not all Area Agencies on Aging and ILCs rank-ordered unmet service needs within their catchment in their areas, making it difficult to discern the greater and less-great needs across the state. The SILC could facilitate the gathering of this information by circulating a short survey to ILCs annually or, minimally, every three years as part of the SPIL needs assessment process.

These findings may not be representative of the range of unmet needs across the state. Four of the six needs assessment studies submitted by ILC represented urban locations, and none was submitted by ILCs in urban areas in the central part of the state. Only one of the two Northern California ILCs represented a rural area. Thus, further investigation is needed to fully portray the unmet service needs of ILC consumers in rural and urban areas of central and northern California.

## Developing and Strengthening the Independent Living Network

Under the Rehabilitation Act, (Title 34 of the Code of Federal Regulation, Part 364.42) as amended, the 2011-13 California State Plan for Independent Living (SPIL) must address the following goal: “Develop and strengthen the Independent Living Network in California.” The “Independent Living Network” is defined as

- Centers for independent living;
- Programs providing independent living services and independent living centers; and
- Other programs providing services for individuals with disabilities.

One suggested approach to strengthening the independent living network is to encourage

collaboration between different parts of the network, such as between ILCs and AAAs in communities of color or between ILCs and TBI advocates and medical rehabilitation providers and professionals.

In the same spirit, the SILC and DOR could facilitate discussions among proponents of different constituencies, such as those focused on cross-disability, and those focused on a single disability, or advocates versus service providers.

As this report has suggested, ILCs are losing ground in their efforts to serve the growing number of people with significant disabilities. One reason for this is the stagnant level of AB 204 and Title VII C funds. Low funding levels are made even worse when Part B and other available state funds are held up during state budget impasses. Thus, increased basic funding could shore

up the capacity of the ILCs to provide services to more individuals with disabilities.

A third suggestion stems from the perception that RSA standards and indicators do not work because ILCs are constantly in trouble. Stronger standards and indicators established by the ILCs, DOR, and the SILC could strengthen the ILC system in California. Initially, improved standards could focus on ILC boards of directors and management staff.

Fourth, it has been suggested that the SILC could strengthen the independent living network infrastructure by 1) upgrading the technology used to support communications among the ILCs including conference calls and web conferences, which could include technical manuals, materials and trainings under the roof of a virtual training library; and 2) providing an environment that promotes dialog and

other communication and encouraging members of the network to communicate freely with each other.

Fifth, although DOR does provide some statewide data to support the analysis of system-wide issues for all ILCs, a more comprehensive centralized data collection and reporting system is needed.

Last but not least, some members of the network have suggested that the SILC itself could provide better support to its constituents and to advise the Governor on public policy issues by having a staff member totally dedicated to tracking and analyzing legislation and regulatory changes, providing testimony at hearings, and engaging in negotiations when required.

## Cross-Cutting Needs and Conclusions

We have looked at the needs of Californians with disabilities from a geographical perspective based on statistical data, and we have used qualitative data reflecting the views of members of the independent living network to assess the needs of underserved minority, ethnic, and disability groups, as



well as unmet service needs that could be addressed by service providers. We have used a variety of statistical and qualitative data from a variety of sources reflecting data collected over the last five years from DOR, ILCs, AAAs, and several other regional and statewide agencies.

Most documents reviewed for this report were written in 2007 or 2008 amidst shrinking federal resources and severe state budget cuts or threats to cut major programs for people with disabilities such as In-Home Supportive Services. This gloomy context heightens awareness of the needs of the 2.3 million Californians with disabilities caught in the oppressive circle of disability, poverty, unemployment, and as we have shown, widespread perceived lack of housing and transportation. The U.S. Census' Current Population Survey shows that 12.8 percent of non-institutionalized person aged 5 and older have

a disability, and that roughly one in four (22.6 percent) of disabled individuals aged 18-64 lived in families with incomes below the poverty level. In addition, only 19.3 percent of Californians aged 18-64 with a work limitation were employed<sup>1</sup>.

Given this context, the results show that people with disabilities in the Inland Empire and Central Valley are the most in need of services from ILCs, and that ILCs in the Central Valley have the greatest gap between need and services. Underserved minority and ethnic groups include Latinos, Native Americans, Asian Americans, and older adults with disabilities, though network

providers strive to address the needs of all people in their catchment areas. ILCs, AAAs and other network providers have universally attempted to improve their ability to provide culturally appropriate services and have plans to increase their capacity to do so.

Underserved disability groups include people with traumatic brain injuries and/or hard-of-hearing or deaf individuals, especially in Los Angeles and rural northern California. The top three unmet service needs begin with housing, transportation and health care needs, each stemming from poverty and limited supplies.

Without more data, it is difficult to describe how geographical

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<sup>1</sup>Bjelland, M.J, Erickson, W. A., Lee, C.G. (2008, November 8), Disability Statistics from the Current Population Survey (CPS). Ithaca, NY: Cornell University Rehabilitation Research and Training Center on Disability, Demographics and Statistics (StatsRRTC). Retrieved December 7, 2009 from [www.disabilitystatistics.org](http://www.disabilitystatistics.org).

area, ethnic group, and disability group needs interact on a statewide basis. However, the data presented here strongly suggest that services gaps in the Inland Empire and Central Valley are affected by the influx of Latinos and Asian Americans into these areas. Also, in service-poor rural areas, ILCs are more likely to serve a greater proportion of older adults than their counterparts in service-rich urban areas.

Responding to the unmet needs described in this report would go a long way in strengthening the independent living network. These efforts may be enhanced by supporting ideas for strengthening individual components of the IL network. This includes encouraging projects that involve the cooperation of ILCs with other providers, such as AAAs and

senior centers in rural areas, employment and training programs, children's service providers, and programs for veterans. These results compellingly suggest the need to advocate for more affordable housing, greater public transportation capacity, and increased access to more affordable health care.

# Appendix A: Catalog of Documents

## **REGIONAL DISABILITY TASK FORCE REPORTS**

- Visible, Diverse and United: A Report of the Bay Area Parents with Disabilities and Deaf Parents Task Force (2006), Bay Area

## **REPORTS FROM EX-OFFICIO STATE AGENCIES AND OTHER STATE AGENCIES AND THEIR CONTRACTORS**

- Disability Rights CA, Advocacy Priorities and Goals for Federal Programs (2008-12), California
- Disability Access Project - Summary report to the Department of Alcohol and Drug Programs (2004-07), California
- Project Abstract - CA Association of Addiction Recovery Resources: Disability Access Project, California
- California State Board of Guide Dogs for the Blind - Strategic Plan (2004-06), California
- California Foundation for Independent Living Centers, Executive Summary - 2006 Pilot Survey (2005-06), California
- CA Department of Rehabilitation - 2009 State Plan Update (2006-08), California
- CA Department of Rehabilitation - 2010 State Plan Update (2006-09), California
- Mobility Action Plan: Phase 1 Implementation Study, Assessing Human Services Transportation Coordination in CA, California

- California Governor's Committee on Employment of People with Disabilities: California Comprehensive Strategy for the Employment of People with Disabilities, California

## **AREA AGENCIES ON AGING: NEEDS ASSESSMENT STUDIES**

- Sonoma County Human Services Department, Adult and Aging Division: Sonoma County Agency on Aging Area Plan (2009-12), Sonoma County
- Housing Alliance for People with Disabilities: Housing Needs of People with Disabilities Assessment (2005), Monterey County
- San Bernardino County Department of Aging and Adult Services: Section 6 Needs Assessments and Priorities (2005), San Bernardino County
- El Dorado County Area Agency on Aging: Establishing Priorities - The planning process (2009-12), El Dorado County Area
- San Diego County Aging and Independence Services: Survey of Older Americans (2000-08), San Diego County
- Community and Senior Services of LA County, Area Agency on Aging: L.A. County Seniors Count! Survey of the Older Adult Population (2008), Los Angeles County
- Area 12 Agency on Aging: Analysis of 2008 Survey, Alpine, Amador, Calaveras, Mariposa, Tuolumne Counties
- Riverside County Office on Aging: Aggregated Needs Assessment Findings from Internal/External Focus Groups Convened in 2008 for the 2009-2012 Strategic Plan, "Bridging the Generations for the Future" (2009-12), Riverside County

- Marin County Department of Health and Human Services, Division of Aging: Marin Health and Human Services Strategic Plan Data Focus Report (2004-14), Marin County

## **INDEPENDENT LIVING CENTERS: NEEDS ASSESSMENT STUDIES**

- Communities Actively Living Independent and Free: CALIF Needs Assessment, Los Angeles
- Silicon Valley Independent Living Center: SVILC External Issues and Trends - Consumer Feedback, A Strategic Planning Briefing (2009), San Jose & Santa Clara County
- FREED Center for Independent Living (2009), Nevada , Sierra, Yuba, Sutter, and Colusa Counties
- Dayle McIntosh Center: Needs Assessment (AB 204 Renewal 2006), Orange County
- Independent Living Resource Center San Francisco: Independent Living Resource Center San Francisco - Strategic Plan 2007-2010 (2007-10), San Francisco
- Independent Living Center of SoCal, Inc.: 2009 Demographic/ Needs Assessment/Survey (2009), Los Angeles County - Antelope Valley
- Westside Center for Independent Living: Needs Assessment Synopsis (2009-11), Los Angeles County

## **INDEPENDENT LIVING CENTERS: 704 ANNUAL PERFORMANCE REPORTS (2008)**

- Section 704 - Annual Performance Report for Centers for Independent Living - CIL Berkeley (Alameda County)
- Section 704 - Annual Performance Report for Centers for Independent Living - Center for Independent Living, Inc, Fruitvale/East Oakland (Alameda County)
- Section 704 - Annual Performance Report for Centers for Independent Living - Center for Independent Living, Inc., Oakland (Alameda County)
- Section 704 - Annual Performance Report for Centers for Independent Living - Placer Independent Resource Services (Alpine, El Dorado, and Placer Counties)
- Section 704 - Annual Performance Report for Centers for Independent Living - Disability Resource Center for Independent Living GRANT#H132A970009 (Amador, Calaveras, Mariposa, Stanislaus, and Tuolumne Counties)
- Section 704 - Annual Performance Report for Centers for Independent Living - Disability Resource Center for Independent Living GRANT#H132A970010 (Amador , Calaveras, Mariposa, San Joaquin, and Tuolumne Counties)
- Section 704 - Annual Performance Report for Centers for Independent Living - Independent Living Services of Northern CA – Chico (Butte, Glenn, Plumas, and Tehama Counties)
- Section 704 - Annual Performance Report for Centers for Independent Living - Independent Living Resource Contra

## Costa County (Contra Costa County)

- Section 704 - Annual Performance Report for Centers for Independent Living - Tri-County Independent Living Inc. (Del Norte, Humboldt, and Trinity Counties)
- Section 704 - Annual Performance Report for Centers for Independent Living - CA Association of the Physically Handicapped, Inc. Fresno County GRANT#H132A970018 (Fresno, King, Madera, and Tulare Counties)
- Section 704 - Annual Performance Report for Centers for Independent Living - CA Association of the Physically Handicapped, Inc. Fresno County GRANT#H132A970018 (Fresno, King, Madera, and Tulare Counties)
- Section 704 - Annual Performance Report for Centers for Independent Living - Access Center of San Diego Inc. (Imperial County)
- Section 704 - Annual Performance Report for Centers for Independent Living - Rolling Start, Inc (Inyo, Mono, and San Bernardino Counties)
- Section 704 - Annual Performance Report for Centers for Independent Living - Independent Living Services of Northern CA (Lassen, Modoc, Shasta, and Siskiyou Counties)
- Section 704 - Annual Performance Report for Centers for Independent Living - Community Rehabilitation Services, Inc. - GRANT#H132A010074 (Los Angeles County)
- Section 704 - Annual Performance Report for Centers for Independent Living - Community Rehabilitation Services, Inc. -

## GRANT#H132A970020 (Los Angeles County)

- Section 704 - Annual Performance Report for Centers for Independent Living - Independent Living Center of Southern CA, Inc. GRANT#H132A870005 (Los Angeles County - Antelope Valley)
- Section 704 - Annual Performance Report for Centers for Independent Living - Independent Living Center of Southern CA, Inc. (Los Angeles County - San Fernando Valley)
- Section 704 - Annual Performance Report for Centers for Independent Living – Marin Center for Independent Living (Marin County)
- Section 704 - Annual Performance Report for Centers for Independent Living - Community Access Center (Riverside County)
- Section 704 - Annual Performance Report for Centers for Independent Living - Resources for Independent Living Inc. (Sacramento & Yolo County)
- Section 704 - Annual Performance Report for Centers for Independent Living - Access Center of San Diego Inc. (San Diego & North County)
- Section 704 - Annual Performance Report for Centers for Independent Living - Independent Living Resource Center, Inc. (San Luis Obispo County)
- Section 704 - Annual Performance Report for Centers for Independent Living - Center for Independence of the Disabled

(San Mateo County)

- Section 704 - Annual Performance Report for Centers for Independent Living - Independent Living Resource Center, Inc. (Santa Barbara & Ventura County)
- Section 704 - Annual Performance Report for Centers for Independent Living - Independent Living Resource Contra Costa County (Solano County)

### **STATISTICAL DATABASES**

- Employment Development Department, State Disability Insurance Program: State Disability Insurance Statistical Information (2004-2009), California
- Division of Adult Parole Operations: Disability Placement Program Statistics (as of 6/30/2009), California
- Centers for Medicare & Medicaid Services, MDS National Quality Indicators: MDS2 Public Quality and Residents Report: MDS Q1a—Third Quarter 2009. Retrieved from [http://www.cms.hhs.gov/MDSPubQlandResRep/06\\_q1areport.asp?isSubmitted=q1a3&date=20&state=CA](http://www.cms.hhs.gov/MDSPubQlandResRep/06_q1areport.asp?isSubmitted=q1a3&date=20&state=CA)

# Appendix B: Requests for Information

## INITIAL REQUEST FOR INFORMATION

Dear \_\_\_\_\_

The State Independent Living Council (SILC) would like to thank those who have contributed to our work over the last two years as we have moved to strengthen the IL Network and make our work more representative of people with disabilities living in the community. Everything you have told us or taught us has helped us do better.

Soon the SILC will be working with the Department of Rehabilitation (DOR) to write the next State Plan for Independent Living (SPIL). This document governs the distribution of Federal funds for independent living programs in California. Before we can start the planning and writing, we want to step back and re-examine the needs of people with disabilities living independently in California. Although we conduct Needs Assessments every three years, the last three years have been financially devastating for our community and there will be concerns in that arena to attend to, as well as other issues.

In particular, we feel like you must have great understanding of the regional or specific community needs for the constituency you represent. You know things about your people that we need to hear!

That's why the SILC is asking if you could **please send us a copy of any Needs Assessments you have commissioned or completed within the last three years.** Even draft reports will be useful to us. Your input will be critical to the success of this initiative.

We will be collecting Needs Assessments from around the state, analyzing the results, and preparing a final summary report. This report will contain a summary of observations and recommendations. For Independent Living Centers and other groups that do not have Needs Assessments, we'll look for other sources of data. The ultimate goal is to write a SPIL that responds to and supports the community.

Our process is very public and we'll be asking for your help with every step.

If you have any questions about this survey, please contact Liz Pazdral at 916-445-0142 or [liz@calsilc.org](mailto:liz@calsilc.org).

Thank you in advance for taking the time to provide us with your data and assist us in identifying independent living development opportunities. We greatly value you, your ideas, and your time.

Sincerely, Liz Pazdral, Executive Director

## **REQUEST FOR IDEAS REGARDING DEVELOPING AND STRENGTHENING THE INDEPENDENT LIVING NETWORK**

This email is being sent to all the email addresses that the SILC has for the 136 agencies and organizations that we polled to compile our Statewide Independent Living Needs Assessment. We are working with the Center for Applied Local Research to complete this Needs Assessment. The final report will help inform the writing of the next State Plan for Independent Living.

Please take the time to answer one or more of the below questions. Your responses will help the researchers finalize and firm up their report.

Under the Rehabilitation Act, as amended (34 CFR 364), the 2011-13 California State Plan for Independent Living (SPIL) must address the following goal: “Develop and strengthen the Independent Living Network in California.” Where

“Independent Living Network” is defined as:

- centers for independent living; and
- programs providing independent living services and independent living centers; and
- other programs providing services for individuals with disabilities.



This inclusive definition is intended to encourage anyone and everyone to provide input for our required Needs Assessment Report on this topic. Here are five questions to help you frame your response.

What are your ideas for developing and strengthening the independent living network in California?

What does the independent living network mean to you?

What parts of the network need to be developed?

What parts of the network should be strengthened?

What policies and actions should DOR and the SILC pursue?



# Appendix C: Supplemental Tables

## TABLE C-1: CALCULATION OF PENETRATION RATES (SCREEN READER ACCESSIBLE)

**Table C-1** shows how the penetration rate in Table 2 is calculated for each of the Independent Living Centers (ILCs) in California.

**Column 1, “Centers,”** lists the name of each of the 29 Independent Living Centers in California and the Counties served by each ILC. Note that Los Angeles County is served by seven ILCs and Alameda is served by two ILCs.

**Column 2, “Total Population,”** is an estimate of the total population of each county based on 2007 Census estimates.

**Column 3, “Disability Population,”** is an estimate of the number of non-institutionalized persons age 5 and older with a disability, also based on 2007 Census estimates.

**Column 4, “Disability Rate,”** is the percentage of people with disabilities for each county calculated by dividing the number of people with a disability in each county (Column 3) divided by the total county population (Column 2) and multiplying by 100.

**Column 5, “Carryover Consumers”** is the number of carryover clients from 2006 served by each ILC in 2007. This figure is derived from Section 704 reports for 2007.

**Column 6, “New Consumers”** is the number of new clients served by each ILC in 2007. This figure is derived from Section 704 reports for 2007.

**Column 7, “Total Consumers”** is the total number of carryover and new consumers served by each ILC.

**Column 8, “Penetration Rate,”** is the percentage of people with disabilities in each catchment area served by each ILC. It is calculated by dividing number of people served by each ILC (Column 8) by the sum of people with a disability in all the counties served by each ILC.



Centers (Counties)	Total Population	Disability Population	Disability Rate	Carryover Consumers	New Consumers	Total Consumers	Penetration Rate
<b>Independent Living Services of Northern California</b> (Butte, Glenn, Lassen, Modoc, Plumas, Shasta, Siskiyou, Tehama)	545,008	119,331	21.9	129	576	705	0.591%
<b>Tri-County ILC</b> (Del Norte, Humboldt, Trinity)	157,755	32,288	20.5	95	218	313	0.969%
<b>FREED</b> (Colusa, Nevada, Sierra, Sutter, Yuba)	256,621	44,749	17.4	714	426	1,140	2.548%
<b>Independent Living Center of Kern County</b> (Kern)	669,253	109,689	16.4	494	205	699	0.637%

*Table C-1 Continued...*

Centers (Counties)	Total Population	Disability Population	Disability Rate	Carryover Consumers	New Consumers	Total Consumers	Penetration Rate
<b>Disability Resource Agency for IL</b> (Amador, Calaveras, Mariposa, San Joaquin, Stanislaus, Tuolumne)	1,200,436	195,232	16.3	857	258	1,115	0.571%
<b>Resources for Independent Living</b> (Sacramento, Yolo)	1,429,735	221,300	15.5	249	625	874	0.395%
<b>Center for Independent Living</b> (Fresno, Kings, Madera, Merced, Tulare)	1,620,672	245,306	15.1	236	323	559	0.228%
<b>Community Resources for Independence</b> (Lake, Mendocino, Napa, Sonoma)	692,804	101,425	14.6	1650	114	1,764	1.739%

*Table C-1 Continued...*

Centers (Counties)	Total Population	Disability Population	Disability Rate	Carryover Consumers	New Consumers	Total Consumers	Penetration Rate
<b>Placer Independent Resource Services</b> (Alpine, El Dorado, Placer)	468,768	65,491	14.0	184	106	290	0.443%
<b>Independent Living Resource Center of San Francisco</b> (San Francisco)	714,684	99,333	13.9	217	307	524	0.528%
<b>Rolling Start, Inc.</b> (Inyo, Mono, San Bernardino)	1,812,320	245,754	13.6	424	321	745	0.303%
<b>Independent Living Resource Center Contra Costa County</b> (Contra Costa, Solano)	1,302,775	172,942	13.3	313	717	1,030	0.596%

*Table C-1 Continued...*

Centers (Counties)	Total Population	Disability Population	Disability Rate	Carryover Consumers	New Consumers	Total Consumers	Penetration Rate
<b>Independent Living Resource Center-Santa Barbara</b> (San Luis Obispo, Santa Barbara, Ventura)	1,332,694	171,898	12.9	1122	511	1,633	0.950%
<b>Community Access Center</b> (Riverside)	1,819,512	230,662	12.7	233	388	621	0.269%
<b>Center for Independent Living Community Resources for Independent Living</b> (Alameda)	1,337,438	169,022	12.6	1,136	2,109	3,245	1.920%

*Table C-1 Continued...*

Centers (Counties)	Total Population	Disability Population	Disability Rate	Carryover Consumers	New Consumers	Total Consumers	Penetration Rate
<b>Communities Actively Living Independent &amp; Free Service Center for Independent Living Southern California Rehabilitation Services Community Rehabilitation Services, Inc. Disabled Resources Center Westside Center For Independent Living, Inc. Independent Living Center of Southern California (Los Angeles)</b>	9,081,896	1,112,923	12.3	6,927	3,813	10,740	0.965%

*Table C-1 Continued...*

Centers (Counties)	Total Population	Disability Population	Disability Rate	Carryover Consumers	New Consumers	Total Consumers	Penetration Rate
<b>Access to Independence of San Diego, Inc.</b> (Imperial, San Diego)	2,768,151	336,659	12.2	711	960	1,671	0.496%
<b>Central Coast Center for Independent Living</b> (Monterey, San Benito, Santa Cruz)	637,016	76,844	12.1	138	237	375	0.488%
<b>Marin Center for Independent Living</b> (Marin)	225,253	27,049	12.0	No data	No data	No data	N/A
<b>Center for Independence of the Disabled</b> (San Mateo)	650,995	70,793	10.9	209	177	386	0.545%

*Table C-1 Continued...*

Centers (Countries)	Total Population	Disability Population	Disability Rate	Carryover Consumers	New Consumers	Total Consumers	Penetration Rate
<b>Silicon Valley Independent Living Center</b> (Santa Clara)	1,584,188	160,620	10.1	318	538	856	0.5333%
<b>Dayle McIntosh Center</b> (Orange)	2,758,025	262,011	9.5	1,779	1,414	3,193	1.219%
<b>Statewide Total ILC Network</b>	33,065,999	4,271,321	12.9	18,135	14,343	32,478	0.760%



## **TABLE C-2: INUNDATION POTENTIAL (SCREEN READER ACCESSIBLE)**

**Table C-2** show how “Inundation Rate” in Table 2 is calculated for each ILC.

**Column 1**, “Centers,” lists the name of each of the 29 Independent Living Centers in California and the counties served by each ILC. Note that Los Angeles County is served by seven ILCs and Alameda is served by two ILCs.

**Column 2**, “Carryover Consumers” is the number of carryover clients from 2006 served by each ILC in 2007. This figure is derived from Section 704 reports for 2007.

**Column 3**, “New Consumers” is the number of new clients served by each ILC in 2007. This figure is derived from Section 704 reports for 2007.

**Column 4**, “Total Consumers” is the total number of carryover and new consumers served by each SILC.

**Column 5**, “Patients Who Want to Return to Community,” is the number nursing home patients who reported that they wanted to return to the community. These estimates are based on data from the Centers on Medicare & Medicaid Services: MDS National Quality Indicators: MDS2 Public Quality and Residents Report: MDS Q1a—Third Quarter 2009. Retrieved from [http://www.cms.hhs.gov/MDSPubQlandResRep/06\\_q1areport.asp?isSubmitted=q1a3&date=20&state=CA](http://www.cms.hhs.gov/MDSPubQlandResRep/06_q1areport.asp?isSubmitted=q1a3&date=20&state=CA)

**Column 6**, “Inundation Rate,” is the percent that the caseload currently served by each ILC will increase if that ILC were to provide Olmstead transitional services and other services to nursing home patients who want to return to the community. This figure is calculated by dividing column 6 by column 5.

Centers (Counties)	Carryover Consumers	New Consumers	Total Consumers	Patients Who Want to Return to the Community	Inundation Potential
<b>Independent Living Services of Northern California</b> (Butte, Glenn, Lassen, Modoc, Plumas, Shasta, Siskiyou, Tehama)	129	576	705	683	97%
<b>Tri-County ILC</b> (Del Norte, Humboldt, Trinity)	95	218	313	133	42%
<b>FREED</b> (Colusa, Nevada, Sierra, Sutter, Yuba)	714	426	1,140	202	18%
<b>Independent Living Center of Kern County</b> (Kern)	494	205	699	300	43%

Table C-2 Continued...

Centers (Counties)	Carryover Consumers	New Consumers	Total Consumers	Patients Who Want to Return to the Community	Inundation Potential
<b>Disability Resource Agency for IL</b> (Amador, Calaveras, Mariposa, San Joaquin, Stanislaus, Tuolumne)	857	258	1,115	1,267	114%
<b>Resources for Independent Living</b> (Sacramento, Yolo)	249	625	874	1,007	115%
<b>Center for Independent Living</b> (Fresno, Kings, Madera, Merced, Tulare)	236	323	559	1,191	213%
<b>Community Resources for Independence</b> (Lake, Mendocino, Napa, Sonoma)	1,650	114	1,764	538	30%

*Table C-2 Continued...*

Centers (Counties)	Carryover Consumers	New Consumers	Total Consumers	Patients Who Want to Return to the Community	Inundation Potential
<b>Placer Independent Resource Services</b> (Alpine, El Dorado, Placer)	184	106	290	362	125%
<b>Independent Living Resource Center of San Francisco</b> (San Francisco)	217	307	524	548	105%
<b>Rolling Start, Inc.</b> (Inyo, Mono, San Bernardino)	424	321	745	1,113	149%
<b>Independent Living Resource Center Contra Costa County</b> (Contra Costa, Solano)	313	717	1,030	876	85%

*Table C-2 Continued...*

Centers (Counties)	Carryover Consumers	New Consumers	Total Consumers	Patients Who Want to Return to the Community	Inundation Potential
<b>Independent Living Resource Center-Santa Barbara</b> (San Luis Obispo, Santa Barbara, Ventura)	1,122	511	1,633	836	51%
<b>Community Access Center</b> (Riverside)	233	388	621	1,237	199%
<b>Center for Independent Living Community Resources for Independent Living</b> (Alameda)	1,136	2,109	3,245	1,168	36%

**Table C-2 Continued...**

Centers (Counties)	Carryover Consumers	New Consumers	Total Consumers	Patients Who Want to Return to the Community	Inundation Potential
<b>Communities Actively Living Independent &amp; Free Service Center for Independent Living Southern California Rehabilitation Services Community Rehabilitation Services, Inc. Disabled Resources Center Westside Center For Independent Living, Inc. Independent Living Center of Southern California (Los Angeles)</b>	6,927	3,813	10,740	7,436	69%

*Table C-2 Continued...*

Centers (Counties)	Carryover Consumers	New Consumers	Total Consumers	Patients Who Want to Return to the Community	Inundation Potential
<b>Access to Independence of San Diego, Inc.</b> (Imperial, San Diego)	711	960	1,671	2,318	139%
<b>Central Coast Center for Independent Living</b> (Monterey, San Benito, Santa Cruz)	138	237	375	456	122%
<b>Marin Center for Independent Living</b> (Marin)	No data	No data	No data	253	N/A

*Table C-2 Continued...*

Centers (Counties)	Carryover Consumers	New Consumers	Total Consumers	Patients Who Want to Return to the Community	Inundation Potential
<b>Center for Independence of the Disabled</b> (San Mateo)	209	177	386	399	103%
<b>Silicon Valley Independent Living Center</b> (Santa Clara)	318	538	856	1,056	123%
<b>Dayle McIntosh Center</b> (Orange)	1,779	1,414	3,193	1,708	53%
<b>Statewide Total ILC Network</b>	18,135	14,343	32,478	25,087	77%

SELF-DETERMINATION  
INDEPENDENCE  
CHOICE

**California State Independent Living Council  
(SILC)**

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