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California Budget Cuts Fray the Long-Term Care Safety Net

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The deep budget cuts enacted by California's legislature in the summer of 2009 will be felt especially among the elderly and infirm. Disabled older adults with low incomes will find it harder to access services and, ultimately, harder to live safely at home.

Low-income older adults with disabilities often rely on multiple programs to remain safely in their homes and out of hospitals and nursing homes. However, California's 2009 budget crisis has resulted in reduced state funding for a broad array of health and social service programs, including those for low-income seniors. Using the limited available data, published research and key informant interviews, this policy brief describes the 2009 state budget cuts for community-based long-term care (LTC) programs and identifies likely consequences for older adults, their families and service providers.

Hundreds of thousands of seniors are likely to lose some or all of the assistance they rely on to remain at home. Available program data suggest that budget cuts are not necessarily targeting the least disabled. Studies from other states document that such cuts increase emergency room, hospital and nursing home use. Experts from a range of organizations dealing with the elderly in California who served as key informants for this research concur that these are likely outcomes from California's budget cuts, along with increased stress on family caregivers (when they exist) and reduced jobs and benefits for paid caregivers.

Long-Term Care Programs Being Cut

- *Supplemental Security Income (SSI/SSP)* is a cash assistance program for very low-income persons age 65 and over, blind or permanently disabled. Receipt of SSI automatically enrolls the elderly in Medi-Cal, and if disabled they may also be eligible for in-home services.
- *In-Home Supportive Services Program (IHSS)* usually requires Medi-Cal eligibility and provides assistance in the home for needed personal care and essential household services that the senior is unable to perform without monitoring or assistance.
- *Adult Day Health Care (AHDC)* requires Medi-Cal eligibility and offers supervised care outside the home during the daytime, including medical monitoring, rehabilitation, socialization and meals.
- *California Department of Aging (CDA) programs* are independent of Medi-Cal and include *Linkages* and the *Community-Based Services Program*. *Linkages* provides case management and assistance with evaluating and coordinating services for low-income seniors while the other program provides a range of supportive services. Eligibility is determined based on economic or social need, or risk of institutionalization.
- *California Department of Mental Health* supports the Caregiver Resource Centers that offer all families that care for persons with



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brain impairments (e.g. Alzheimer's): respite care, caregiver education and other support.

Many older Californians rely on one or more of these programs for meeting basic needs, including *personal care* (such as bathing or dressing) and *domestic care* (preparing meals or doing laundry). State funded programs such as ADHC and IHHS, as well as CDA funded services, offer essential help to impaired elders who do not have family assistance, and supplement critical care provided by their families.

Federal law requires that state programs for the disabled support continued residence in the community when feasible and desired by the recipient.¹ An effective long-term care “safety net” for older persons and their families requires multiple community-based supportive services. About half of CDA and ADHC recipients rely on two or more such services simultaneously.² These programs, in conjunction with available family and other informal care, enable older persons to remain safely in the community and improve the mental and physical health of caregivers.

Older Adults Need Community-Based Long-Term Care

Nationally, 12% of older adults have difficulty with domestic care activities such as cooking and cleaning (called Instrumental Activities of Daily Living – IADLs), and another 26% also have difficulty with personal care activities such as bathing and dressing (called Activities of Daily Living – ADLs).³ Half of older adults

with ADL difficulties report needing personal assistance, with higher rates among those with low incomes and living alone. One in 10 of those needing ADL assistance has unmet needs that can result in adverse consequences, such as dehydration and falls. Census data reports that 1.3 million older adults (one-third of all older Californians) have difficulty with basic physical activities; over 70% with low incomes who receive SSI report physical difficulties.

Most older adults with disabilities only receive assistance from family and friends. Nationally, 5% of those age 70 and over with a disability receive only formal paid assistance and 48% receive only unpaid assistance. An additional 9% receive both paid and unpaid help, while 38% have no help. Those with higher levels of disability and those living alone are the most likely to receive paid help.⁴ Research shows that providing assistance to those with functional impairments delays institutionalization. Exhibit 1 presents a case study of how public services assist older adults who remain in their homes.

Those unable to live safely at home may be institutionalized in nursing homes, where approximately 75,000 Californians age 65 and older lived in 2007.⁵ Medi-Cal pays about \$55,000 for a year of nursing home care, costing the program \$3.6 billion annually.⁶ Another \$3.8 billion is spent on community-based services. However, California ranks only 24th nationally in total Medi-Cal spending per resident for all long-term care services, which suggests that the state budget for LTC is not excessive.⁷

Exhibit 1

Case Study from Key Informant: Matching Needs and Services

Nancy is a 91 year old woman who lives with her 92 year old husband who worked in construction in Southern California. They rely on Social Security and SSI to pay their living expenses, and receive Medicare and Medi-Cal to pay for health care. Nancy is diabetic with osteoporosis and Alzheimer's disease. She needs assistance with bathing and dressing, and requires supervision for her other ADLs. She needs help with personal hygiene and is dependent on all other IADLs. Nancy primarily relies on her husband along with help from a worker paid by IHSS (66 hours per month for the couple), and she attends ADHC five days a week. The therapy provided at ADHC has allowed her to move about with greater agility and helped slow her physical decline. The worker is essential for shopping, laundry, help with bathing and meals on the days she is in the home. The IHSS worker reduces Nancy's risk of falls by keeping clutter down in the house, taking the laundry to the washing machine in the apartment's basement, and helping her get in and out of the tub.

The 2009 Budget Cuts and Their Impact

Exhibit 2 summarizes the status of the programs before the 2009 cuts, the governor's proposals for reductions and the actual cuts signed into law. The table also identifies the source of funding for each program and shows

that state general funds supporting IHSS and ADHC are matched by other funds. Thus, each \$1 cut in state funds for IHSS reduces total program spending by \$4. The following summarizes how these cuts are likely to impact older adults, their families and providers.

California's 2009 State Budget Cuts to Community-Based Long-Term Care for Older Adults

Exhibit 2

Program	Pre-Cut Levels	Governor's Proposed Cuts as of 5/30/09	2009 Budget Cuts As Enacted (including Governor's Vetoes)	Source of Funds	Impact
Supplemental Security Income (SSI/SSP)	<ul style="list-style-type: none"> • \$907/month maximum for individuals on 1/1/09 • \$1,579/month for couples on 1/1/09 • 552,847 elderly received in 12/08 	<ul style="list-style-type: none"> • To \$830/month maximum for individuals • \$1,407/month for couples 	<ul style="list-style-type: none"> • To \$845/month maximum for individuals • \$1,407/month for couples • 2011 cost of living adjustment eliminated • \$702.5 million less state general funds 	Only state funds (SSP) involved in cuts	<ul style="list-style-type: none"> • All elderly (552,847) who received SSI/SSP have their total income reduced
In-Home Supportive Services (IHSS)	<ul style="list-style-type: none"> • \$1.9 billion in State General Fund (08-09) • 445,584 of all ages received IHSS in June 2009, approx. 60% are elderly • All Functional Index Scores[†] (FIS) 1-5 served • All Functional Limitation Rankings[†] (FLR) 2-5 for domestic and related services-received hours 	<ul style="list-style-type: none"> • Eliminate all IHSS services for FIS[†] <3 • Eliminate all domestic and related services for those with FIS <4, all FLRs • Reduce state participation in IHSS wages to \$8/hr + \$.60 in health benefits • Eliminate share of cost subsidy • Increase fraud and abuse prevention 	<ul style="list-style-type: none"> • \$268.2 million (14%) state general fund reduction • \$138 million from reduced services • Balance from less fraud and administration cuts*** • No IHSS services to FIS[†] <2 • No hours for domestic and related service if related FLR[†] <4 • Eliminate share of cost subsidy • State funding for local Public Authorities cut \$13.5 million 	61% federal, 25% state general funds and 14% local funds (under Medi-Cal program)**	<ul style="list-style-type: none"> • 36,179 recipients of all ages lose all hours of service • 97,020 of all ages lose some hours (domestic services) • 9,277 of all ages lose share of cost subsidy
Adult Day Health Care (ADHC)	<ul style="list-style-type: none"> • \$214 million in state general funds • 37,000 recipients • Benefit maximum of 5 days/week 	<ul style="list-style-type: none"> • Eliminate 	<ul style="list-style-type: none"> • \$28.1 million state general fund reduction • Benefit maximum 3 days/week 	61% federal and 39% state general funds (under Medi-Cal program)**	<ul style="list-style-type: none"> • 8,000 recipients will lose 2 days/week
Department of Aging	<ul style="list-style-type: none"> • \$50 million state general funds for all programs (08-09) • Linkages: 5,529 elders • Brown Bag: 27,000 elders • Respite Purchase of Service: 695 families • Senior Companion: 17,630 hours • Alzheimer's Day Care Resource Center: 3,232 elders 	<ul style="list-style-type: none"> • Eliminate MSSP • Eliminate Linkages • Eliminate Community-Based Services Program • Total saving of \$24.2 million 	<ul style="list-style-type: none"> • \$15.8 million (32%) state general fund reduction*** • \$6.4 million, eliminate Linkages • \$4 million, eliminate Community-Based Services Program (Brown Bag, Respite Purchase of Service, Senior Companion, Alzheimer's Day Care Resource Center) 	Only state funds involved in cuts, but Brown Bag program leveraged by substantial food donations	<ul style="list-style-type: none"> • All recipients (over 35,000) lose services
Caregiver Resource Centers*	<ul style="list-style-type: none"> • \$10.5 million state general funds • 16,838 persons served (2006-07) 	<ul style="list-style-type: none"> • Eliminate 	<ul style="list-style-type: none"> • \$7.6 million (66%) state general fund reduction 	Only state funds involved in cuts	<ul style="list-style-type: none"> • Fewer clients and hours; some centers may close

* Department of Mental Health

** Reflects enhanced federal match rate effective through 12/31/10

*** Includes governor's final vetoes of budget that was passed; many of these additional cuts are being challenged in court

† FIS reflects average hours assigned based on statewide patterns, but may not accurately indicate hours assigned to a specific individual; FLR reflects level of need for assistance with a specific task (3=needs some human help, 2=needs verbal assistance, 1= no assistance).

Budget Cuts Negatively Impact California's Older Adults

The programs cut by the 2009 budget assist the most vulnerable older adults: those with low incomes who need assistance to remain at home. The cumulative impact is likely greater than that of an individual program. While some older adults will feel the impact immediately, key informants predict that others will “limp along” for months before reaching a health or financial crisis.

SSI/SSP cuts will reduce the income of more than one-half million older adults.

In January 2009, SSI/SSP benefits supplemented a single elder's other income to bring it up to \$907 per month. By October 2009, California's program will only bring their income to \$845 per month. Living in the community requires sufficient income to pay for basic rent, food, medical care, transportation and other expenses. SSI/SSP payments in California were insufficient for these basic costs before the budget cuts.⁸ SSI/SSP benefits, for the first time in many years, now fail to raise single elders above the inadequate federal poverty level. As many as 30,000 seniors became ineligible for SSI/SSP because their other income was slightly above the lowered eligibility level.⁹ Those who lost SSI/SSP also lost automatic enrollment in Medi-Cal and may not re-enroll even when eligible.

Some Budget Cuts Target the Most Disabled.

Key informants describe legislative attempts to limit cuts to those with the least needs. However, ADHC (cutting those with the maximum of 4-5 days per week) and CDA cuts (elimination of *Linkages* which assist those with complicated LTC needs) negatively impact the most disabled. The Alzheimer's Day Care Resource Centers (ADCRC) program by CDA was described by one key informant as serving those “with nowhere else to go” because of the severity of their dementia.

An estimated 20% of ADHC recipients will lose 1-2 days per week of care. No systematic data are available to further characterize these recipients. ADHC key informants describe those losing service days as the most vulnerable and with few

alternatives. Some clients were identified as having avoided ER trips due to the nurse monitoring onsite that they will not have access to during the lost ADHC days. Several informants note that a sizeable number of clients who are in ADHC five days per week have Alzheimer's, and the cuts to other programs compound the effects of the lost ADHC days. For the half of ADHC recipients who also receive IHSS, an unknown proportion will also have their IHSS hours reduced. Those losing ADHC days may be eligible to increase their IHSS hours after a reassessment, but key informants expect long delays in reassessments due to other cuts.

An estimated 8% of IHSS recipients of all ages will lose all benefits, and an additional 22% will have service hours reduced.

Recent statewide data to profile IHSS recipients are unavailable. Data from two large urban counties document the level of need of older adults who will lose services. In these counties about 15% of older IHSS recipients will lose all services due to state budget cuts. Of these, about half live alone, one-quarter are moderately or intermittently confused, and almost all need help with domestic activities. They will lose an average of 25-30 hours of assistance per month. An additional 10-30% of all older IHSS recipients in these two counties will keep some hours, but the time allocated for help with domestic activities will be eliminated under the state's new rules. Of those with reduced hours of help, over one-third live alone, almost half are over age 80, and about one-third suffer from memory problems. They will lose around 15 hours per month, about one-quarter of their total help.⁹

IHSS recipients face cuts based on assessment criteria designed for other purposes.

IHSS eligibility criteria was previously based on the need for assistance to remain safely at home. A complicated scoring system was then used to determine the total number of hours of assistance required. Parts of this scoring system are now used to eliminate benefits or reduce hours (Exhibit 3). Key informants identify this as a poor method of identifying those with the least need and see it as too complex to implement. In addition, numerous key

IHSS Cuts Misuse Program Assessment Scores

Exhibit 3

IHSS cuts are based on the Functional Index Score (FIS), which is a weighted average of 11 out of 14 different assessed areas needed for independent living. FIS was created to provide uniform IHSS assessments of clients. The assessment includes the physical and mental limitations of a client; however, the computer-generated calculation of the FIS does not include the full range of disability ratings assessed. For example, the average FIS does not include ratings of the mental limitation areas, or the most severe rating for any area. Consequently, the FIS when used to determine eligibility inadequately captures those who are limited by their mental functioning to carry out household and personal tasks. This oversight may place some older adults with impaired cognitive functioning at risk of injury and institutionalization. In addition, an IHSS recipient may lose hours if they score too low on any of the four domestic assistance tasks. For example, a recipient who is able to reheat meals but not prepare them will lose all hours allowed for meal preparation since they need “some” but not “a lot” of assistance (3.5 to 7 hours per week).

informants predict that appeals of the scores by those who lose benefits will slow the entire eligibility system. Those without family support are the least likely to have the resources to appeal and may be the first to feel the service reductions.

Cuts may weaken the consumer control over their care, which is a key feature of IHSS.

Cutting hours for specific tasks and new policies promoted to reduce fraud are described by several key informants as potentially reducing consumer control. For example, an IHSS recipient can lose all 15 hours per month for cooking and cleaning under the new budget. However, a consumer may occasionally request a cooked meal rather than an authorized bath. Some key informants fear this reallocation of time may be considered fraud.

IHSS administrative cuts will weaken services provided by local public authorities.

Public authorities assist with screening, training and placing nonfamily homecare workers. They also provide a registry for backup workers that can be used when the regular worker is sick or not available. Key informants indicate that these services will be reduced, leading to slower referrals and possibly less screening of workers.

Cuts reduce services that fill gaps in other state programs. CDA programs target elders with the most social and economic need, but have eligibility rules that are more flexible than IHSS and ADHC. The *Linkages* program

provides case management services to those not eligible for Medi-Cal. Key informants expect this loss to leave thousands of disabled seniors and their families uninformed about the full range of fragmented community-based LTC services that could help them remain at home. Department of Mental Health cuts to the Caregiver Resources Centers further weaken the network of information and support available to caregivers.

Lack of adequate data is a barrier to assessing the full impact of budget cuts.

An analysis of similar budget cuts in Michigan found that reducing service hours led to increases in emergency room use, hospitalization, permanent nursing home placement and increased caregiver burden. Other studies similarly document the usefulness of these services in reducing medical care use and improving the quality of life of the older adults who receive the care.⁹ These types of studies are not currently possible in California with existing data.

Budget Cuts will Negatively Impact Families

Key informants note that family caregivers rely on most of the community programs discussed previously and will face added psychological and economic burdens. Among IHSS recipients, two in five receive complementary unpaid help in addition to their paid hours.¹⁰ While informal caregiving is usually undertaken willingly, it can carry an enormous economic cost for the caregivers. Informal caregivers each lose an estimated \$660,000 over their lifetime in Social Security

benefits, pension benefits and lost wages.¹¹ Most caregivers are women (75%), have annual incomes below \$40,000 (69%), and work outside the home (50%; 71% of whom work full time). A majority of employed caregivers report that they have missed work, arrived late for work or left work early due to caregiving activities.¹² Younger caregivers may not only interrupt employment, but also forgo educational opportunities and reduce future economic advancement.

Many caregivers also experience physical and mental health problems due to providing care. Almost half of caregivers in California have depressive symptoms: nearly one-third report sleep interruption; one-quarter physical strain; and one-fifth financial hardship. California caregivers, compared to non-caregivers, are more likely to report reduced immune response, poor physical health and more chronic conditions.¹² Those most likely to experience physical strain, emotional stress and financial hardship in California are low income Latinas.¹³

Caregiving hardships for families can lead to higher rates of institutionalization for older adults. High levels of emotional stress and burden lead to earlier nursing home placement. Community-based services can reduce caregiver stress and provide a respite from caregiving (ADHC or caregiver resource centers, for example), allow informal caregivers to focus on less stressful care (such as IHSS), and increase the total caregiving resources available to keep an elder independent.¹⁴ Key informants anticipate that increased demands on the family due to reduced formal care will burn out the caregiving capacity of many families and result in earlier institutionalization.

Budget Cuts Will Reduce Community Care Provider Capacity

Community-based long-term care providers range from nonprofit agencies and private businesses to individuals. Individual providers are likely to be most impacted by the IHSS cuts, most of whom have low-incomes and many of whom are family members. It will be difficult under the current economic

conditions for these workers to replace the lost work hours. Loss of work hours will also contribute to loss of health insurance for some workers.

New policies to reduce alleged fraud and abuse can negatively impact individual IHSS service providers. New requirements for fingerprinting, random home visits and other fraud prevention activities will likely slow down the processing of new applications for assistance and the employment of new workers. The current largely manual payroll system cannot provide systematic data on potentially inaccurate payments.¹⁵ Policymakers, advocates and providers express doubt that savings from reduced fraud would result from these actions.

Nonprofit and private providers may also reduce workers or close. ADHC rates are frozen in the current budget and the reduction of service days will reduce revenues at all centers. The potential loss of revenue is not quantifiable due to lack of data, but key informant interviews found disparate impacts based on the size and resource level of ADHCs. The state estimates that 20% of clients at ADHCs will be impacted. However, some ADHCs rely both on Medi-Cal ADHC funding as well as CDA Alzheimer's Day Care Center funding, the latter being totally eliminated. Combined with local government budget reductions, key informants predict that some smaller agencies will close and all centers will expect to lay-off some staff.

Strategies to Improve Community-Based Services for Vulnerable Older Adults

California's 2009 budget cuts have frayed the community-based LTC safety net, with the largest numbers of elders being impacted by reductions to SSI and IHSS. The U.S. Supreme Court, in the *Olmstead* decision, found that disabled public assistance recipients had the right to live in the least restrictive environment, typically the community.¹ Different types of policies can help repair the safety net and keep elders living safely in their homes.

Policymakers have discussed the fragmentation of California's community-based LTC programs

for many years. The 38 programs administered by five different departments at the state level have inconsistent eligibility criteria, service design, oversight and data systems.¹⁶ The fragmentation is reinforced by current budget cuts, which were designed with little or no programmatic input by legislative policy committees or outside experts. Individual program cuts were based primarily on their budgetary impact and the larger picture of the LTC system goals was overlooked. Key informants suggest following state models such as Washington that uses a single point of entry into their long-term care programs and integrates the provision and financing of long-term care. Reducing fragmentation does not necessarily require increased spending, but does require attention to policy goals.

A 2009 state budget provision requires the state to move more seniors and the disabled into Medi-Cal managed care to save costs, which requires a federal waiver of Medicaid rules. This change could also be used to improve the coordination of long-term care services. A successful managed LTC model is the Program of All Inclusive Care of the Elderly (PACE). This prepaid, integrated program reduces costs and improves community-based LTC for disabled elderly.¹⁷ Any managed care for disabled seniors should incorporate best practices such as integrated long-term care benefits and case management that focus on the elder's needs, not just the lowest cost.

A different model involves providing recipients with a flexible budget to purchase and manage any assistance they need, along with professional advice about service options.¹⁸ The goal of the “cash and counseling” program is to eliminate service silos and coordinate care while maximizing consumer choice and control.

All strategies to alleviate the fraying of state-funded long-term care should include collecting and disseminating representative and reliable data. The lack of client-centered data across programs makes it impossible to determine how many low-income disabled older adults receive appropriate long-term care services, or to track the impact of cuts.

Several key informants express frustration at the lack of data available to comprehensively assess the outcomes of this year's cuts. Ideally, the state should initiate a survey of recipients that assesses the needs, resources and service use of recipients across programs. At a minimum, the state should mandate the use of a common identifier for recipients and a minimum set of data elements for all programs so that administrative data can be used to track users of multiple programs.

Methods

This brief was prepared after an extensive review of the existing literature that evaluates home and community-based services, risks of institutionalization and evaluations of California's LTC programs. Information on the state budget cuts came from published documents. Santa Clara and San Diego counties graciously provided tables from their administrative data on older adults receiving IHSS services who will experience service cuts. We also interviewed 20 key informants who are service providers, advocates, public officials and experts to obtain informed assessments of the likely impacts of the impending program reductions.

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