Community-Based Long-Term Care: Potential Consequences of California's 2009 Budget Cuts

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Introduction

California was once a leader in innovating new ways to provide long-term care services that allow older adults and the disabled to remain safely in their homes as long as possible. In the early 1970s, for example, a San Francisco organization called On Lok innovated a comprehensive program that created an adult day health center and supportive in home services to allow seniors to remain out of nursing homes. By 1990 this model, now called the Program of All-inclusive Care for the Elderly (PACE), had been successfully replicated elsewhere and became a Medicare/Medicaid waiver program that is now available nationally (http://www.npaonline.org/website/article.asp?id=12). The state was also a laboratory for the development of the Social HMO, consumer directed home care services, and caregiver support services.

The innovative spirit of the 1970s and 1980s is long past, and for the last several years budget considerations have dominated long-term care policy making in the state. Budget driven policy came to a peak in 2009 as the world-wide recession led to California's first drop in state revenues and a historic gap between revenues and expenditures. Complicated political dynamics and policy constrains led the governor and legislature to focus on program cuts as the major means to balancing the budget. This report finds that 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 more difficult 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 report describes the 2009 state budget cuts for home and 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 (for those fortunate enough to have a family caregiver) and reduced jobs and benefits for paid caregivers. This report begins with a summary of the cuts and provides detailed discussions of how those cuts will impact the major programs and populations affected. It offers a summary of our key informant interviews on this topic as well as a summary of the published literature on the effectiveness of these types of programs. We end with a call for California to return to its past innovative spirit of designing new ways to help disabled older adults remain safely at home. A policy brief that summarizes this report is available at http://new.healthpolicy.ucla.edu/pubs/Publication.aspx?pubID=380.

Details of 2009 Budget Cuts and Sources of Information

California's 2009 State Budget Cuts to Community-Based Long-Term Care for Older Adults					
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)	• **$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	• To $830/month maximum for individuals • $1,407/ month for couples	• 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	• All elderly (**552,847)** who received SSI/SSP have their total income reduced
In-Home Supportive Services (IHSS)	• **$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 • Functional Limitation Rankings† (FLR) 2-5 for domestic and related services receive hours	• 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	• **$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)**	• **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)	• **$214 million** • **37,000 recipients** • Benefit maximum of 5 days / week	• Eliminate	• **$28.1 million** state general fund reduction • Benefit maximum **3 days** / week	61% federal and 39% state general funds (under Medi-Cal program)**	• **8,000** recipients will lose 2 days/week
Department of Aging	• **$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	• Eliminate MSSP • Eliminate Linkages • Eliminate Community Based Services Program • Total saving of $24.2 million	• **$15.8 million (32%) state general fund reduction, including*****: • $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	• All recipients (over **35,000**) lose services
Caregiver Resource Centers*	• **$10.5 million** state general funds • **16,838** persons served (2006-07)	• Eliminate	• **$7.6 million** (66%) state general fund reduction	Only state funds involved in cuts	• 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).

Data Sources

Supplemental Security Income (SSI/SSP)

Reductions in SSI/SSP Benefit Levels
http://www.pascla.org/Pages/Legislative%20Updates/LU1.htm

Office of Retirement and Disability Policy: SSI Recipients by State and County, 2008
http://www.ssa.gov/policy/docs/statcomps/ssi_sc/2008/ca.html

CHHS Budget Facts for 2009-10 (August 2009)
http://www.chhs.ca.gov/initiatives/Documents/BBFinal.pdf

In-Home Supportive Services (IHSS)

Budget Cuts/Changes to IHSS
http://www.pascla.org/Pages/Legislative%20Updates/LU1.htm

CHHS Budget Facts for 2009-10 (August 2009)
http://www.chhs.ca.gov/initiatives/Documents/BBFinal.pdf

Caseload data from IHSS monthly reports:
http://www.cdss.ca.gov/agedblinddisabled/res/pdf/2009JuneMgmtStats.pdf

Legislative Analyst's Office (LAO). 24 March 2009. In-Home Supportive Services: Background and Caseload Components.
http://www.lao.ca.gov/handouts/socservices/2009/IHSS_Background_and_Caseloads_03_24_09.pdf

Information on Governor's May 2009 proposed cuts:
http://www.disabilityrightsca.org/News/2009-05-15_May_revise.pdf

2009-10 May Revisions – General Fund Proposals
http://www.dof.ca.gov/budget/historical/2009-10/may_revision/documents/May_Revision_2009-10_General_Fund_Proposals.pdf

Adult Day Health Care (ADHC)

California Budget Project: Governor Signs Budget Revisions
http://www.cbp.org/documents/090727_Governor_Signs_Budget.pdf (revised Aug. 5, 2009)

Total budget from
http://www.dhcs.ca.gov/dataandstats/reports/mcestimates/Documents/2009_may_estimate/M09_03_Budget_Year_Tab.pdf p.2

Number of clients losing benefits
http://www.nsclc.org/documents/complaint-brantley-et-al-v-maxwell-jolly/at_download/attachment

Department of Aging (CDA)

CHHS Budget Facts for 2009-10 (August 2009),
http://www.chhs.ca.gov/initiatives/Documents/BBFinal.pdf

Historical budget from DoF, 2008-09 budget as enacted http://2008-09.archives.ebudget.ca.gov/Enacted/StateAgencyBudgets/4000/4170/department.html

Department of Aging: Comparison of Governor's May Revision and LAO Alternative
www.lao.ca.gov/handouts/conf_comm/2009/Department_of_Aging_Comparison_06.09.09.pdf

Caregiver Resource Centers (Department of Mental Health)

2009-10 Budget Conference Committee on SB 61, June 5, 2009.
http://www.cdcan.us/budget/2009-2010/BudgetConferenceCommitteeCOMPLETEAgenda06052009-Health-6509CCHealth.pdf

California's Caregiver Resource Center System, Program Highlights Fiscal Year 2006-07.
http://www.caregiver.org/caregiver/jsp/content/pdfs/2006-07_Highlights_MK_20080418.pdf

CHHS Budget Facts for 2009-10 (August 2009),
http://www.chhs.ca.gov/initiatives/Documents/BBFinal.pdf

Impact of Budget Cuts on Supplemental Security Income Recipients

Supplemental Security Income/State Supplementary Payment (SSI/SSP) is a federal/state income support program that provides a monthly cash benefits to low-income aged, blind, or disabled individuals or couples. Single recipients can not have over $2000 in assets, $3000 for a couple, other than their home. California is one of 23 states that supplement the federal SSI payment for the typical aged individual living independently with the SSP. Approximately 1.27 million children and adults received monthly SSI/SSP assistance in December 2008. Those recipients originally qualified for the program as disabled (870,418 or 69 percent), aged (366,861 or 29 percent), and blind (19,921 or 2 percent). In December 2008 there were 552,847 recipients who were age 65 and over (43.5 percent). (U.S. Social Security Administration 2009).

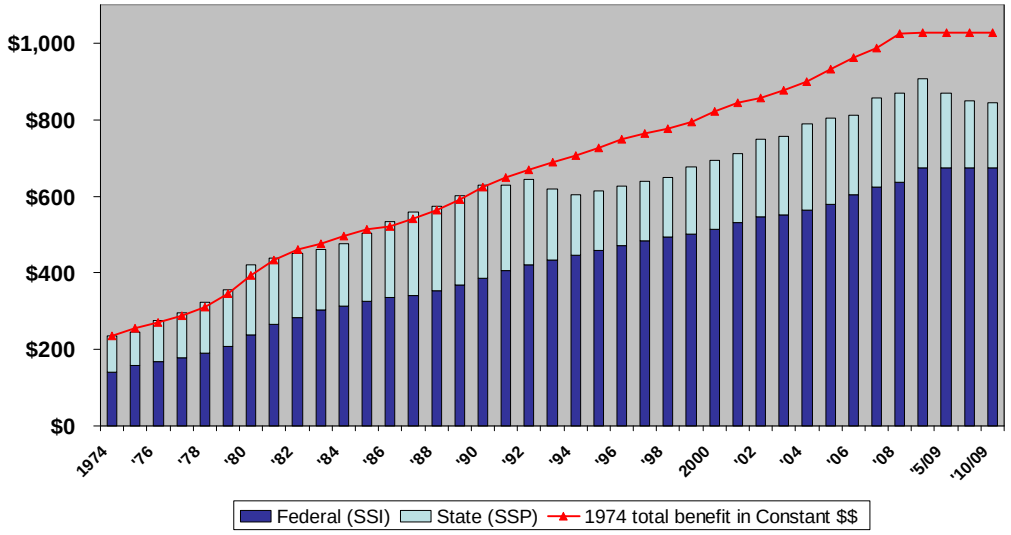
2009 Cuts

The state-funded Cost-of-Living Adjustment (COLA) was suspended in the February budget for 2009-10 effective May 1, 2009 ($362.8 million general funds (GF) savings). SSI/SSP grants were then reduced by 2.3 percent effective July 1, 2009, reducing grants from $870 to $850 for individuals and $1,524 to $1,489 for couples ($230.7 million GF savings).

The Amended Budget for 2009-10 permanently eliminates automatic COLAs for SSI/SSP recipients. SSI/SSP grants to individuals and couples will be reduced effective Nov. 1, 2009. Approximately 1 million individuals receiving SSI/SSP will see a .6 percent reduction in their monthly grant, from $850 per month for the maximum grant to $845 per month ($42 million GF savings). Approximately 245,363 couples receiving SSI/SSP will see their grants reduced to the minimum allowed under federal law, from $1,489 per month for the maximum grant to $1,407, a reduction of $82 per month ($67 million GF savings) (California Health And Human Services Agency 2009).

When SSI was established in California in 1974, the SSI/SSP benefit maximum was $235 for an individual. The inflation-adjusted value of that income in 2009 is $1027. While the federal government increases the value of its SSI benefit each year according to the Consumer Price Index (CPI), California has not. As a result, the value of the total SSI/SSP maximum has fallen by 18%. As Chart 1 demonstrates, California provided cost of living increases that roughly matched the federal increases until the early mid-1990s when the state-funded SSP portion was first cut. All of the increases in the state SSP in the last decade have been erased with the latest round of cuts which returns the state's portion of the SSI/SSP maximum to the lowest level it has been since 1998.

SSI/SSP Payment Maximum
Single aged or disabled person, California



Sources: www.cfpa.net/CashoutinCA2003.pdf, www.socialsecurity.gov/policy/docs/statcomps/ssi_asr/2008/sect01.htm, www.socialsecurity.gov/policy/docs/progdesc/ssi_st_asst/, www.bls.gov/data/inflation_calculator.htm

Impact

Living in the community requires sufficient income to pay for rent, food, medical care, transportation, and other basic expenses. This is a particular challenge since California has one of the highest costs of living in the country (ACCRA 2008). Supplemental Security Income (SSI) payments in California were not enough to pay for the basic costs faced by older adults before the benefit reductions, let alone pay for any in-home assistance. Based on 2007 data, the basic cost of a living for older adults in California was about 200% of (twice) the federal poverty level (Wallace & Molina 2008). After the latest round of reductions, the SSI/SSP benefit for an individual will be at 94% of the Federal Poverty Guideline (DHHS 2009) or less than half of the amount that the Elder Index calculates based on the costs of living in California's counties.

Benefit cuts will reduce the income that over one-half million seniors use to pay for necessities., and the benefit reduction will leave as many as 30,000 seniors who live alone without any SSI benefits. Recipients who live alone will, for the first time in many years, have incomes below the inadequate federal poverty level. In addition, those losing SSI will no longer automatically be enrolled in Medi-Cal (California's Medicaid program). California allows seniors with few or no assets to "spend down" to Medi-Cal and LTC eligibility by paying out of pocket for medical care expenses until their remaining income hits the Medi-Cal eligibility line, which is now higher than the SSI line. The budget cuts will require some seniors who are already struggling economically to pay more out of pocket before obtaining public assistance for LTC.

Medi-Cal Eligibility. All Californians who receive SSI/SSP also are automatically enrolled in Medi-Cal without any additional paperwork on the part of the recipient. Those older adults who are no longer eligible for SSI/SSP due to the budget cuts are also no longer automatically enrolled in Medi-Cal. Due to federal law, however, the Medi-Cal eligibility income will remain at $1133 for individuals and $1525 for couples (compared to the SSI levels of $850 single, $1407 couple) (CA DCHS 2009). It is possible that those losing benefits will be allowed to remain on Medi-Cal because of their prior eligibility. Those with incomes between the Medi-Cal eligibility level and the new lower SSI eligibility level may not realize that they are eligible for Medi-Cal (and therefore IHSS, ADHC, and other Medi-Cal funded community-based long-term care services) with no share of cost (i.e. they do not have to incur medical expenses that reduces their income, called "spend down," to the eligibility level. The further that SSI falls below the Medi-Cal eligibility level, the more likely it is that eligible older adults will not know to apply for needed long-term care benefits.

Other Issues

Food Stamps. When SSI was established in California in 1974, the state decided to provide cash instead of food stamps to SSI recipients. At the time, this was seen as benefiting recipients since they automatically received the value of the food stamps in their monthly check. It also saved the state substantial administrative costs in not having to determine eligibility and enroll low income aged, blind, and disabled persons in a different program. In the subsequent 35 years the value of the "cash out" has not risen, while SSI recipients continue to not be eligible for food stamps. Single elders who no longer receive SSI may be eligible for food stamps, which are available to older adults with incomes below 100% of the Federal Poverty level. If the elder lives in the a family setting with younger adults who receive food stamps, losing SSI will result in the elder's remaining income now being counted as part of the larger family unit's income for the purpose of food stamp allocations. While on SSI, none of the elder's income counts towards the family income for purposes of food stamps (Arnold and Marinacci 2003). The net result is likely to be a reduction in the aggregate food stamp allotment for the whole family.

Impact of Budget Cuts to In-Home Supportive Services (IHSS) Program

Background

With a budget in FY2008-09 of about $5.5 billion, the IHSS program currently serves nearly 450,000 low-income Californians of all ages with disabilities, approximately 60 percent of whom are over the age of 65. Since 1994, when the program was folded into Medi-Cal as the state-plan personal assistance benefit, the state has received federal Medicaid funding for 49% of program costs; the state (34%) and counties (17%) support the remainder. The overarching goal of the program is to assist eligible persons who live at home to remain safely in their homes and avoid typically less desirable and more expensive institutional care. IHSS eligibility derives from eligibility for income assistance from SSI (Supplemental Security Income); those who are aged, blind and disabled, have assets of less than $2,000 excluding house and car, and whose income falls at or below SSI levels ($907 for an individual and $1,579 for a couple in January 2009) are eligible for IHSS services. Until now, persons with higher incomes could also "spend down" to IHSS eligibility, assuming they met other requirements. These eligibles have paid a share of providers' salaries out-of-pocket and are known as "share of cost" recipients. For IHSS recipients who qualify for the Medi-Cal Medically Needy program and have a share of cost, the state pays a portion of a recipient's share of cost to reduce the financial burden of paying out of pocket for IHSS services.

Those eligible for IHSS can receive up to 283 hours per month of reimbursed services. Actual authorized hours are determined by the counties through a home assessment that focuses on the prospective recipient's ability to perform a range of basic daily activities, assesses cognitive functioning, and calculates the number of monthly service hours using a complex state formula. IHSS funds a range of services to those judged to be unable to remain safely at home without assistance. Covered services include personal care (e.g., bathing , dressing, and feeding), domestic and related chores (e.g., laundry, cooking, cleaning, and shopping), paramedical services (e.g., injections, catheters, foley bags, feeding tubes, etc.), protective supervision, and transportation to medical appointments.

Not only does IHSS provide essential supportive services to low-income people of all ages with disabling illnesses and conditions, but the program does so by allowing recipients and their families considerable discretion in managing those services in their homes. IHSS uses what is known as a "consumer-directed model" of service delivery, in which recipients are authorized to recruit, hire, train and supervise their own service workers, with direct payment by the state to those workers for certified hours. Recipients are free to hire anyone they choose, meaning that they can hire family members or friends, something older recipients are especially likely to do. Nationally, IHSS has long been recognized for its consumer-directed approach, and with federal support many other states are now emulating California's pioneering program. Consumer direction allows the recipient the flexibility within program guidelines to schedule and design the package of services they most need to remain independently at home. Studies which have compared the outcomes of services delivered under consumer direction and traditional agency services have consistently shown that recipients have greater satisfaction, more positive health outcomes, and better quality of life under consumer directed approaches like IHSS.

IHSS represents a dilemma for policy makers in the State of California. On the one hand, the population it serves – close to a half-million aged, disabled, and blind - is surely among our very neediest and at the same time the costliest in terms of public funds for medical care and nursing homes. The services IHSS provides likely keep many thousands of Californians living at home, relatively healthy, and not seeking care in emergency rooms and nursing homes. On the other hand, the program's caseload has more than doubled in the last decade (from just over 200,000 in 1998-99), the average annual cost per recipient has doubled in that time to about $13,000 in 2008-09, and the state general fund portion of IHSS costs grew by three and one-half times (LAO, 3-24-09). In the presence of a giant budget deficit, and in the absence of a political will to increase revenues by raising taxes, IHSS has become a target for major budget cuts.

Prior to the recent budget cuts, the state projected that for fiscal year 2009-10 the IHSS program would fund supportive services for approximately 462,000 recipients to be provided by about 376,000 individual providers with approximately 60 percent of IHSS recipients over the age of 65. Also, around 60 percent of providers are family members, and a significant but unmeasured number are friends and acquaintances. In an ideal world, families and friends would fill the gaps created by the cuts now being implemented, and with some admitted stress, people would not be worse off by much. Our analysis suggests that the picture is far more complicated than that.

Summary of IHSS Cuts

The public mission of IHSS is to ensure that people receive the assistance they need to perform these tasks and thus remain at home. Under statute, an IHSS recipient "would be unable to remain safely in his or her home if these services were not provided" (California Welfare & Institutions Code Section 14132.95). The most significant of the state's budget cuts to In-Home Supportive Services (IHSS) use the Functional Index Score (FIS) and selected Functional Limitation Rankings (FLR) to determine who will continue to receive services and who will experience reduced or completely eliminated service hours. These scores and rankings result from assessments done periodically by a county worker who rates the ability of eligible applicants to perform a range of specific living tasks considered essential to maintain independence. According to the California Department of Social Services, the FIS tool was not intended to determine eligibility; rather it was created to provide uniform IHSS assessments of the clients' relative dependence on human assistance.

There are two separate processes that produce the final FIS: first, the social worker's assessment of the physical and mental limitations of a client; and second, a computer-generated calculation to produce an overall FIS. The social worker's assessment provides a Functional Limitation Ranking (FLR) for each of 14 tasks in terms of need for human assistance.[2] However, the

[2] ***Process 1: Client Assessment***
A social worker ranks each client's physical and mental functioning. There are 11 separate areas of physical functioning (4 household tasks: housework, laundry, shopping and meal preparation; and 7 personal tasks: mobility, bathing, dressing, bowel, bladder and menstrual, transfer, eating and respiration) and 3 separate areas of mental functioning (memory, orientation and judgment). Some of the physical tasks are ranked 1-5 to measure a client's dependence on human assistance, 1-being independent and 5 being dependent, or not able to perform the task with or without human assistance; a score of 6 is reserved for those with "paramedical" needs. Each area of the mental functions is ranked 1, 2 or 5 to determine whether a person is at risk and needs protective services, 1-no problem, 2 – mild problem and 5 – severe problem. A person is considered at high risk of injury and provided with protective services if they have a score of 5 in at least one of the areas of mental functioning.

calculation of the FIS is based only on *some* of the FLRs given for the client's physical limitations.[3] The FIS does not include the FLRs given for the client's mental limitations and need for protective services or any FLRs that indicate a paramedical need. Consequently, the FIS, as it is being used by the state to determine eligibility of services, may not capture those persons who are limited by their mental functioning to carry out household and personal tasks.

The IHSS budget cuts approved in July 2009 are targeted at recipients with an overall "Functional Index Score"(FIS) below 2.0 who will no longer receive any IHSS benefit as well as recipients with a Functional Limitation Ranking (FLR) below 4.0 on any of four domestic and related services who will lose hours associated with these services. Additionally, qualified medically needy IHSS recipients with a share of cost will lose the state's share of cost subsidy. Our efforts to secure statewide program data from the CA Department of Social Services have been unsuccessful and estimating the number of older adults affected by these cuts has been a daunting task. Though we have utilized program data from two large urban counties (Santa Clara and San Diego Counties) to estimate the numbers of people with FIS scores below 2.0 or FLR below 4.0 in domestic and related service who will lose all or some services by the state cuts, we found estimates and analysis of estimates to vary across counties in ways we do not yet understand. The inability to provide more accurate statewide estimates and the lack of data on the characteristics of older adults losing services highlights the need for careful monitoring of these cuts as they are implemented and experienced by older Californians. During this early pre-implementation phase, program data from these two counties provides a glimpse of who might be affected by the cuts. Of all low-income IHSS recipients, between 22 and 47 percent are targeted by the recent cuts, and approximately 60 percent are over the age of 65 (See Tables 1-3, Appendix A).

IHSS recipients 65 and older:

- Among all older adults 65 and over who will lose all or some IHSS services, about 70 percent are female, over 40 percent live alone and close to a third have memory impairments. (See Table 4, Appendix A)
- Of those 65 and older who will be impacted by the cuts, 30 to 56 percent will lose *all* IHSS services: close to two-thirds of these are female, half live alone and close to half do not have a family provider. (See Table 5, Appendix A)
- Of the remaining 44 to 70 percent of older adults who will lose hours associated with domestic and related services, three-quarters are female, close to 40 percent live alone and over a third have memory impairments and no family provider. (See Table 6, Appendix A)

Statewide estimates indicate there are 36,179 IHSS recipients of all ages who will lose all hours of services, an additional 97,020 IHSS recipients of all ages lose some hours for domestic and related services and 9,277 of all ages lose share of cost subsidy. Extrapolating data trends from

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[3] ***Process 2: Overall FIS Calculation***
To determine the overall FIS assigned to an IHSS recipient a complex and computer-generated calculation is used to weight and average the various scores of the functional components given in the assessment. However, the calculation of the FIS is based solely on the 11 areas of physical functioning and does not include the 3 areas of mental functioning. Consequently, the FIS does not capture those who are limited by their mental functioning to carry out household and personal tasks.

Santa Clara and San Diego County, there may be close to 80,000 IHSS recipients age 65 and over who will be losing all or some of their hours of services statewide with roughly 56,000 who are female, 32,000 who live alone and 24,000 with cognitive impairments. Without access to statewide program data, it is difficult to accurately assess the extent of these cuts and to provide better information about the characteristics of older adults being impacted, which raises many questions and concerns about how these cuts will be implemented.

How will these cuts be implemented?

There are six components to the IHSS cuts:

1. Recipients with FIS below 2.0 (i.e. with scores of 1.00-1.99) will lose all paid hours of services, because they are presumed to be the least needy of recipients. The assumption made by the state budget cuts that an FIS score below 2 represents someone who needs fewer services is inaccurate. There are two important components of an individual's assessment that are not factored into the calculations of the FIS. First, an individual's need for paramedical services is not reflected in the FIS. Second, the FLR rankings for memory, orientation and judgment, that determine if a person needs protective supervision, are not included in the calculation of the FIS. Recipients may be mechanically able to perform basic tasks, but because of cognitive limitations may need reminding and monitoring to perform them. While reminders and monitoring may seem to be minor, without them a recipient may not remember to eat or take needed medications, which in turn can lead to the deterioration of a client's overall health status. The vetoed exclusions for IHSS recipients with protective services, paramedical need and those with more than 120 hours of authorized hours would have captured those individuals who crucially need and receive more IHSS services than is reflected in an FIS below 2. If these exclusions are not retained, this oversight will likely place many older adults at risk, especially those with impaired cognitive functioning, when they no longer have the IHSS service hours they need to remain safely in their home. Ignoring cognitive status may put a number of older recipients at greater risk of loss of services and a decline in independence. (See Case Example 1, Appendix B)

In the two counties for which we have detailed program data, these recipients represent 12.7% and 15.7% of all cases, respectively. All will have their IHSS eligibility terminated and their service hours eliminated (i.e. reduced to zero). Initial estimates suggest that an inordinate number of children with disabilities will be affected by these cuts, especially those with developmental disabilities and other cognitive limitations. Older adults with cognitive limitations will also be affected, although numbers are difficult to estimate. In Santa Clara County, close to 1,300 older people will be affected and in San Diego County, just over 2,000 older recipients will lose their IHSS eligibility and thus all of their IHSS service funding, representing about one in eight program recipients (13%) over age 65. (See Table 5, Appendix A)

2. All recipients who have FIS above 2.0 will lose paid hours for any of four domestic and related services (housework, laundry, shopping, and meal preparation) for which they have a FLR below 4.0. In other words, if on any of these four tasks, the county assessment rates them as needing less than "substantial human help" (and thus perhaps some or quite a bit, but short of substantial), the assigned hours for that task (or tasks) will be eliminated. Again, the FLRs for cognitive functioning and paramedical need are not taken into consideration in this process of cuts. (See Case Example 2, Appendix B)

Initial analysis of the two study counties showed an unexpected variance in the FLR reductions between the two counties. Due to the lack of state level or other county data, it is difficult to explain this variance; differences across counties may be attributed to difference in recipient levels of disability or it may indicate a difference in county training and assessments. A 1994 evaluation of the IHSS assessment indicates that while overall the FIS is a reliable tool, the individual FLRs are less reliable, especially for the domestic and related tasks.

For all IHSS recipients with an FIS above 2.0 in the two counties, between 9 and 31 percent have an FLR below 4.0 in one or more of the four domestic and related services and will have the hours associated with these services eliminated from their benefits. In San Diego County, an estimated 4,690 older recipients will lose hours for (one or more) domestic services, or about one-third of all San Diego County IHSS recipients 65 and older, whereas in Santa Clara County, an estimated 1029 older adults will lose domestic and related service hours, representing about one-tenth of all Santa Clara County IHSS recipients 65 and older. (See Table 6, Appendix A)

3. Because of their low incomes, most IHSS recipients receive supportive services at home at no personal cost. Some otherwise eligible IHSS recipients whose income exceeds SSI levels may also be eligible by paying a "share of cost" (SOC) for the services. In 1998, the State agreed to provide a subsidy to SOC recipients to allay the burden of this cost, which currently averages $427 per month. The July budget bill eliminates this state subsidy as of October 1. After that date, those eligible under SOC will have to bear the full cost of this cost-sharing arrangement. An estimated 9,300 recipients will be affected statewide, many of them over age 65 (UDWA, Budget Report, 7-28-09)

4. In the budget bill passed by the Legislature, exemptions were made for any IHSS recipient needing protective services, paramedical services or receiving more than 120 hours. If retained, these exemptions will prevent between 7 and 12 percent of older adults from having their IHSS services cut. Since the FIS does not include the FLRs for any cognitive limitations (i.e. needing protective services) or paramedical services, these exemptions are crucial to preventing those considered at highest-risk from having their services cut. Though the Governor vetoed these exemptions, the protective supervision and paramedical services exemptions have been retained; however, they may be waived by the Director of the California Department of Social Services (CDPSS) to maintain federal financial participation (FFP). If these exemptions are waived by CDPSS, these high-risk individuals will have their IHSS benefits eliminated.

5. IHSS administrative cuts will likely weaken services provided by local Public Authorities (PA), which were established in the last decade to provide worker registries for recipients recruiting new workers and to train and support workers. Many PAs have shortened their operating hours and have scaled back staffing, reducing their capacity to provide timely services for recipients and caregivers. Some PAs have reported they will no longer be able to provide on-call services, and all PAs are likely to experience delays in processing background checks and registering caregivers, delays in responding to questions and concerns from workers, recipients and family members, as well as a reduction in the frequency and range of training they offer new workers.

6. Bills signed into law will implement several changes to the IHSS Program designed to combat fraud and abuse. 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. Policymakers, advocates and providers express serious doubts that any savings from reduced fraud would result from these actions.

The Impact of IHSS Cuts Summarized:

Older IHSS Recipients-

a. Cognitive functioning issues have explicitly been excluded in determining service cuts, so that older persons at lower levels of physical impairment will have less reminding and monitoring and be more at risk of placement outside the home.
b. Domestic services are in some respects the "glue" that permits older people to stay in their homes. Shopping and meal preparation are especially essential, since they influence how much and how well older people eat. Weight loss is an indicator for families that a loved one is not succeeding at home, especially those living alone, and can lead to what one observer has predicted will be families thinking sooner about nursing home placement.
c. Total hours will be cut substantially for some older people. There is no evidence that family and friends will automatically step in and fill gaps in care. Those with FIS below 2.0 are especially vulnerable, but the larger numbers with FLRs below 4 in domestic and related tasks will sustain partial cuts that will attenuate what one observer termed "the fragile individualized safety net" cobbled together by families with (up to now) significant assistance from the state. Most older people with chronic conditions do not get better (and certainly not suddenly better) but experience slow decline. Providing fewer services is not responsive to this pattern of need.
d. Cuts may weaken consumer direction and thus recipient control over their care. For example, an IHSS recipient may lose all 15 hours per month for cooking and cleaning under the new budget cuts. However, because she directs her own services, a recipient may occasionally request a cooked meal rather than an authorized bath. Some key informants fear that exercising recipient discretion may soon be considered "fraud" under these new cutbacks .
e. For IHSS recipients who have a change in their functional status, they can appeal any loss or reduction in services. Those with cognitive impairments and those without family support or an outside advocate are the least likely to have the resources to appeal and may be the first to feel the service reductions.

Families-

a. More than half of IHSS workers are paid family members. Some families will experience significant cuts in total family income as a result of cuts in service hours. The ability of the family to fill the gaps created by the cuts will be undermined by the impact of those very cuts on the family economy.
b. Not all IHSS-paid family members are devoted spouses; some are nieces, nephews and grandchildren for whom this is their only paid work. IHSS cuts will mean the loss of primary jobs for some unspecified number of family members, who may then have to look elsewhere for work and end their family-based service provision.
c. IHSS cuts will place a further burden on informal resources provided by families. Legally-responsible adults like spouses are already stretched very thin in terms of the physical and economic resources they devote to care giving. We believe that the strains resulting from these cuts will weaken the family care system over time.

d. Experts in the field whom we have interviewed have predicted that families will be thinking sooner about out-of-home placement for the IHSS recipient. Over time, we expect to see nursing home placements happen sooner within this population, as the capacity of the recipient to remain at home is eroded.

IHSS workers-

a. With cuts in service hours, many workers may have their incomes reduced, especially those workers providing domestic services.
b. With cuts in service hours, some workers may see their employment benefits reduced, since they must meet a minimum hours requirement (35 per week) to qualify for job-related benefits.
c. For some unspecified number of workers, IHSS cuts represent the loss of their primary job. In many cases, these workers will have to look outside supportive home care for new jobs.
d. Cuts in service hours may result in disrupted service relationships with recipients. Both workers and recipients may experience more strains as they try to cope with fewer hours and continuing or escalating needs.

Conclusions

At this early stage, we can only speculate about the precise impact these IHSS cuts will have on older Californians and others dependent on supportive home-based services. As these budget cuts are being implemented, it is therefore essential that recipient data are collected and disseminated by the State that allow analysts and advocates to monitor cuts in IHSS service hours and to assess the various ways in which these cuts actually affect the lives of those dependent upon services. Those receiving IHSS services are California's poorest and most dependent physically and cognitively. Calculating the budgetary impact of cuts in essential services is only the first step in understanding the impact of these cuts on the lives of older Californians and others trying to maintain their dignity and independence at home.

Appendix A: Data Tables for Santa Clara and San Diego County

Table 1 IHSS recipients, all ages

IHSS Data For Santa Clara and San Diego Counties - 2009
IHSS Recipients, All Ages

	Santa Clara County	San Diego County
Total IHSS Recipients, all ages	16,282	24,629
% of total	100.0%	100.0%
Age:		
Age 65 and over	11,531	13,850
% of total	70.8%	56.2%
Age 18-64	3,856	9,378
% of total	23.7%	38.1%
Age 0-17	895	1,401
% of total	23.2%	14.9%
All or Some IHSS hours lost:		
Recipients losing all or some hours	3,551	11,593
% of total	21.8%	47.1%
Recipients losing ALL hours only* (FIS<2)**	2,064	3,882
% of total	12.7%	15.8%
Recipients losing SOME hours only* (FLR<4)***	1,487	7,711
% of total	9.1%	31.3%
Hours lost:		
Average hours/case:	24.0	24.6
Min - Max hours:	.5 – 265.6	0.0 - 283

*For demographics see Tables 2 and 3, respectively.
****** Functional Index Score (FIS) reflects average hours assigned based on statewide patterns, but may not accurately indicate hours assigned to a specific individual. Recipients with an FIS<2 will lose ALL IHSS hours and services. ***Functional Limitation Ranking (FLR) reflects level of need for assistance with a specific task (4=can perform with a lot of human help, 3=needs some human help, 2=needs verbal assistance, 1= no assistance). Recipients with an FLR<4 for any domestic and related service (i.e. housework, laundry, shopping and meal preparation) will lose hours associated with that service.

Table 2 IHSS recipients losing ALL hours, all ages

IHSS Data For Santa Clara and San Diego Counties - 2009

IHSS Recipients Losing **ALL** Hours, All Ages
(FIS < 2)*

		Santa Clara County	San Diego County
Total IHSS Recipients losing all hours, all ages		2,064	3,882
% of total		100.0%	100.0%
Age:	Age 65 and over	1292	2003
	% of total	62.6%	51.6%
	Age 18-64	390	1298
	% of total	18.9%	33.4%
	Age 0-17	382	581
	% of total	18.5%	15.0%
Gender:	Female	1167	2234
	% of total	56.5%	57.5%
	Male	897	1648
	% of total	43.5%	42.5%
Living Arrangement:			
	Living Alone	684	1898
	% of total	33.1%	48.9%
Cognitive Assessment:			
	Memory Impairment (FLR >=2**)	735	1280
	% of total	35.6%	33.0%
Type of Provider:			
	No Family Provider	844	1749
	% of total	40.9%	45.1%
Hours lost:			
	Average hours/case:	32.5	43.3
	Min - Max hours:	1.0 - 265.6	0.0 - 283

***** Functional Index Score (FIS) reflects average hours assigned based on statewide patterns, but may not accurately indicate hours assigned to a specific individual. Recipients with an FIS<2 will lose ALL IHSS hours and services. **Functional Limitation Ranking (FLR) for Memory assessment has 3 possible rankings: 1-no deficit, 2-moderate or intermittent deficit, 5-severe memory deficit, needs protective services. Recipients with FLR >=2 have memory impairments (i.e. need reminders) and may need protective supervision. (CDSS - Need for Protective Services_SOC821.pdf)

Table 3 IHSS recipients losing SOME hours, all ages

IHSS Data For Santa Clara and San Diego Counties - 2009

IHSS Recipients Losing **SOME** Hours, All Ages
(FLR < 4 for domestic and related services)*

		Santa Clara County	San Diego County
Total IHSS Recipients losing some hours, all ages		1,487	7,711
% of total		100.0%	100.0%
Age:	Age 65 and over	1029	4690
	% of total	69.2%	60.8%
	Age 18-64	448	2995
	% of total	30.1%	38.8%
	Age 0-17	10	26
	% of total	0.7%	0.3%
Gender:	Female	1040	5391
	% of total	69.9%	69.9%
	Male	447	2320
	% of total	30.1%	30.1%
Living Arrangement:			
	Living Alone	458	2895
	% of total	30.8%	37.5%
Cognitive Assessment:			
	Memory Impairment (FLR >=2**)	653	2785
	% of total	43.9%	36.1%
Type of Provider:			
	No Family Provider	545	3001
	% of total	36.7%	38.9%
Hours lost:			
	Average hours/case:	12.3	15.3
	Min - Max hours:	.05 - 52.0	.04 - 52.8

*Functional Limitation Ranking (FLR) reflects level of need for assistance with a specific task (4=can perform with a lot of human help, 3=needs some human help, 2=needs verbal assistance, 1= no assistance). Recipients with an FLR<4 for any domestic and related service (i.e. housework, laundry, shopping and meal preparation) will lose hours associated with that service. **FLR for Memory assessment has 3 possible rankings: 1-no deficit, 2-moderate or intermittent deficit, 5-severe memory deficit, needs protective services. Recipients with FLR >=2 have memory impairments (i.e. need reminders) and may need protective supervision. (CDSS - Need for Protective Services_SOC821.pdf)

Table 4 IHSS recipients losing all or some hours, age 65 and over

IHSS Data For Santa Clara and San Diego Counties - 2009
IHSS Recipients Losing **All or Some** Hours, Age 65 and over
(FIS<2* or FLR<4** for domestic and related services)

	Santa Clara County	San Diego County
Total IHSS Recipients losing all or some hours, age 65 and over	2,321	6,693
% of total	100.0%	100.0%
Age:		
Age 90 and over	81	399
% of total	3.5%	6.0%
Age 80-89	846	2,497
% of total	36.4%	37.3%
Age 70-79	1,145	2,822
% of total	49.3%	42.2%
Age 65-69	249	975
% of total	10.7%	14.6%
Gender:		
Female	1,599	4,853
% of total	68.9%	72.5%
Male	722	1,835
% of total	31.1%	27.4%
Living Arrangement:		
Living Alone	862	3,061
% of total	37.1%	45.7%
Cognitive Assessment:		
Memory Impairment (FLR>=2***)	753	2,013
% of total	32.4%	30.1%
Type of Provider		
No Family Provider	964	2,633
% of total	41.5%	39.3%
Hours lost:		
Average hours/case:	20.1	20.3
Min - Max hours:	.69 - 195.0	0.0 - 227.2

* Functional Index Score (FIS) reflects average hours assigned based on statewide patterns, but may not accurately indicate hours assigned to a specific individual. Recipients with an FIS<2 will lose ALL hours. **Functional Limitation

Ranking (FLR) reflects level of need for assistance with a specific task (4=can perform with a lot of human help, 3=needs some human help, 2=needs verbal assistance, 1= no assistance). Recipients with an FLR<4 for any domestic and related service (i.e. housework, laundry, shopping and meal preparation) will lose hours associated with that service. ***FLR for Memory assessment has 3 possible rankings: 1-no deficit, 2-moderate or intermittent deficit, 5-severe memory deficit, needs protective services. Recipients with FLR >=2 have memory impairments (i.e. need reminders) and may need protective supervision. (CDSS - Need for Protective Services_SOC821.pdf)

Table 5 IHSS recipients losing ALL hours, age 65 and over

IHSS Data For Santa Clara and San Diego Counties - 2009
IHSS Recipients Losing **ALL** Hours, Age 65 and over
(FIS<2)*

		Santa Clara County	San Diego County
Total IHSS Recipients losing all hours, age 65 and over		1,292	2,003
% of total		100.0%	100.0%
Age:	Age 90 and over	49	85
	% of total	3.8%	4.2%
	Age 80-89	454	671
	% of total	35.1%	33.5%
	Age 70-79	656	913
	% of total	50.8%	45.6%
	Age 65-69	133	334
	% of total	10.3%	16.7%
Gender:	Female	836	1,328
	% of total	64.7%	66.3%
	Male	456	675
	% of total	35.3%	33.7%
Living Arrangement:			
	Living Alone	503	1,183
	% of total	38.9%	59.1%
Cognitive Assessment:			
	Memory Impairment (FLR>=2**)	313	462
	% of total	24.2%	23.1%
Type of Provider			
	No Family Provider	595	1,000
	% of total	46.1%	49.9%
Hours lost:			
	Average hours/case:	25.8	30.5
	Min - Max hours:	1.0 - 195.0	.0 - 227.2

*Functional Index Score (FIS) reflects average hours assigned based on statewide patterns, but may not accurately indicate hours assigned to a specific individual. Recipients with an FIS<2 will lose ALL hours.
**Functional Limitation Ranking (FLR) for Memory assessment has 3 possible rankings: 1-no deficit, 2-moderate or intermittent deficit, 5-severe memory deficit, needs protective services. Recipients with FLR >=2 have memory impairments (i.e. need reminders) and may need protective supervision. (CDSS - Need for Protective Services_SOC821.pdf)

Table 6 IHSS recipients losing SOME hours, age 65 and over

IHSS Data For Santa Clara and San Diego Counties - 2009
IHSS Recipients Losing **SOME** Hours, Age 65 and over
(FLR < 4 for domestic and related services)*

		Santa Clara County	San Diego County
Total IHSS Recipients losing hours, age 65 and over		1,029	4,690
% of total		100.0%	100.0%
Age:	Age 90 and over	32	314
	% of total	3.1%	6.7%
	Age 80-89	392	1,826
	% of total	38.1%	38.9%
	Age 70-79	489	1,909
	%o of total	47.5%	40.7%
	Age 65-69	116	641
	% of total	11.3%	13.7%
Gender:	Female	763	3,530
	% of total	74.1%	75.3%
	Male	266	1,160
	% of total	25.9%	24.7%
Living Arrangement:			
	Living Alone	359	1,878
	% of total	34.9%	40.0%
Cognitive Assessment:			
	Memory Impairment (FLR>=2**)	440	1,551
	% of total	42.8%	33.1%
Type of Provider:			
	No Family Provider	369	1,633
	% of total	35.9%	34.8%
Hours lost:			
	Average hours/case:	13.1	15.9
	Min - Max hours:	0.69 - 52.0	.04 - 52.0

*Functional Limitation Ranking (FLR) reflects level of need for assistance with a specific task (4=can perform with a lot of human help, 3=needs some human help, 2=needs verbal assistance, 1= no assistance). Recipients with an FLR<4 for any domestic and related service (i.e. housework, laundry, shopping and meal preparation) will lose hours associated with that service. **FLR for Memory assessment has 3 possible rankings: 1-no deficit, 2-moderate or intermittent deficit, 5-severe memory deficit, needs protective services. Recipients with FLR >=2 have memory impairments (i.e. need reminders) and may need protective supervision. (CDSS - Need for Protective Services_SOC821.pdf)

Appendix B: Case Examples of IHSS Recipients

Case Example 1 (FIS < 2):

George is a 78 year old man who will lose *all* of his IHSS services because his overall Functional Index Score (FIS) is a 1.89 (.10 points below the state budget cutoff.). According to the social worker's assessment, George needs verbal reminders for some personal tasks such as bathing and dressing and needs some to a lot of human assistance with housework, laundry, shopping and meal preparation. However, not captured in George's FIS, are the 200 authorized hours per month and the protective supervision George needs for his severe cognitive impairment, both of which help him to remain safely in his home Protective supervision is provided to individuals who have at least one Functional Limitation Ranking (FLR) of 5 in any of the three categories (memory, orientation and judgment) of the cognitive assessment, possible FLRs for cognitive assessment are 1-no deficit, 2-moderate or intermittent deficit, 5-severe deficit. George has an FLR of 5 in all three categories, placing George at high risk for injury, rapid health deterioration and institutionalization.

Case Example 2 (FLR < 4 for domestic and related services):

Ann, an 80-year old woman eligible for IHSS, has been given an overall FIS of 3. Fortunately, she will not be eliminated from IHSS, but will be affected by a reduction in domestic and related service hours. Ann has a ranking of 5, or is at high risk of injury and needing protective services, for the memory component of the cognitive assessment. Ann has a ranking of 2 on several of the domestic and related services including shopping and meal preparation and clean-up, meaning she is physically able to perform the tasks with reminders and protective supervision. Ann will face a reduction in hours for these services because her rankings for these areas are less than 4. Given Ann's impaired cognitive functioning that has not been factored in to the domestic and related services rankings, Ann will not be able to consistently or safely perform the tasks of shopping for food or preparing and cleaning up her meals. She will also not receive the reminders she needs to take the medications she needs for high blood pressure and diabetes with her meals, putting Ann at high-risk for rapid deterioration of her health and premature placement in a nursing home.

Impact of Budget Cuts to Adult Day Health Care

Adult day care programs provide services and supervision to adults with physical or mental impairments during the day with the main goal of preventing institutionalization in long-term facilities. All these facilities provide social services and social interaction, while a subset called Adult Day Health Care (ADHC) also provide an array of medical services using nurses, therapists, and dieticians (Fisher Center Alzheimer's website). Some facilities may specialize in Alzheimer's or dementia care, often referred as Alzheimer's Day Care Resource Centers. ADHCs require licensure for Medicaid reimbursement (Senior Resource.com website).

ADHC services range from psychological evaluations, therapy (physical, occupational, speech), wound care, medication administration, and social work, to bathing and hair washing assistance, feeding assistance, and transportation. Meals (97%) and personal care activities are the most common type of service provided (O'Keefe & Siebenaler, 2006).

Industry profile

Adult day service facilities have grown significantly in recent years. The majority of these organizations (79%) are licensed or certified by the state as ADHCs and can provide medical services. There were 197 licensed ADHCs in 1997 and 338 in 2007 (CAADS, 2007). Many of these facilities (53%) have a total enrollment of 20-60, and average daily attendance of 10-30 participants (54%) (O'Keefe & Siebenaler, 2006). In 2009 ADHCs in California receive $76.27 per day per attending Medicaid participants; however, this payment structure is designed to change in early 2012 to a reduced fee for core services and additional payment for individuals receiving additional services.

Participant profile

Specific data on characteristics of the California ADHC participants are scarce. National data on adult day service participants find that the average age of participants is 72. Participants with dementia (52%), frail elderly (41%), and physically disabled (23%) constitute the majority. Most (60%) are Medicaid eligible or poor and 36% of facilities care for mostly (75-100%) Medicaid eligible participants. Toileting (43%) and walking (37%) are the most prevalent activities of daily living difficulties. Seventy seven percent are white and the great majority live with relatives. Only a few (11%) live alone. The most frequent reason (50%) for discharge from adult day facilities is placement in a residential setting, followed by death (23%), and decline in functional status (16%) (O'Keefe & Siebenaler, 2006). Fifty percent of all ADHC recipients in California also receive IHHS and MSSP services, indicating a high level of need for help and supervision (California DHS 2004).

ADHC benefits for elders and caregivers

Several quasi-experimental studies have documented the ADHC health benefits to elders, specifically physical, psychosocial, and behavioral improvements. These benefits include shorter nighttime sleep problems and fewer depressive symptoms (Femia et al, 2007). Elderly participants with dementia who engaged in more activities through ADHCs demonstrated a greater decline in restless behavior (Woodhead et al, 2005). A study in Japan found elder adult day care participants had a lower mortality rate than those who did not attend day care (Kuzuya et al, 2006). Other studies did not indicate a change in physical or psychological health of ADHC participants (Rothman et al, 1993). However a reduction in loneliness, feelings of anxiety, and depression was observed in a study of Canadian elders participating in such programs (Baumgarten et al, 2002). Further research is needed in this area.

ADHCs provide respite care for caregivers by relieving them of their duties for a few hours a day to rest physically and psychologically, or by allowing them to engage in paid employment. Studies demonstrate caregivers of ADHC recipients experience less stress, improved psychological well being (less depression and anger), and less time spent dealing with behavior problems, but no reduction in the time spent helping with ADLs or memory problems (Zarit et al, 1998; Jarrot et al, 2000). ADHC participation is also associated with a decrease in levels of subjective vs. objective burden and increased morale among caregivers (Kosloski & Montgomery, 1993). More frequent ADHC attendance is associated with less caregiver burden (Baumgarten et al, 2002).

The role of ADHC on long term institutionalization and medical care utilization

The primary role of ADHCs is to prevent institutionalization of physically and mentally impaired adults. Higher financial spending on home and community based services have led to lower risk of nursing home use, especially for older adults without children (Muramatsu et al, 2007). More specifically, reduction in Medicaid home and community bases services are associated with increased hospitalizations, emergency room visits, and permanent nursing home placement (D'Souza et al, 2009). ADHC providers and participants' families have self-reported delayed or prevented institutionalizations (p25, O'Keefe & Siebenaler, 2006). Further studies are needed to assess the role of ADHC programs in preventing nursing home admissions due to difficulties in conducting such studies (Dabelko & Zimmerman, 2008).

California's ADHC program

The ADHC program is funded under Medi-Cal (California's Medicaid) and is administered by the California Department of Aging. Over 300 ADHC centers in California (CA Dept of Aging website) provide services to an estimated 36,000 elders through Medi-Cal (CAADS press release, 2009). The expenditures for the program are estimated at $1.1 million for a six month period (California DHS 2004). Those attending more than 3 times per week suffer from a high level of physical and mental impairment and are generally dependent for multiple ADLs and IADLs.

The ADHC eligibility criteria prior to 2009 budget cuts are extensive and rigorous and participants must meet all of the eligibility criteria to qualify (California DHS Medi-Cal website). Eligibility criteria specifically target individuals with function and/or cognitive impairment who require continuous supervision in performing activities of daily living. The program is designed "… to avoid or delay the use of institutional services, including, but not limited to, hospital emergency department services, inpatient acute care hospital services, inpatient mental health services, or placement in a nursing facility or a nursing or intermediate care facility" or to avoid placement to a more costly institutional level of care from a less costly one (CA DHS Medi-Cal website). The number of days of attendance commensurate with the level of need for supervision and full-time attendance (5 days per week) is granted to those with lowest level of independent functioning. Key informant interviews indicated that approval for 4 or 5 days per week is difficult to receive and is restricted to the very frail and those in great need of continuous monitoring and supervision.

2009 California cuts to ADHC program

As of September 2009, ADHC participants can only attend these programs for 3 days per week, regardless of need for such care. The cuts are estimated to impact 8,000 (20%) elders with the highest level of disability and in danger of permanent nursing home placement. In the absence of ADHC services, these disabled elders will most likely forego continuous supervision, meals, medication administration, wound care, physical exercise, personal hygiene, and social interaction for at least two extra days a week. These elders do not have financial resources to pay for such services privately and their caregivers may not be able to provide such care due to employment or child care obligations.

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. 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. 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.

Employed caregivers have the option of leaving the disabled elders at home alone, quit their jobs, or seek assistance from neighbors and relatives. Lack of supervision for elders with dementia is dangerous due to the high risk for adverse events such as falls, loss of consciousness, dehydration, malnutrition, and wandering. Even for caregivers who are not in the waged labor force, caregiving hardships and overload can lead to higher rates of institutionalization for older adults. High levels of emotional stress and burden lead to

earlier nursing home placement. ADHC services can reduce caregiver stress and provide a respite from caregiving and increase the total caregiving resources available to keep an elder independent (Gaugler et al., 2003; Mittelman et al., 2006). 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.

The cuts will also impact ADHC facilities proportional to the percentage of 5-day and 4-day participants. The per-diem payment structure by Medi-Cal for ADHC services will mean reduced organization income. 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. Faced with such cuts, ADHCs may lay-off their employees, close their doors one or more days a week, or go out of business. Under each scenario, loss of income and jobs for ADHC staff is the likely outcome. Small ADHC facilities may not have the opportunity to reduce the impact of the cuts by enrolling new participants, especially those with a larger percentage of Medi-Cal participants. According to key informants, such facilities often operate in low-income areas with few eligible individuals who can pay the per-diem rate out-of-pocket and/or face competition with other existing ADHCs in the vicinity for the same eligible population.

ADHC Case Examples

The following representative case summary examples of Medi-Cal beneficiaries who were receiving Adult Day Health Care Services (ADHC) for five days per week before the most recent budget cuts. The profiles describe the needs of the individuals and the assessment of the ADHC staff of the likely consequences of reductions in service. The names, exact ages, and other details have been slightly modified to maintain confidentiality, but they do reflect the situations of actual clients.

Participant Profile 1

Mr. Z is a 94 year old male living with his 90 year old wife. He is diagnosed with mild dementia, osteoporosis, and high blood pressure. He suffers from chronic pain in his lower back and extremities. Mr. Z independently self-feeds, but would highly benefit from supervision in all his other activities of daily living. As for the instrumental activities of daily living, he needs assistance with money management and in accessing resources. He is dependent on help for housework, laundry, meal preparation, shopping, and transportation. In addition, he is at risk for falls and for social isolation. His wife is dependent on him so the only support he gets is from the paid provider with a combined husband/wife allocation of 66 (IHSS) hours.

Mr. Z attends the ADHC five days a week. His activities, social interactions, and therapeutic treatment plans have had a significant impact on his life. The therapy and exercises have allowed him to move about with greater ease. He presents himself with confidence. Without the five days of program, Mr. Z will be isolated and will find it extremely difficult to maintain his home with his wife. Financially, it is almost impossible to have a caregiver provide all of the required services for a total of 66 hours for the two for the entire month. His frailty level would increase and his sense of independence would decrease as he would need to augment his attention to meeting the needs of his wife on non-program days. If his level of independence declines further, he is at risk of not being able to provide any care for his wife and that would therefore increase the likelihood of her (and possibly his) placement in a skilled nursing facility.

Participant Profile 2

Mr. T is a 90 year old male. He suffered a massive coronary vascular artery c/L left hemiparesis (artery x 2 x>30 yrs) and multiple fall accidents. He has been diagnosed with seizure disorder, hypertension, and Alzheimer's. He suffers from physical and cognitive impairment. He is wheelchair bound, and lacks adequate family support at home. Mr. T lives with his daughter and extended family but is home alone most of the day when not at the ADHC due to family's work and school schedule. He has had 3 different caregivers in the past 12 months and requires direct assistance with most of his activities of daily living and all of his instrumental activities of daily living due to left-side hemiparesis and cognitive impairment. He is incontinent of bladder and bowel and requires 2-person assist.

Mr. T requires assistance with feeding and receives one-on-one physical and occupational therapy services. He requires two people to assist him in toileting. He requires constant cuing for therapeutic activities. He is able to hold a conversation for a short period of time and answer some of the questions during social worker one-on-one intervention. The participant has demonstrated improvements in the last 12 months with social worker intervention and is able to feed himself since receiving the appropriate tools. He has been in the hospital at least 2 times in the past 6 months due to pressure sores. The patient is no longer able to bear weight since his return in April 2009.

The social worker spoke to the patient's daughter regarding the decreased days and encouraged Mr. T be transferred to another program where he would receive additional assistance and care. The daughter refused. The daughter does not want her father so far from home just in case of an emergency. In addition, she does not want to switch his primary care provider. She was explained the risks of returning to the emergency room or nursing home placement if Mr. T does not receive the care that he requires. During the summer the patient's grandson is able to assist with his care and the daughter has hired a private caregiver to stay with him in the afternoon until she gets home from work. She stated that she has no other choice but to leave him with the caregiver on the 2 days that he would be cut from the ADHC. She is concerned about his care but there is no other family support and she is the primary provider.

Participant Profile 3

Ms. E is a 73 year woman diagnosed with hypertension, arrhythmias, stroke, pain in her left hand and knee, OA, insomnia and bipolar disorder. This summer of 2009, Ms. E had a surgery to have a peacemaker implanted. At this time, Ms. E demonstrated difficulty performing her activities of daily living and instrumental activities of daily living. Her left-side joint pain limits her from doing certain things. Currently, Ms. E is using a cane to assist her when she walks. Ms. E lives alone in a senior complex. While Ms. E has IHSS, her sister visits her 3 times per week and takes her food.

Ms. E attends ADHC five times per week and when Ms. E is at the center she enjoys doing arts-n-crafts and therapy. Ms. E has been attending ADHC for 9 months. ADHC staff has seen an improvement on her physical and emotional condition. At the beginning of her attendance, she isolated herself and spoke to nobody, however, now she carries a conversation with other participants and staff. The activities provided at the center have helped her become increasingly social and physically active. Ms. E's family will be impacted by the reduction in services. Ms. E will require additional assistance at home. Although she receives IHHS, she will need more hours. Ms. E is at-risk of becoming isolated. She lives alone and has an increased risk of developing feelings of sadness. When Ms. E is home alone, she does not go out, only watches TV, and sleeps. The reduction in hours will augment her risk of becoming hospitalized or entering a convalescent home to acquire the needed assistance.

Participant Profile 4

Mr. X is a 69 year old male. He has had multiple brain surgeries and came to the center after living in skilled nursing for four years while experiencing daily seizures. Mr. X is married and his wife is the primary caregiver. She does everything for him and answers his constant repeated questions and addresses his often illogical debates on various subjects. She is committed to caring for him at home, especially after his past unsuccessful skilled nursing placement history.

Mr. X has attended ADHC five days per week for 10 years. Mr. X's brain injury affects every part of his life. The structure of the ADHC program and expertise of the staff have offered him some stability and "normalcy" in his otherwise extremely difficult life. A month ago Mr. X's wife was diagnosed with rectal cancer. She is currently undergoing chemotherapy and radiation in preparation for surgery. In addition, their only son, who had been assisting with some of the care of his dad, was deployed to Iraq. ADHC staff is assisting with referrals and offering support, but this is an extremely difficult time for Mr. X and his family. If Mr. X's attendance days were reduced from 5 days to 3 days per week, placement would be the only option.

Participant Profile 5

Mrs. C is a 79-year-old woman who suffers from Alzheimer's, diabetes, and osteoporosis. She has poor sight in one eye resulting in poor balance. She has a history of

wandering and falls, which resulted in emergency hospital visits. This patient's level of confusion is so severe that the family reports their mother gets lost within their own home. Her family has attached bells to her slippers so they can keep track of her during her wandering at night. Her family had to "adult proof" the home by placing locks on cabinets and gates to maintain a safer home environment. Without these safety measures, Mrs. C has been known to climb into the shower by herself and burn herself with the hot water. Unsupervised she is at serious risk for injury to herself.

Mrs. C is unable to monitor her blood sugar and is dependent on family and ADHC staff to administer her daily medication. Mrs. C lives with her daughter and son-in-law. The financial viability of this family requires both daughter and son-in-law to work during the day. The family would be unable to care for Mrs. C without the ADHC respite provides. ADHC services are providing skilled nursing monitoring and assistance with all her personal care needs. If Mrs. C's days were reduced to 3 times per week immediate placement to skilled nursing home would be the only option for this family.

Participant Profile 6

Mrs. E is an 89 year old woman who lives with son and daughter-in-law. They live in a rural setting. Mrs. E suffers from Alzheimer's disease, insulin-dependent diabetes, and incontinence of bladder and bowel. Mrs. E. attends ADHC 5 days per week for medical monitoring, and a safe environment. The daughter-in-law benefits from the respite services that ADHC provides. The daughter-in-law is stressed due to Mrs. E's night wandering, propensity to spread feces, and aggressive behavior. The program provides ongoing stimulation which results in less wakeful hours during the night. In addition, the son was diagnosed with Alzheimer's disease 2 years ago and the daughter-in-law is also a full-time caregiver for him. Reducing ADHC for this family would make the 24/7 responsibilities of caring for two cognitively impaired individuals too much for one person. Mrs. E would need to be permanently placed in a nursing facility.

While most ADHC participants are elderly, they also serve younger disabled adults who need on-going assistance. The following profiles provide examples of participants who are under age 65 and use ADHC, modified for anonymity but based on actual cases.

Participant Profile A

The participant is a 48-year-old woman who suffers from severe mental retardation, infantile cerebral palsy, spastic quadriplegia, seizure disorder, gastritis, and anemia. She is non-verbal, non-ambulatory/wheelchair bound, incontinent of bowel and bladder and requires the use of adult diapers. She is on a thickened puree diet and requires maximum assistance for feeding as well as all other personal care needs. The participant lives with her mother. The mother is the primary caregiver for not only the participant but for this participant's father as well. The father has suffered a stroke, is home-bound and also requires a maximum level of care. The mother is experiencing major levels of caregiver

burnout and relies heavily on the skilled care and respite provided by ADHC services. ADHC services are providing skilled nursing monitoring and assistance in all participant's instrumental activities of daily living and activities of daily living. If the participant's days were reduced to 3 times per week the burden placed on the caregiver will create enough hardship to likely lead to placement of one or both of these family members into skilled nursing facility care.

Participant Profile B

The participant is a 47 year old male. He suffers from left side paralysis, paraplegia, incontinence, lack of vision in his right eye, left side drooling, and he has right side facial bone removal. The participant has a difficult time communicating due to the removal of the bones in his face. He is also confined to a wheelchair while at ADHC. He requires assistance or is dependent on all his activities of daily living and instrumental activities of daily living. The participant's wife provides round the clock care for him when he is at home. The participant enjoys participating in physical and occupational therapies on his days of attendance. He was enrolled on February 2009 and he has made fair improvements. He has been socializing well with others despite his lack of communication skills. The participant's wife has benefitted tremendously by receiving the respite that she critically needs. His speech has had a slight improvement due to the social interaction that he receives at ADHC. The reduction of days for the participant will cause a financial burden and a reduction of respite received by his wife. The participant's wife will have to decrease her work hours to provide care for her husband. The participant enjoys coming to ADHC because it offers him a distraction from his regular routine. If he were not to come to ADHC, he would most likely need a skilled nursing facility so that his wife would be able to continue to work.

Impact of Budget Cuts on California Department of Aging (CDA) Services

The California Department of Aging (CDA) provides programs to assist older adults and their family caregivers. Many of the programs provided by the CDA are essential to an older adult who wishes to remain comfortably and safely in their home and in their community. Eligibility for programs is determined based on economic or social need or risk of institutionalization. While the CDAs mission is to promote the independence and well-being of older adults and families to improve quality of life, state budget cuts to these programs create a barrier to fulfilling this mission.

2009 Cuts & Impact

The State budget cuts impacted every California Department of Aging (CDA) program between 10% and 51%. Statewide cuts to aging programs totaled over $13 million. The most drastic cuts for older adults and family caregivers include:

- **Elimination of the Linkages Program**, which provides care management and coordinated support services to vulnerable older adults experiencing a decline in their functional status. The Linkages Program is designed to be a "gap filler" which assists individuals at risk of institutionalization through case management and limited purchase of needed services. Established in 1985, there are 36 programs, one in each Area Agency on Aging (AAA) in the state. (http://www.aging.ca.gov/aaa/guidance/Linkages_Program_Manual.pdf) 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.
- **Elimination of the Respite Purchase of Service** is part of the linkages program. It provides funds to pay for needed respite to low-income family caregivers to reduce burnout, depressive symptoms, poor physical health and other hardships experienced among caregivers.
- **Elimination of funding for the 36 Alzheimer's Day Care Resource Centers (ADCRC),** which serve older adults with moderate to severe cognitive impairment. The first sites started in 1986 and grew to 52 sites in 1999 (http://www.aging.ca.gov/aaa/guidance/adcrc_policy_procedure_manual.pdf). This program provides supplemental funding to support the extra level of care and supervision required by those with severe Alzheimer's that extends beyond what Adult Day Care programs can otherwise provide. About one-third of ADCRC's are Adult Day Health Care Centers (ADHC) which also obtain Medi-Cal funding. The others are social model centers that do not obtain Medi-Cal support. Many ADHCs rely on this funding to provide dedicated space and trained staff for older adults with severe cognitive impairments. Without this funding, many ADHCs will no longer be able to provide these services and some centers will have to close. The ADCRC program was described by one key informant as serving those "with nowhere else to go" because of the severity of their dementia.

- **Elimination of Brown Bag Program** was established in 1981 to provide surplus and donated edible fruits, vegetable and other food products to low income older adults. Most of the food is donated, and many of those working on the program are volunteers, leading one evaluation of the program to estimate that every state dollar spent on the Brown Bag program generated $35 worth of services (Alameda County Community Food Bank, 2003). Additional funding reductions to the Congregate Nutrition and Home Delivered meals program will put many frail and homebound older adults at nutritional risk.
- **State funding elimination for the Elder Abuse Prevention and Ombudsman programs,** which protects helpless older adults in nursing homes and other senior facilities that are physically or cognitively unable to speak for themselves or seek protection. While there is no on-going state funding for this program, AB392 (Feuer) redirected $1.6 million in funds from the Federal Health Facilities Citation Penalties Account to continue the program in 2009-10 to supplement the $2.7 million in available federal funds. As recently as 2007-08, California spent $3.9 million in general funds to support the program. Reduction in funding is projected to reduce the number of complaints that can be officially logged, and a reduction in the number of resolved complaints. (California Senate Rules Committee, 2009).

These and other CDA programs fill an important gap in other state programs for disabled older adults. Cuts to many of the long-term care supportive services for older adults will have a cumulative impact that may lead to deterioration in the health status of low-income older Californians and their premature institutionalization.

Caregiver Resource Centers (Department of Mental Health)

Caregiver Resource Centers (CRCs) are a statewide system funded by the California Department of Mental Health. Established in 1984, the system consists of eleven CRCs that aim to support caregivers so that consumers can remain in their homes as long as possible. The centers offer respite care, caregiver education, support groups, counseling, web-based resources, retreats and legal financial consultation to families caring for an adult with a degenerative brain disease or a brain impairment which occurred after the age of 18 (e.g. Alzheimer's Disease, Parkinson's) and/or family caregivers of frail adults, 60 years or older. The function as a single point of entry for referral to the full range of caregiver services, in addition to providing direct services.

In fiscal year 2006-07, 40,231 families and individuals received one or more CRC services (http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=2179):

- 23,393 people attended CRC education and training events;
- 6,783 new clients went through the intake process (extended telephone consultation to determine the families' situation and immediate needs);
- 3,730 clients received comprehensive assessment;
- 13,561 clients received in-person family consultation with CRC professional staff (a total of 36,955 hours);
- 1,586 families received respite assistance (financial assistance to allow primary caregiver a break to attend to personal or health needs).
- At the end of fiscal year 2006-07, 5,697 family caregivers were on respite waiting lists at CRCs in California. The average client wait-time for CRC respite assistance was 24 months, representing a decrease from the previous year of about two months.

CRCs are community-based services that provide respite from caregiving, and allow informal caregivers to focus on less stressful care (e.g. IHSS). CRCs assess the practical, emotional and financial needs of an adult with a disabling condition and their family. CRCs provide limited financial assistance for in-home support, adult day care services, short-term or weekend care, and transportation. For example, depending on fund availability, the Bay Area CRC provides a stipend of up to $800 for respite care expenses to eligible caregivers. The Bay Area CRC also offers caregivers assistance for long term respite by giving up to $3600/yr. However, currently there is a 2-3 year waiting list for these services (Family Caregiver Alliance, 2009). In addition, to providing caregivers education through specialized workshops on diagnosis, treatment, long-term care planning, and stress management, CRCs offer short-term individual, family, and/or group counseling for emotional support and legal consultations regarding powers of attorney, estate and financial planning, conservatorships, and community property laws. Community-based services, like those offered by CRCs, increase the total caregiving

resources available to keep an older adult independent (Gaugler et al., 2003; Mittelman et al., 2006).

2009 Cuts & Impact

The 2009 California Department of Mental Health budget cuts to CRCs will weaken the network of information and support available to caregivers. CRCs currently operate on a $10.2 million budget. The CRCs budget will be cut by $6.7 million (66%) of state general funds, leaving it to operate only on $3.5 million. To adapt to a budget reduction, CRCs will service fewer clients, decrease hours of operation, and reduce services to families. Key informants reported that some of the smaller centers may close and that all family caregivers who currently rely on CRC services will experience decreased support (see also Family Care Alliance, 2009). When families face caregiving hardships, such as those under high levels of emotional stress, they have higher rates of premature institutionalization.

Impact of Budget Cuts on Caregivers

It is estimated that nearly 300,000 older Californians rely on supportive service programs for assistance in meeting their basic functional needs including assistance with Activities of Daily Living (ADLs) i.e., bathing, dressing, toileting, as well as, Instrumental Activities of Daily Living (IADLs) i.e., lifting, preparing meals, managing money. Community based long term care programs such as ADHC and IHHS, as well as services included under the Older American's Act e.g., meals and transportation, provide a critical *supplement* to the care already provided by family members. Often times these programs and services are utilized together to create a package of supportive services e.g., home delivered meals, physical therapy, medication management, that acts as a long term care "safety net" for older persons and their families. It is estimated that 30%-40% of Californians age 65+ utilize two or more community based long term care services simultaneously according to key informants and program analyses from 2002.

These programs i.e., IHSS, ADHC, other Department of Aging Programs, and the Caregiver Resource Centers, in conjunction with informal care or family caregiving, increase the ability of older persons to remain in the community and out of institutions such as skilled nursing facilities. It is believed that cut backs and reductions in services under these programs will put more older persons at risk for institutionalization and increase the financial, health, and mental health burden already experienced by informal/family caregivers (D'Souza et al, 2009). Approximately 75% of long term care in the United States is provided by informal caregivers including family, friends, and neighbors (Family Caregiver Alliance, 2009). Nationally, approximately 44 million individuals provide 37 billion hours of unpaid care to adult family members or friends with chronic disabling medical conditions that prevent them from doing daily activities without assistance, representing an estimated economic value of $375 billion (Houser & Gibson, 2008). In California it is estimated that 4 million caregivers (18% of the total

adult population in California) provide 4.3 billion hours of care per year, representing an economic value of $45 billion (Gibson and Houser, 2007).

While informal caregiving has an enormous economic value, and is more often then not undertaken willingly by family and friends, it carries with it an enormous economic cost for caregivers (Feinberg and Newman, 2005). It is estimated that informal caregivers individually lose about $659,139 over their lifetime including: $25,494 in Social Security benefits; $67,202 in pension benefits; and $566,433 in lost wages (AARP, 2008). Caregivers in California for the most part are women (75%); have annual incomes below $40,000 (69%), work outside the home (50%) with the majority working full time (71%) (CCRC, 2005; Scharlach et al., 2003). Caregiving duties often impact a caregiver's employment, with 21% to 58% of working California caregivers reporting that they have missed work, arrived late for work or left work early due to caregiving activities (Family Caregiver Alliance, 2007; Scharlach et al., 2003). Among younger caregivers, caring for an aging parent or grandparent may mean not only an interruption in employment or work activities but also forgoing educational opportunities and therefore opportunities for economic advancement over their life course (Villa and Torres-Gil, 2001).

In addition to the economic cost, caregivers also experience health and mental health issues that are often the result of providing care. A statewide survey utilizing a representative sample of caregivers in California finds that a significant number provide assistance with palliative care i.e., basic functioning, including: toileting (23%) diapering (14%), bathing, (19%), feeding (19%), dressing (27%) and transferring from bed to chair (37%). This kind of care can be both mentally and physically taxing, especially when caring for those that are cognitively impaired. It is estimated among those receiving care in California, up to 36% have sever memory problems (Scharlach et al, 2003); and 62% have a cognitive impairments caused by unspecified dementia or Alzheimer's disease (CCRC, 2005).

Moreover, almost half of caregivers surveyed in California have depressive symptomotology; nearly one third report sleep interruption; a quarter report physical strain and nearly on fifth report financial hardship (Scharlach et al., 2003). California caregivers when compared to non-caregivers are more likely to report reduced immune response, poor physical health, and more chronic conditions (Family Caregiver Alliance, 2007). Among ethnic minority caregivers, the burden of care seems to be greater. Ethnic minority families tend to provide more care and report worse physical health than their non-Hispanic white counterparts (Pinquart and Sorenson, 2005). This is consistent with Scharlach et al, 2003, who found that among California caregivers those most vulnerable and most likely to experience physical strain, emotional stress, and financial hardship are low income Latinas. We can expect that the cutbacks in supportive services will magnify the health and mental health issues caregivers already experience.

Under the current California budget, IHHS, ADHC, and other supportive services will experience budget and service reductions that will impact those caring for older family members. Specifically, under the In-Home Supportive Services (IHSS) Program, $268.2 million dollars will be cut which will result in 36,179 IHSS recipients **(**all ages) will

losing all hours of service, with an additional 97,020 IHHS recipients (all ages) losing some hours. This will impact about one-third of all recipients. These are all persons who were judged to be unable to remain safely at home without the additional assistance. IHHS services include personal care (e.g., bathing , dressing, and feeding), domestic and related chores (e.g., laundry, cooking, cleaning, and shopping), paramedical services (e.g., injections, catheters, foley bags, feeding tubes, etc.), protective supervision, and transportation to medical appointments. Cutbacks in funding and services under the ADHC program which provides respite, therapies, nutrition and other social services to frail, impoverished, (often times demented) older persons in a community setting, include a $28.1 million budget reduction and elimination of two days of a five day service week. It is estimated that 8000 older adults will be impacted by these cuts. Supportive services under the Department of Aging (CDA) will be cut by $15.8 million which is expected to impact 35,000 older persons over the age of 65, which will reduce or eliminate a number of services that caregivers depend on such as the Alzheimer's Day Care Resource Centers. And the Department of Mental Health (DMH) funding for the Caregiver Resource Centers will decline by two-thirds, providing a further loss of caregivers of seniors with Alzheimer's. The loss of services provided by IHHS, ADHC, CDA and DMH will mean that families will need to provide even more hours of support to their loved ones in order for them to remain in the community and out of an institution. While families have a preference for caring for their older family members in the home, and already provide the bulk of care. As evidenced above, doing so without the supplemental assistance provided by the above programs is will be impossible for some of them. The increased hours of care and lack of support associated with these cuts in services will render the population of caregivers further at risk for health, mental health and economic hardship, and increase the number of older persons that are institutionalized.

Key Informants – Summary of Common Themes in August 2009 Interviews

During August and early September 2009, CHPR researchers interviewed 20 key informants, including service providers, advocates, public officials and local agencies. Key informants were selected for their expertise and experience in Long Term Care (LTC) programs at the state and local level. A common set of questions were asked of each respondent addressing the 2009 California budget cuts and the likely impact on older adults, families, and providers. The key informant's insights highlighted critical issues facing recipients of LTC services resulting from the recent cuts in services.

Several key issues were consistently raised by the key informants. Every key informant, providers, advocates, and public officials, stated that low-income, disabled, and frail older adults would be negatively impacted by the 2009 California budget cuts. Providers and advocates expect that reduced services for older adults will lead to an increase in emergency room use, hospitalizations, and nursing home admissions. The reduction and elimination of services are predicted to affect the health of elders and their ability to stay in the community.

Many key informants discussed the accumulation of cuts from several programs and the added impact it will have on the older adults who receive services from more than one program. As one key informant said, cuts to the programs "involves the same people." The cuts to LTC services are only compounded by the cuts to SSI and Medi-Cal. An older advocate and recipient of services emphasized that finances and housing were issues she and her peers dealt with on a daily basis. As the safety net of LTC programs is being cut, key informants fear that few alternatives exist and additional pressure will be placed on families.

The reductions and elimination of home and community based programs leaves many elders with "no where to turn" as one key informant stated. While providers and local agencies are working to replace the gaps in services with the minimal resources left, additional burdens of care on the family will be the "breaking point" for many. According to one advocate, families have already built "personalized ad hoc safety nets," but the recent cuts will only add more strain to families as they will have to dedicate more time and resources to their elderly family member.

In addition to expecting health and financial problems for elders and their families, key informants were very concerned with the future of their agencies and providers. Many key informants expect limitations and decreases to the type and amount of services they will be able to provide. They expressed frustration with certain aspects of the budget, such as the fraud requirements in IHSS and the use of Functional Index scores as cut offs for services.

Many key informants are working to make sense of the budget cuts and the impacts the cuts will have on older adults, their families, and providers, however, data is not readily available. One ADHC provider pointed out that their agency is scrambling to evaluate the impact of the budget cuts on their clients. Several key informants stated that the lack of data is making it difficult for providers to identify those who will be most affected by the loss of services.

A more detailed analysis of the interviews (below) identifies the main themes and issues addressed by the key informants. All expressed great concern over the impact the cuts and elimination of long term care programs would have on the older adults, their families, and providers.

Impact on Older Adults

- Several key informants expect an increase in ER use, hospitalizations, and nursing home admissions. Older persons will have to manage on their own or depend on family members for care. A lack of services may be the breaking point for elders.
- The older adults using the LTC services are vulnerable, low-income, and disabled. The loss of services "will make those who are sick, sicker."
- Several providers mentioned trying to coordinate services. ADHCs were attempting to have IHSS fill in the gaps for those with reduced ADHC services and vise versa, but new restrictions to eligibility for services from the 2009 budget does not make coordination of programs easy.
- Many providers, advocates, and public officials stated that many elders had "nowhere to go" – a couple counties have no available nursing home beds, long term care programs are being cut and reduced, local agencies have less funding to provide services. Older persons are left with limited options and limited resources.
- Providers are worried elders who have been cut from ADHC or IHSS will become socially isolated. If individuals lose their caregivers completely, no one will be there to assist them when they need help. "Our main concern is that they could get in big trouble real fast." The cuts will hit those with no family the hardest. There is no one to pick up the slack.
- Some key informants expect an increase in elder abuse as families become more strained, however other key informants believe elder abuse is rare and not a high risk.

IHSS

- Many older adults require reminders to take medications and follow through with doctor appointments. Limited oversight and assistance with these tasks can have eventual effects on the older adult. As one IHSS provider noted, cuts in domestic services will result in inadequate nutrition for elders and an increase in falls.
- Even those with low FI scores are vulnerable because many have no one else to help them. Loss of one thing can be a "tipping point." Many key informants stated that using FI scores to determine cuts does not identify those with the least need.
- FI scores can be appealed and reassessed; however, key informants expect an influx of appeals and staff shortage will slow the process.
- IHSS is a core component of what allows older adults to continue living in the community. IHSS workers are on the "front line of prevention; they communicate medical concerns to physicians, social workers, and others."

SSI

- SSI has received several cuts in the past year. Even before the cuts, older adults still struggled with their incomes. Cutting "share of cost" adds another cost for those already on a very low income.
- Housing is a large expense for most elders, although the issue is not often addressed, as one key informant stated. Older adults living in the community have to juggle low incomes with the often high prices of housing in California. One

elder and advocate thought there was a lack of low-income housing for older adults.

ADHC

- An ADHC director felt the cuts to ADHC affect those who need it the most. ADHCs provide stability and monitoring for disabled elders who cannot be on their own.
- As one key informant reminded us, approval for 4 and 5 days a week of ADHC is difficult to receive. Individuals who receive approval for 4 and 5 days are frail and in great need of monitored care.
- Some older adults will seek other resources immediately, such as hospitalization or nursing homes, while others will "limp along for several months."
- The elimination of Alzheimer's Day Care Resource Centers will especially impact clients with Alzheimer's as they will have "no where else to go." Other providers often will not take elders with severe cognitive problems.

Impact on Families

- All key informants recognize that a great amount of care is already being provided by families. Additional burdens of care on the family may serve as the "breaking point" for many. Key informants fear that a lack of care can result in increased hospitalizations or nursing home admissions.
- Families and older adults will have to combine a patchwork of formal and informal services, although both are already strained. Families have already built "personalized ad hoc safety nets," but the recent cuts will only add more strain to families.
- There is little consideration for the effect on mental and physical health for the caregiver. Mental and physical health components are significant determinants of what happens to the care of the recipient. Resources for caregivers are extremely limited.

IHSS

- Family support is one of the most important indicators for people being able to function as high as they can. IHSS allows for the integration of family members in a caregiving role as employees, however "family support is not valued by politicians," as stated by an IHSS provider.
- It is possible that family will compensate for some of the lost IHSS hours, but this is unlikely for those with no current family or informal support. Even if family members are able to help, the burden, stress, and financial costs that come with caregiving may be too much to be absorbed by the family. When families lack options that can buffer the caregiving burdens the often consider nursing homes sooner.
- Family members who serve as IHSS workers rely on the income, the cuts will "take a toll" on the family. Economic pressures may force the caregiver to look

- For ethnic minorities, in-home care is critical because it allows them to choose a caregiver that can speak their language and cook the foods they prefer. Also, many are hesitant to place family members in nursing homes, creating more stress on the family.
- One provider noted that IHSS improves the quality of life for the older patient as well as the family member who serves as a caregiver. Both are happier, the older adult remains in the home and the caregiver receives some reimbursement for their work.

ADHC

- An ADHC advocate stated that families build their entire schedule around ADHC 5 days a week. Eliminating two full days of care causes a huge disruption to the family structure.
- Family members depend on ADHCs, especially those family caregivers who work outside of the home. Several key informants provided examples of family and spousal caregivers who are also elderly with their own medical problems. Both young and older caregivers use ADHC as a source of respite and daily care, allowing the elder to remain in the home.

Impact on Providers

- Large and small providers commented that cuts in one program often affect the whole organization, especially administrative costs of their core operating services. Lay-offs are inevitable and many are concerned over the amount of services they will be able to provide.
- In the example of a larger LTC provider running several programs, a greater demand will be placed on the few programs that were not cut this budget cycle, such as MSSP and PACE. Cuts in one program create a greater demand on the other programs, with no additional funding or resources.
- Providers are trying to identify who will be affected by the budget cuts, but the lack of local and state data make it difficult. One key informant complained of not having data on "cross-users," those that use multiple services and will be affected by the budget cuts from multiple sources. Overall, key informants expressed frustration at the lack of data available for the evaluation of LTC programs.

IHSS

- For IHSS workers who provide domestic services to several clients, cuts may result in a significant loss of work and income. Many IHSS providers are themselves low-income.
- IHSS fingerprinting and other fraud requirements are seen as a distraction that will not provide any real savings.

- IHSS workers may need to limit the type of tasks they do and the amount of time allocated for each task. Some key informants are worried that workers who continue to perform tasks outside of the guidelines will be committing fraud.
- Functional Index scores now have more meanings since they can result in receiving services or receiving nothing. Several legislative, provider, and advocates agree that FI scores are a poor tool to determine least need of IHSS. The fear is that those who are in need will no longer be eligible for IHSS hours and that appeals to FI scores will further congest the enrollment process.

IHSS Public Authorities

- Quality matches between recipient and in-home care provider will be more difficult, which can lead to increased turnover. Delays on background checks and enrollment of the provider are also expected.
- Loss of on call coverage – this service allows providers to call in when they are sick or cannot work. If the recipient has urgent needs, a temporary provider will be sent to the recipient. Due to the budget cuts, counties will not be able to provide this service anymore. Thus, if the provider is sick and out for two weeks, this can potentially be life threatening for many people on their program.

ADHC

- Several ADHCs will reduce their days and hours of operation. Smaller ADHCs are affected the most, with some expecting to close down. Elimination of Alzheimer's Day Care Resource Centers is especially damaging to the smaller ADHCs who depend on the funding to provide services.
- Staff has already been layed off, with more lay-offs expected in the coming months as the cuts are implemented.
- Implementing the cuts is also difficult because ADHCs have rules and regulations they must adhere to in order to remain open. Regardless of their funding, they must provide a certain level of services.

Long Term Care Reform Suggestions

- "Global budgeting for LTC" – core of the system is integration, diversion, and Home and Community Based Services.
- Several key informants agreed that better integration of LTC services is needed. A central point of entry, such as the LTC programs in Washington, would be a good alternative.
- A system that matches the individual's needs with the services provided. Also, those in critical need would benefit from brief intensive care management.
- In-home care is critical, especially for older minorities that prefer to receive care in the home from family members, receiving care in their language and culture.
- Several key informants felt that current LTC programs are pertinent and effective, but better integration and consistent funding would enhance the current programs.

What Existing Research Tells us About the Effectiveness of Community-Based Long-term Care and Outcomes of Expansions and Cuts to Services

In-Home Supportive Services

Background

California's In-Home Supportive Services (IHSS) is a $5.5 billion program (funded through federal, state, and county funds) with 444,000 recipients. The overarching goal of the program is to help people remain safely in their own homes and avoid more expensive and less desirable institutional care. To qualify for IHSS, recipients must be disabled, blind, or elderly (65 and older). Their assets must be less than $2,000 excluding their house and car. Income eligibility is tied to the SSI payment level which was $907 in January 2009 for an individual and $1579 for a couple (SSI payment levels have since been decreased in the July 2009 budget). Persons with income higher than this can "spend down" to that level and become eligible, following Medi-Cal eligibility rules. Recipients who are in this situation are said to have a "share of cost" and must pay a share of their providers' salaries. Participation in IHSS has doubled in the last ten years and continues to grow faster than other California public assistance programs (Adkisson et al, 2009).

Characteristics of IHSS recipients

- IHSS recipients are generally older adults; almost 60% are over the age of 65. Two thirds of recipients are women.
- Authorized hours are determined by a scoring system. IHSS recipients may be authorized between 1 and 283 hours of services each month, depending on their determined need. Sixty percent of recipients received under 80 hours of services.
- Family members often serve as IHSS providers. Approximately 63% of IHSS recipients have a relative as an IHSS provider. About one-half of IHSS providers live in the same household as the recipient.
- The most common reasons for ending IHSS include death (29%), changes in Medi-Cal eligbility (22%) or entering a nursing home (15%).

(Waterstone et al, 2004; California Department of Social Services, 2002; LAO, 3-24-09)

Consequences for Elderly Recipients

There is relatively little research available on the consequences of reducing homemaker or personal care services for the frail elderly. However, a body of literature has documented various outcomes for the elderly who have received similar home and community-based services.

Health Status

- One study of "low-tech" home care services (comparable to IHSS services) found that the treatment group in the home care program had higher cognitive status scores, more social contacts, and fewer unmet needs for care than the control

group, although there was no effect on mortality. Significantly better cognitive functioning and reduced unmet needs in the treatment group were found at nine months and a continued beneficial effect of treatment on cognitive status was observed at 48 months (authors caution interpretation of four-year findings as only 18% of clients were still alive and receiving community care at that time).

- Levels of disability: in the study, clients were homebound, chronically impaired elderly in need of medical and social services but did not require skilled nursing care. Mean IADL scores for treatment and comparison groups were 7.0 and 8.5, respectively. Mean ADL scores for treatment and comparison groups were 9.5 and 10.5, respectively. (Hughes, Conrad et al. 1988)

Nursing Home Use among IHSS Recipients

The goal of home and community based services, such as IHSS and other in-home care programs, is to remain in the community. Several studies have documented, with mixed results, the impact IHSS and in-home care services can have on limiting nursing home admissions.

- Two studies report incidence of nursing home placement among IHSS recipients: 5.9% among those age 65 and older in 2005, suggesting that IHSS in general is doing a good job of enabling recipients to remain in the community [The report does not give a reference population for this comparison- this was an author's inference.] (Newcomer and Kang 2008).

- Using DSS exit data compiled over the period from August 1998 to December 200, the Legislative Analyst's Office reports that 9% of IHSS recipients exit to state facility nursing homes and 6% exit to some other type of out of home care (2004).

- 3 of 8 experimental or quasi-experimental studies that included nursing home placement as an outcome for home care programs found the home care group to have fewer nursing home admissions. Alternatively, one study resulted in the home care group having more nursing home placements (Hedrick and Inui 1986)

- One study of "low-tech" home care services (comparable to IHSS services) found that they significantly reduced the risk of nursing home admissions (Hughes, Manheim et al. 1987)

- A study of dementia caregivers found that those individuals who utilized in-home help services earlier in their dementia caregiving careers were more likely to delay institutionalization (Gaugler, Kane et al. 2005)

- One study found that an increasing amount of formal services was associated with reduced risk of nursing home use for cognitively impaired older persons (Jette, Tennstedt et al. 1995)

- A comparison of five home and community based services (HCBS) in Florida found that when controlling for other factors, the presence of a caregiver reduced

expected nursing home days by 3.20 days. The strongest predictor of per member/per month nursing home days was the presence of an available caregiver (Mitchell, Salmon et al. 2006)

- A review of eight home and community based services found no reductions in nursing home use as a result of home care (Weissert 1985)

- One study found that a higher level of state expenditures on HCBS was associated with higher probabilities of using formal personal assistance, either by itself or in combination with informal assistance, and a lower probability of receiving no assistance. To the extent that supportive formal services can reduce the stress on the caregiver (because of freedom to engage in other activities and freedom from the emotional pressure of having primary responsibility) the authors conclude that a higher level of HCBS commitment may actually strengthen the informal care system (Muramatsu and Campbell 2002)

Utilization of Health Services

- Among elderly and disabled persons, unmet need for ADL tasks is associated with higher levels of emergency room visits and hospitalizations (Allen 1999)

- Individuals receiving personal assistance services (PAS) were significantly more likely to receive prevention health care than those on a waiting list for PAS (1997)

- One study of 13 PACE sites of enrollees with one or more ADL dependencies found that those who lived with unmet ADL needs before enrollment were more likely to have a hospital admission before PACE enrollment and an acute admission in the first six weeks after enrollment but not after 6 weeks of receiving PACE services (Sands, Wang et al. 2006)

Unmet Needs

Several studies have documented a link between unmet long-term care needs and adverse health consequences

- People with unmet need for personal assistance are more likely than those whose needs are met to experience adverse consequences including discomfort, weight loss, dehydration, falls, and burns (Allen and Mor 1997; Niefeld, O'Brien et al. 1999; Laplante, Kaye et al. 2004)

- Two studies found that of people with any unmet need for help with ADLs, approximately half report at least one of five consequences because of lack of assistance: not being able to bathe, dress, get in and out of the bed or a chair, use the toilet, or eat. Consistent with other findings, this study finds that when holding disability level constant, people with paid care are significantly less likely to have unmet needs than those who do not get paid care (Desai, Lentzner et al. 2001; Komisar, Feder et al. 2005)

- Among elderly and disabled persons, unmet need for ADL tasks is associated with higher levels of emergency room visits and hospitalizations (Allen 1999)

- States with higher Medicaid spending on home and community-based services had lower rates of unmet ADL needs among low-income seniors; there was no difference in unmet needs among higher income seniors, indicating that public HCBS spending resulted in lower unmet needs. (Kemper et al. 2008).

Consequences on IHSS Providers and Caregivers

Caregivers are impacted physically, emotionally, and financially when providing care, even when they are paid IHSS providers.

Profile of California Caregivers

A California statewide survey of caregivers (telephone interview of random sample of 1,643 state residents who provide care to someone age 50 or over) describes caregiver characteristics, type of caregiving, and impact of caregiving.

- California caregivers have an average age of 50.87 years, slightly older than caregivers nationally. Three-fourths are women, 60% are married, and 31% have children under the age of 18 living at home (as compared with 41% nationally). Sixty-one percent are White/Caucasian, 25% are Hispanic/Latino, 6% Black/African American, and 5% Asian. Most caregivers were born in the US (86%), but a notable number (6%) report Mexico as their country of origin. (Scharlach, Sirotnik et al. 2003)

- About half of California's caregivers are employed – 35% full-time and 14% part-time. Three-fourths of caregivers (74%) evaluate their health as good, very good, or excellent, with 26% indicating that their health is fair or poor; 28% report health or emotional problems. (Scharlach, Sirotnik et al. 2003)

- Caregiving can have negative impacts on the caregiver's health and well-being. One third of caregivers report high levels of emotional stress associated with providing care, while 18% report high levels of physical strain, and 15% report high levels of financial hardship. More than one-fifth report suffering either physical or emotional problems as a result of their care giving responsibilities, and one-fourth report sleep disruptions. More than one-fifth have no one they can go to for support and understanding regarding their caregiving situation. (Scharlach, Sirotnik et al. 2003)

- California caregivers who experience the highest levels of financial hardship, physical strain, and emotional stress, are more likely to be female, Latino, low income, and in poor health. They are more likely to care for someone with mental illness/emotional problems, dementia/memory problems, behavioral problems, or stroke or paralysis. Furthermore, they are more likely to report that the caregiving situation has created family conflict and has been a significant hardship for their families. (Scharlach, Sirotnik et al. 2003)

Working Caregivers

- *Negative effects on work:* Employees' caregiving responsibilities can have a variety of negative impacts on their work. Some of these include: 1) lost time from work; 2) decreased productivity; 3) lost career opportunities; 4) unpaid leaves of absence; 5) early retirement; and 6) decreased lifetime earnings. (Neal and Wagner 2001)

- *Negative health effects of caregiving:* While some findings point to the positive benefits of the caregiving experience, most studies focus on the stress, burden and negative health effects of caregiving. Consequences include increased risk of becoming depressed (Schulz, O'Brien et al. 1995; Neal, Hammer et al. 1999) , feeling stressed, strained, exhausted or fatigued (1997) and reporting more health problems (e.g., arthritis, insomnia, diabetes, obesity, weight gain) (Schulz, O'Brien et al. 1995)

Cost of Caregiving

- Key findings from 2006 Metlife Caregiving Cost Study:
    - The total estimated cost to employers for full-time employees with intense caregiving responsibilities is $17.1 billion.
    - The average cost per employee for those with intense caregiving responsibilities is $2,441
    - The total estimated cost to employers for all full-time, employed caregivers is $33.6 billion
    - The average cost per employee for all fulltime, employed caregivers is $2,110. (2006) (Metlife 2006)

Adult Day Health Care

Background

Adult Day Health Care (ADHC) is a community-based program administered by the California Department of Aging that provides a variety of services to elder adults through a day care program. In California, there are 38,000 elders who receive ADHC services through Medi-Cal. ADHC serves elders who need some assistance, but do not want 24 hour care in a nursing home facility. There are currently over 300 ADHC centers in California with varying degrees of services, including medical services, personal care services, psychological services, social services, hot meal and nutritional counseling, and transportation services (CA Dept. Aging website). Use of ADHC has several potential benefits to the elder participant, as well as to the family and caregivers.

The ADHC population

- A national survey in 2001-2002 found the average ADHC participant is 72 years old and approximately half experience some form of dementia (Partners in Caregiving, 2001).
- Participants need a variety of services, in particular assistance with activities of daily living (ADLs). Thirty seven percent of ADHC participants need help walking and 24% need help eating (Partners in Caregiving, 2001).
- Living arrangements: 11% of ADHC participants live alone, while 35% live with a child and 20% with a spouse (Partners in Caregiving, 2001).
- Adult Day Health Care participants use the day care services as a source of assistance with personal care, but it also serves as a source of respite for the family members who serve as caregivers.

ADHC Benefits for Elders

There are several quasi-experimental studies documenting the health benefits to elders who attend ADHC programs. A few randomized studies have been performed reviewing the potential benefits of ADHC programs, with mixed results. Further research is needed, in particular improving the evaluation of outcomes for ADHC participants (Dabelko & Zimmerman, 2008).

- A quasi-experimental study with dementia patients found that elderly patients experienced shorter night-time sleep problems on days he or she attended adult day care services. Attending adult day services led to fewer depressive symptoms and less agitated behavior, although not statistically significant (Femia et al, 2007).

- Another study found that elders with dementia who took part in more engaging activities in adult day care, such as games and discussion groups, demonstrated a greater decline in restless behavior than those who engaged in fewer activities. The study also resulted in an increase in restless and mood behaviors for participants who attended more days of adult day care. Although the increase is small, the authors attribute the unexpected results to higher levels of restless and

mood behaviors at baseline for participants who attend day care more frequently (Woodhead et al, 2005).

- A study in Japan with a sample of 1,673 elderly participants found that elders who attend day care services have a lower mortality rate than those who do not attend day care. Those who use day care services two and three times a week have a 63% and 44% lower hazard ratio of mortality, respectively, than participants who do not use day care services (Kuzuya et al, 2006).

- A Veteran's Administration randomized control study at four sites did not show significant improvement in physical or psychological health for those who participated in ADHC compared to those who did not (Rothman et al, 1993).
    - When the authors examined subgroups of the patients, a possible selection bias emerged for those who attended ADHC. Results indicate that patients who were not married, satisfied with their social support network, and not in the hospital at the beginning of the study and attended ADHC had lower sickness profile scores. (Rothman et al, 1993).

- A randomized control study with 212 elders in Montreal, Canada did not demonstrate improvement in depression, anxiety, or functional ability among the elders who attended an adult day center (Baumgarten et al, 2002).
    - However, interviews revealed that two thirds of the elders who attended the adult day center reported feeling less lonely and about half felt less anxious and less depressed (Baumgarten et al, 2002).

ADHC Benefits for Caregivers

Adult day health care allows caregivers to forfeit their duties for a few hours a day, providing a source of respite. This extra time allows caregivers to rest physically and psychologically, benefiting both the caregiver and the elder.

- A quasi-experimental study with dementia patients found that caregivers using ADHC for their relatives experienced less stress (less overload and worry/strain) and better psychological well being (less depression and anger). Attending ADHC also allowed employed and unemployed caregivers to spend less time dealing with behavior problems. However, there was no change in the time caregivers spent helping their relatives with ADLs or memory problems (Zarti et al, 1998; Jarrot et al, 2000).

- Frequency of ADHC attendance is another factor that can benefit the caregiver. A randomized study in Canada resulted in caregivers feeling less burden when their elderly family member had high ADHC attendance compared to caregivers of elders with low attendance (Baumgarten et al, 2002).

- An evaluation of the Michigan Model Projects Specialized Respite Care program, which provides respite through adult day care, in-home care, or a combination, found that caregivers who used respite care reported a decrease in the level of subjective burden felt. There was no difference in objective burden (demands on

caregiver's time) between those who used respite and those who did not. The caregiver's morale, measured by feelings of loneliness, anxiety, and optimism, was significantly higher for those using some form of respite care (Kosloski & Montgomery, 1993).

- A quasi-experimental study provided the experimental groups with adult day services for the elderly patient and case management for the caregiver, while the control group received adult day services for the elder only. The addition of case management for the caregiver resulted in decreased depression for the caregiver, as well as improved confidence in the management of the elderly patient's behaviors (Gitlin et al, 2006).

ADHC Effects on Nursing Home Use

ADHC programs are desirable because they allow elders to remain in their homes longer, support family caregiving, and potentially prevent nursing home admissions. The actual ability of ADHC programs to prevent nursing home admissions is difficult to assess due to low institutionalization rates in studies, as well as difficulty in operationalizing institutionalization (Dabelko & Zimmerman, 2008).

- A national survey, used to examine the number of nursing home admissions between 1995 and 2002 found that seniors without children had a lower risk of entering a nursing home in states that spent more on home and community based services (HCBS) than in states which spent less. Thus, increasing HCBS per capita expenditures by 100% would decrease the risk of entering a nursing home for childless seniors by 34.6% (Muramatsu et al, 2007).

- A quasi-experimental study provided the experimental group with ADHC for the elderly patient and case management for the caregiver, while the control group received ADHC for the elder only. The additional case management for the caregiver resulted in fewer transitions to nursing homes, with 12% of the elders in the experimental group admitted to nursing homes versus 27% of the elders in the control group admitted to nursing homes. (Gitlin et al, 2006).

- A review of ADHC by the Assistant Secretary for Planning and Evaluation (ASPE) found that providers and families believed ADHC delayed or prevented institutionalization by assisting caregivers. Many providers felt ADHC was a "caregiver's last hope of maintaining their family member in the community" (p25, ASPE, 2006).

- In a study of Alzheimer's patients examining those who use adult day care and those who do not, results show that use of adult day care is associated with nursing home placement. The authors hypothesize that those who use ADHC may be more inclined to use services, eventually leading to the use of a nursing home (McCann et al, 2005)

Case Management – MSSP

While California's Multipurpose Senior Service Program (MSSP) was not cut in the 2009 budget, its sister program Linkages was. Linkages provided a lower level of service than MSSP, but both programs share the principle of case management to assist elders live in the community. The following literature review focuses on MSSP, but the lessons learned may extend to Linkages as well.

Background (from CA Dept. of Aging MSSP website)

Local Multipurpose Senior Service Program (MSSP) sites provide social and health care management for Medi-Cal eligible frail elderly clients who are certifiable for placement in a nursing facility but who wish to remain in the community. The goal of the program is to arrange for and monitor the use of community services to prevent or delay premature institutional placement of these frail clients. The services must be provided at a cost lower than that of nursing facility care.

Clients eligible for the program must be 65 years of age or older, live within a site's service area, be able to be served within MSSP's cost limitations, be appropriate for care management services, currently eligible for Medi-Cal, and certified or certifiable for placement in a nursing facility. MSSP site staff make this certification determination based upon Medi-Cal criteria for placement.

Under a federal Medicaid Home and Community-Based, Long-Term Care Services Waiver, MSSP provides comprehensive care management to assist frail elderly persons to remain at home. The program, which began in 1977 with eight sites, has expanded to 41 sites statewide and can serve up to 11,789 clients per month.

The services that may be provided with MSSP funds include:

- Care Management (core service provided; coordinates the following and can provide payment for gap-filling services in these areas as well)
- Adult Day Care / Support Center
- Housing assistance
- Chore and Personal Care Assistance
- Protective Supervision
- Respite
- Transportation
- Meal Services
- Social Services
- Communications Services

Case Management Review

An early evaluation of California's MSSP program found increased longevity, decreased nursing home days, and decreased hospital days (in 1982) among recipients (Miller, et al

1985).

Case Management Interventions

Several recent review articles have summarized the results of a wide variety of community case management interventions for the frail elderly.

- One literature review of 10 relevant randomized controlled trials found that no case management programs reported an increase in service use and cost; two studies reported reduced services use and savings in health care costs (Oeseburg, et al 2009).

- Another review of elderly case management interventions found mixed results including no effects on hospital admission, outpatient visits, or emergency department visits in some studies, with less hospital admissions and/or shorter lengths of stay in other studies. Also, several studies found fewer nursing home admissions for those with case management (Hallberg et al, 2004).

- Overall, evidence of cost-effectiveness for case management programs for the elderly is mixed, though several programs report positive outcomes, including better quality of life for elderly patients, reduced mortality, and less functional decline.

Nursing Home Predictors and LTC services

Background

Since its inception, Medicaid has provided coverage for nursing homes, focusing long term care services on institutionalization. The Omnibus Budget Reconciliation Act in 1981 allowed for home and community based service (HCBS) coverage through Medicaid, with the objective of preventing institutionalization (Wade & Hendrickson, 2008). Researchers have studied the factors that lead to institutionalization, with hopes of understanding how to delay nursing home admission. While there is much research on the individual factors that predict institutionalization, few studies have examined the impact of home and community based services (HCBS) on nursing home admissions.

Individual Level Characteristics as Predictors:

Literature reviews by Gaugler et al (2007) and Kersting (2001) indicate that nursing home predictors vary greatly, but most predictors are based on the elder's functional status, living arrangements, and caregiver characteristics.

Elder Characteristics:

- A review of the literature resulted in 77 reports from 12 final data sources used in the meta-analysis. Significant predictors to nursing home admission include older age, annual income of less than $5,000, and Caucasian race/ethnicity. Also, older adults who were married or had living children had lower odds of entering a nursing home, while older adults who lived alone had nearly twice the odds of entering a nursing home. Older adults who have 3 or more ADL dependencies have 3.25 times the odds of entering a nursing home. (Gaugler et al, 2007)

- A review of the literature by Kersting found that income is a complex predictor and attention should be given to its measure. Several studies have demonstrated that once you control for race, social support, and functional status, income is no longer a significant predictor to nursing home use. Home ownership is a potential predictor, mainly because patients often need to spend down to be eligible for Medicaid, and families need to make sure the home is not used as a source of income in Medicaid eligibility. (Kersting, 2001)

- Kersting also used data from the Longitudinal Study of Aging from 1984 to 1990 in order to examine social support, poverty, race, gender, age, and functional status as predictors to nursing home use. Results found that those living with a spouse or living with children have a 0.58 reduced risk of admission into a nursing home compared to those who live alone. Being active in the community (a combined score of church attendance, volunteer work, satisfaction with level of activity, and recreational activities) also reduced the risk of nursing home admission. In regards to income, results found the income group more than 3 times the poverty level to be significant in reducing the risk of nursing home admission. No other income variables, such as home ownership, proved to be significant predictors. The study found ADLs and IADLs to be important

predictors. Elders with four ADLs or IADLs had a 1.81 times the risk of nursing home use compared to elders with no functional problems. (Kersting, 2001)

Caregiver characteristics

- One study found that caregivers with higher levels of burden are 1.54 times more likely to use nursing homes sooner. Also, caregivers who rated their health as poor had a 1.44 higher risk of institutionalization sooner. (Gaugler et al, 2003)

- Data from the National Longitudinal Caregiver Study was used to identify the reasons caregivers decide to institutionalize their family member. Study participants receiving the care had been diagnosed with Alzheimer's or vascular dementia, and were part of the VA. The most common reason for institutionalization given by 65% of the caregivers was "my loved one needed more advanced skilled care than I could provide." The second most common reason, with 49% of caregivers stating "my health would not permit me to continue caregiving." (Buhr et al, 2006)

- A recent VA study with dementia patients also found that caregivers who reported their life was not satisfying were 2.3 times more likely to institutionalize compared with those whose life was very satisfying. Caregivers who reported the highest task burden were 5.1 times more likely to seek formal care. (Buhr et al, 2006)

Home and Community Based Services as Predictors

Recent studies are beginning to analyze the use of home and community based services (HCBS) and their impact on nursing home admissions. Results are mixed, with some studies demonstrating delayed nursing home admission when HCBS programs are available, but other studies indicate use of community services are a stepping stone to institutionalization. The reasons for the mixed benefits of HCBS are complex.

- Studies by Gaugler point to the importance of beginning the services early. Other researchers hypothesize that caregivers who use home and community based services are more stressed or have a family member with declining functional abilities, leading to institutionalization sooner (McCann et al, 2005).

- Gaugler, Kane, Kane, and Newcomer review past studies which have yielded mixed results in terms of the benefits of community-based long-term care. They cite studies that demonstrate that 22% to 50% of dementia caregivers refuse community-based long-term care services. Caregivers who do use services have relatives with more severe cognitive and functional behaviors and experience more distress. Studies have shown that families provide caregiving assistance 3-4 years before seeking community-based long-term care services (Gaugler et al, 2005). Community based services may be accessed late into the elder's declining health, leading to the appearance of sooner institutionalization with community services than without.

ADHC Effects on Nursing Home Use

- A quasi-experimental study providing adult day services for the elderly patient and case management for the caregiver resulted in fewer transitions to nursing homes, 12% in case management group versus 27% without case management (Gitlin et al, 2006).

- A review of ADHC by the Assistant Secretary for Planning and Evaluation (ASPE) collected data through site visits and in-depth interviews with providers and family participants. Providers and families believed ADHC delayed or prevented institutionalization by assisting caregivers and allowing the elder to remain in the community. Many providers felt ADHC was a "caregiver's last hope of maintaining their family member in the community" (p25, ASPE, 2006).

- In a study of Alzheimer's patients who use adult day care versus those who do not, results show that use of adult day care is associated with nursing home placement. The risk of nursing home placement was significantly greater for men than for women, and the risk increased with older age and days of adult day care. Also, of those that attended adult day care more frequently, men had a higher risk of nursing home placement.(McCann et al, 2005)
    - Associations were not found for living arrangements, thus in this study, living with a spouse, child, or alone, did not make a difference to nursing home use or adult day care use. (McCann et al, 2005)
    - The authors also found that among adult day care users, strong predictors of nursing home placement included the patient's disease characteristics and caregiver burden. (McCann et al, 2005)
    - The authors pose several reasons why adult day care does not delay nursing home placement. One is the time in which adult day care is initiated. Caregivers may wait too long to place the patient in adult day care, attenuating any possible benefits from the day care services. ADHC may also be a source of assistance for caregivers who experience more stress, leading to an increased willingness to consider a nursing home. The caregiver may also receive encouragement from providers or other caregivers associated with the adult day care program to initiate institutionalization. (McCann et al., 2005)

- For Alzheimer's patients, nursing home placement is associated with a decrease in level of cognitive function as well as a more rapid decline in cognition. (Adult day care attendees had a lower level of cognitive function at baseline). For patients who had attended adult day care before nursing home placement, the acceleration of cognitive decline was lessened. Adult day care serves to improve the transition to a nursing home for Alzheimer's patients by lessening their cognitive decline once admitted to a nursing home. (Wilson et al., 2007)

In-Home Care Effects on Nursing Home Use

- One study examines the use of community-based services, specifically in-home help and adult day services, and nursing home use. Data was used from Medicare Alzheimer's Disease Demonstration Evaluation, MADDE, which provided case

management to the experimental group and no case management to the control group. The study found that caregivers who utilized in-home care earlier in their caregiving career were associated with delayed institutionalization. (Gaugler et al, 2005)

- An association was not found for the timing of adult day services, possibly because there were low utilization rates of adult day services. (Gaugler et al, 2005)

- The study reviews outcomes before and after the Balanced Budget Act of 1997, which resulted in decreases in the amount of Medicare home health use. Results indicate an increase (from 7.8 to 8.8%) in skilled nursing facility use between 1997 and 1999 among home health users, possibly because of the limits on home health payments. Multivariate analysis results demonstrate a 10% increase in skilled nursing facility admissions for home health patients after the Balanced Budget Act of 1997. Also, for home health patients, ER incidences increased by 10% and mortality increased by 8%. The authors demonstrated that service use did change as a result of Medicare home health cuts. (McCall et al, 2002)

HCBS Effects on Nursing Home Use

- A study using data from the 1993 and 1995 AHEAD (Assets and Health Dynamics of the Oldest Old) survey examined Medicaid policies across several states to identify their impact on nursing home admissions. Results find that Medicaid policies are not associated with risk of nursing home entry. However, individual level health indicators, such as age, marital status, homeownership, and cognitive function, are predictive of nursing home admission. Medicaid policies were not found to affect the risk of nursing home admissions. The author notes that recent changes in Medicaid policies, including changes in financial incentive structures and delivery systems, may be limiting the results. For example, hospitals have reduced hospital stays by increasing the use of nursing homes as post-acute settings. (Aykan, 2002)

- A national survey, used to examine the number of nursing home admissions between 1995 and 2002 found that seniors without children had a lower risk of entering a nursing home in states that spent more on home and community based services (HCBS) than in states which spent less. Thus, increasing HCBS per capita expenditures by 100% would decrease the risk of entering a nursing home for childless seniors by 34.6% (Muramatsu et al., 2007).

- Due to budget reductions in Michigan's Medicaid program, formal services decreased by 11%. As a result, Medicaid participants had a 20% higher probability of being placed in a nursing home compared to baseline (D'Souza et al, 2009).

- Medicaid home care waiver program in South Carolina found that program enrollees were notably more frail in 2005 than in 1995, suggesting that the home

care waiver program was a successful effort to help individuals age in place in the community, delaying institutionalization (Pande et al. 2007)

- Two meta-analyses found that HCBS did reduce nursing home use in a majority of studies, but nursing home cost reductions were more than offset by the increased costs of providing HCBS services to those who would remain at home even without the additional services (Kemper et al. 1987; Weissert et al. 1988)

- Use of community based services, which include chore, personal care, and adult day care, were analyzed in a study with dementia patients and their caregivers. Results demonstrate that caregivers who use low levels of in-home chore services were 1.34 times more likely to institutionalize their family member earlier compared to caregivers who used no services. Caregivers who used a moderate amount of personal care services were 0.78 times less likely to use a nursing home. For adult day care, patients who used low or high amounts of adult day care were 1.30 times more likely to use a nursing home sooner. (Gaugler et al, 2003)

- While some studies have found that use of HCBS leads to a higher risk for nursing home admissions, the reasons for this are complex. Some authors hypothesize that caregivers who use HCBS are more stressed or have a family member with declining functional abilities, leading to institutionalization sooner (McCann et al, 2005). Other authors suggest that the home and community based services are not used early enough. HCBS evaluation may need to focus on the timing and initial health of the older adult in order to fully assess the impact of home and community based services on nursing home use.

Cost-Effectiveness of HCBS

Overall, evidence on the cost-effectiveness of HCBS is somewhat mixed.

- Two meta-analyses found that HCBS did reduce nursing home use in a majority of studies, but nursing home cost reductions were more than offset by the increased costs of providing HCBS services to those who would remain at home even without the additional services (Kemper et al, 1987; Weissert et al, 1988)

- Several studies show that home and community based services are cost-effective (Chappell, Dlitt et al. 2004; Mollica, Kassner et al. 2009) . A GAO study found that long-term care programs in three states were able to serve more beneficiaries with available dollars and slow the rate of growth in LTC expenditures by expanding HCBS and limiting supply and use of nursing facility beds (1994). An HCBS demonstration in Vermont reduced the number of Medicaid nursing facility residents by 9 percent and increased HCBS caseloads by 155 percent with spending growth less than half of what the state projected when the HCBS program was designed (Crowley and O'Malley, 2008)

- One study shows that while the expansion of HCBS appears to entail a short-term increase in spending, it is followed by a reduction in institutional spending and long-term cost savings (Kaye et al. 2009)

Conclusion

California's 2009 budget cuts have frayed the community-based long-term care (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 the ADA gave disabled public assistance recipients the right to live in the least restrictive environment, typically the community (California Health and Human Services Agency, 2003). Different types of policies can help repair the LTC safety net and allow as many elders as possible to continue living safely in their own homes.

Policymakers have discussed the fragmentation of California's home and 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 (Expert Panel to Review California Department of Aging Structure, 2004). The fragmentation is reinforced by the 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.

California should work to return to its position as a LTC innovator that it held 20 years ago. Looking to the future in order to create a more effective and efficient LTC system in the state can start with adopting innovations from other states. Key informants suggest following models such as Washington's system that uses a single point of entry into their long-term care programs, and integrates the provision and financing of long-term care. Wisconsin is another state that uses a single point of entry and provides a more integrated system of care that has been the subject of several positive evaluations (Grabowski, 2006). Reducing fragmentation does not necessarily require increased spending, but does require attention to policy goals.

The 2009 California budget 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 (Bodenheimer, 1999). Medi-Cal managed care currently exists in California for low-income children and their parents, but those plans are not designed for the different and complex needs of the disabled and elderly that involve long-term care. 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 (Benjamin and Fennell, 2007). The goal of the "cash and counseling" program is to eliminate service silos and coordinate care while maximizing consumer choice and control. This approach is currently being implemented as a demonstration program in

several states and builds on the philosophy of consumer control that undergirds California's IHSS program.

All strategies to alleviate the fraying of state-funded safety-net of home and community 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.

The 2009 budget cuts to California's home and community-based long-term care system will result in real hardships for older adults, their families, and service providers. Now that the state has its focus on the components of the LTC system, it should continue its scrutiny and design a *better* system that maximizes the number of older adults who can safely remain in their homes.

Methodology

This report was prepared after an extensive search for publicly available data on California's long-term care (LTC) services, older adults receiving LTC services, and a thorough review of the existing literature on home and community based service evaluations, institutionalization risks, and evaluations of California's LTC programs. The information in this report draws on multiple sources including the limited data available, published information and key informant interviews.

Statewide data for In-home Supportive Services (IHSS) and older adults was not publicly available. However, Santa Clara and San Diego counties graciously provided aggregate data from the Case Management Information Payrolling System (CMIPS) using a data extraction tool created by Santa Clara County. Both counties provided separate tables for all ages and older adults receiving IHSS services and those who will experience service cuts. This data was analyzed by research staff to identify trends to create the county comparison tables in this report.

Statewide data for Adult Day Health Care (ADHC) recipients and providers, as well as other programs affected, was not available. Case studies of older adults attending ADHC 4 and 5 days were provided by advocacy and service providers. Data on other programs was obtained from published documents and key informants.

The scope of the literature review focused on the evaluations of home and community based services and any effects from providing or taking away those services, the risks of institutionalization among older adults, and any evaluations of California LTC programs. The literature reviews were conducted through Medline and PubMed searches. Additional documents on California LTC programs were obtained from published materials from the program.

Information on the state budget cuts came from various published documents. The overall state budget cuts were followed in the budget updates provided by the California Department of Finance. Program specific budget cut information and analyses were obtained from published documents provided by the state departments administering a specific program as well as documents published by advocacy organizations.

Research staff interviewed 20 key informants between August and early September 2009. Key informants included long-term care service providers, advocates, experts and public officials. A semi-structured interview guide was used for each respondent to obtain information on the 2009 budget cuts to long-term care services and any potential impacts to older adults receiving services, their families and providers. Key informants were selected based on their experience and expertise with the multiple programs and services targeted for cuts. All interviews were tape recorded and summarized, with research staff coding all of the interviews to identify common themes and key information. The protocol for the interview phase of the study was approved by the UCLA Office for the Protection of Human Subjects.

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