SOUTHERN AREA CONSORTIUM OF HUMAN SERVICES

Literature Review:
Does In-Home Supportive Services Prevent Nursing Home Care?

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EXECUTIVE SUMMARY:

Southern Area Consortium of Human Services (SACHS) has performed an analysis of available In-Home Supportive Services (IHSS) program data, and existing literature. This analysis was performed at the request of the SACHS Directors to answer the following question, "*Does In-Home Supportive Services (IHSS) prevent nursing home care?*" The purpose of this report is to assess if the proposed outcome of the IHSS Program- maintaining or improving functional independence of the participants, resulting in the delay or altogether prevention of institutionalization, is being met.

A major barrier was encountered during this research project, an inability to gain access to the most recent and advantageous IHSS Program data. The California Department of Social Services (CDSS) oversees the IHSS data and payroll system known as Case Management and Information and Payroll System (CMIPS). CDSS only publicly reports statewide and county monthly data on: IHSS caseload, hours paid, expenditures, and recipient functional index scores for all of its counties (collected from the IHSS CMIPS online report system). Unfortunately, current statewide or individual county data on the variable we pursued, '*Discontinuance from IHSS Eligibility by Reason*,' was not made available to us prior to the publication of this report. Therefore only data pulled from this variable at a previous time period (2001) could be analyzed in this report.

This literature review also highlights existing research and studies on IHSS and similar consumer-driven programs. Further insight into the effects the IHSS program has on consumer satisfaction and quality of life are provided.

IHSS PROGRAM BACKGROUND

(California Association of Public Authorities, 2008)

- **Summary:** IHSS provides an alternative to out-of-home care, by providing state, county and federal funding that enables program recipients to hire a home care worker. IHSS is the largest publicly funded nonmedical program in the nation designed to help people with disabilities, the elderly, and blind—and with limited resources—live safely at home.
- **Purpose:** IHSS is the primary service for implementing the U.S. Supreme Court's Olmstead Decision which gave people with disabilities the choice to live independently. Founded in 1973, the core goal of the IHSS program remains the prevention of premature or unnecessary placement of recipients in institutions (skilled nursing facilities, community care facilities or hospitals). For elderly persons, the focus of supportive services has been to maintain current levels of functioning at home and to slow what is seen as inevitable decline.
- **Types of IHSS Programs:** There are three different IHSS programs: The Medi–Cal Personal Care Services Program (PCSP), The IHSS Independence Plus Waiver Program (IPWP) and The Original or Residual IHSS Program (IHSS–R). The PCSP and IPWP programs are funded with Federal, State and County dollars, while the IHSS–R program is funded with State and County dollars only. Each of these programs provides the same services, but have different eligibility criteria.
- **Eligibility:** Individuals eligible for IHSS services are disabled, age 65 or older, or blind and unable to live safely at home without help and financially unable to purchase needed services. All SSI/SSP recipients are eligible for IHSS benefits if they demonstrate an assessed need for IHSS services.
- **Services:** Through a series of assessments performed by county social workers, IHSS recipients can be authorized for up to 283 hours per month of services, and are authorized to hire their own caregivers.
    - Services may include housecleaning, meal preparation, laundry, grocery shopping, personal care services (such as bowel and bladder care, bathing, grooming, paramedical services, accompaniment to medical appointments, and protective supervision for individuals whose mental status or cognitive functioning poses a threat to their safety and well-being).
- **California IHSS Program Administration:** The program is overseen by the state government, administered in 58 counties, and funded by a combination of federal, state and county dollars. Approximately 99% of IHSS cases are eligible for federal funding which pays for 50% of the costs of those cases.
- **Average Number of IHSS cases in California**: For 2007-08, the average monthly caseload was approximately 389,000 cases. California has a unique long-term care system. Whereas nation-wide, there are 2 people living in nursing homes for every one person who receives long-term care in the home; in California there are three homecare recipients for every nursing home resident. California's per capita Medicaid expenditures on long term care are approximately 1/2 of the national average, in large part, because its long-term care system relies so heavily on home and community-based care.

- **Expected Growth:** Historically the demand for IHSS service has been increasing steadily and will continue in the foreseeable future absent any statutory changes in the program. There will be a growing need for IHSS as the caseload is projected to reach 500,000 consumers by 2012. Focusing on the elderly alone, California has more people who are age 65 and older than any other state, and the number is expected to grow dramatically in the years to come, with most of the growth predicted to occur between 2010 and 2030. By the year 2020, the number of people in California age 65 and older is projected to nearly double to more than 6.5 million. Conservatively, this will represent approximately 14 percent of California's total population. The greatest growth within the older population will be among the oldest Californians, those aged 85 and older.

CALIFORNIA IHSS CMIPS DATA-PROGRAM EXIT

In June 2002, a report titled *In-Home Supportive Services: Recipient Report* was released by California Department of Social Services (CDSS) Data Analysis and Publications Branch. Data used in this report is from the Department of Social Services database generated from the IHSS Case Management, Information and Payrolling System (CMIPS). Monthly CMIPS recipient files from January 1998 through December 2001 were combined to create a full program record for each IHSS recipient, from entry to exit. Because the database can track persons over time, it is possible to determine how long recipients were active in the IHSS Program, how often they exit and re-enter, and how their service needs change over time.

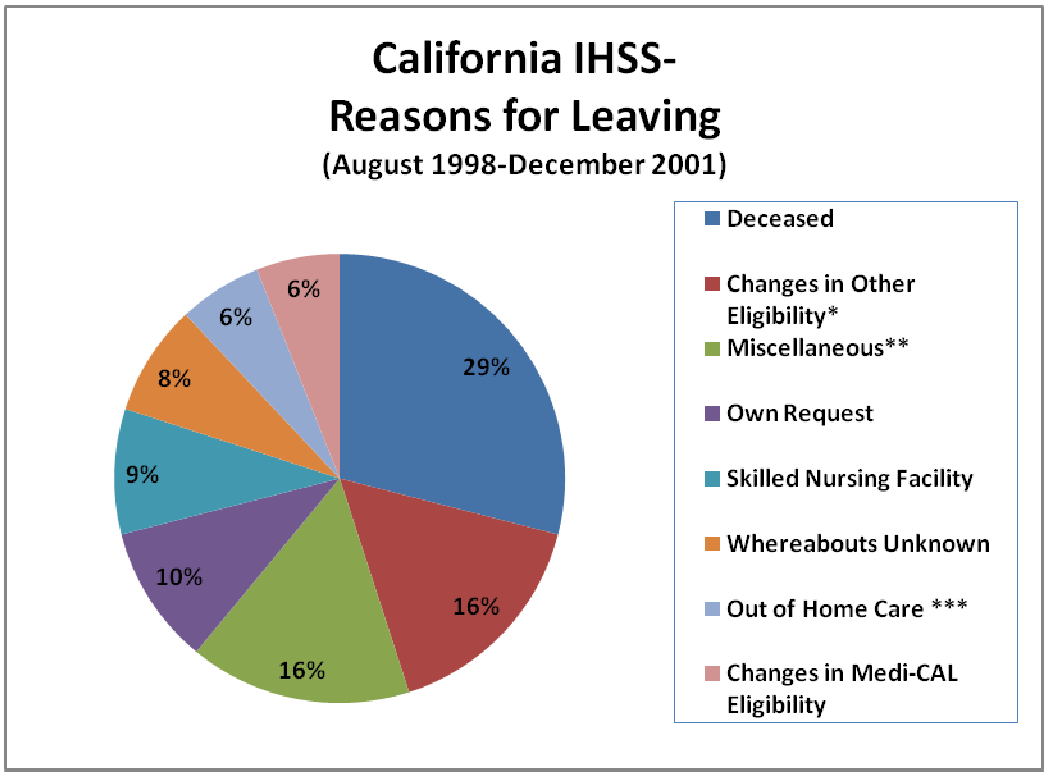
This report includes the demographic characteristics of the IHSS population in December 2001 and in addition tracked recipients longitudinally, reporting on their reasons for exiting the IHSS program. By tracking where recipients go when they leave the IHSS Program, we can determine how many are exiting IHSS to enter nursing home care. We can also track their demographic characteristics, which may predict populations that at a greater risk for institutionalization.

As a reminder it is recommended that caution is practiced when interpreting the data provided below due to an array of variables not reflected. Consider that since data for this report was gathered, there has been about a 60% increase in total IHSS recipients in the State of California (according to the IHSS Management Statistics Summary, 2008). Therefore, in order to draw conclusions from this data set would be assuming that similar data trends continued over the last six years, and the demographic characteristics of recipients have remained fairly constant. Access to a more recent data pull via CMIPS II could provide contrasting data than what is highlighted below.

Available Data:

There were 153,377 recipients who were terminated from the IHSS Program between August 1998 and December 2001. As Figure 1 below displays, the most common reason for recipients exiting the IHSS Program was death (29%), followed by changes in Medi-Cal or other eligibility (22%) and entering out-of home/nursing home care (15%).

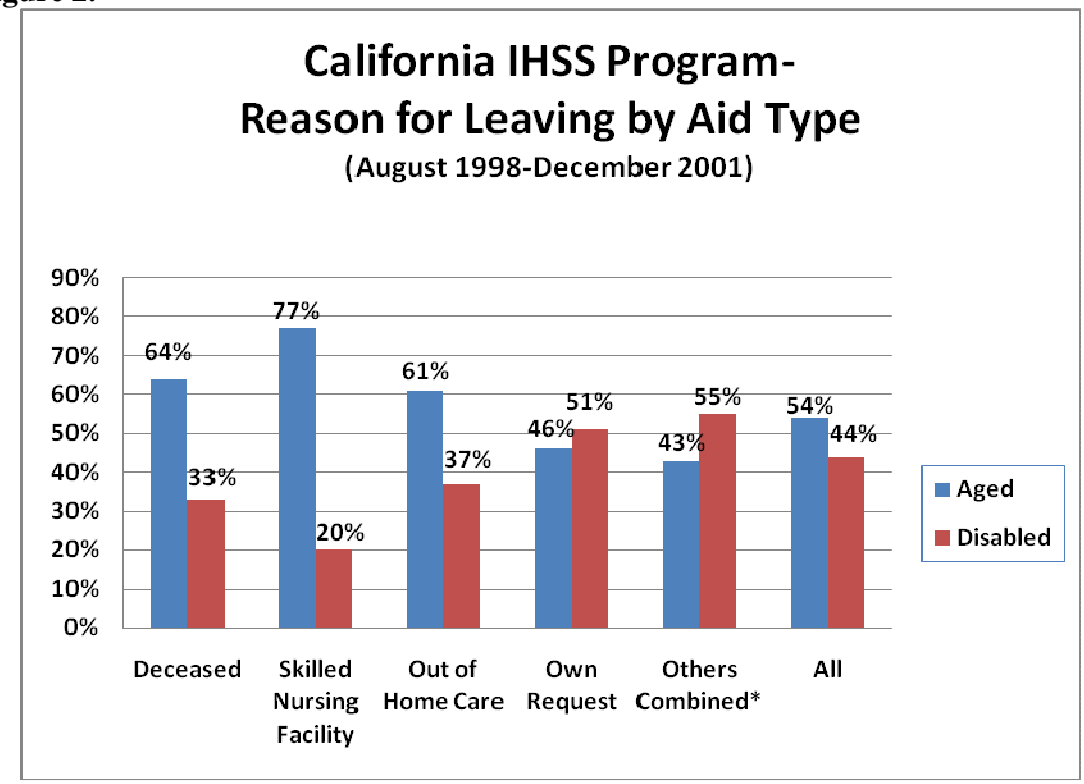
Figure 1.



* Other Eligibility - Includes share of cost changes, board and care, living arrangement changes
** Miscellaneous - Includes County transfers, improper coding
*** Out of Home - Community Care Facility, Intermediate Care Facility, and Hospital

Although Aged recipients were approximately 47 percent of the IHSS population, they represented 54 percent of all the exits. As Figure 2 shows, there was a notable difference between reasons for exit between the aged and disabled IHSS populations. Aged recipients were more likely to leave the program because they died or enter more intensive care, while disabled recipients were more likely to leave of their own accord or for reasons associated with administrative issues such as changes in eligibility. Two-thirds of those that left IHSS due to death are aged.

Figure 2.



* Out of Home - Community Care Facility, Intermediate Care Facility, and Hospital

** Others Combined- Includes share of cost changes, board and care, living arrangement changes, County transfers, improper coding

As Table 1 shows, only one-quarter (26%) of those who left the IHSS Program returned. The recipients least likely to return to the Program were those who moved to a skilled nursing facility (only 11% returned after leaving the program for the first time) or other out -of-home care facilities (only 22% returned after leaving the program for the first time).

The recipients most likely to return are those whose whereabouts were unknown for some period of time or those with 'other' eligibility changes such as living arrangement changes or share of cost changes.

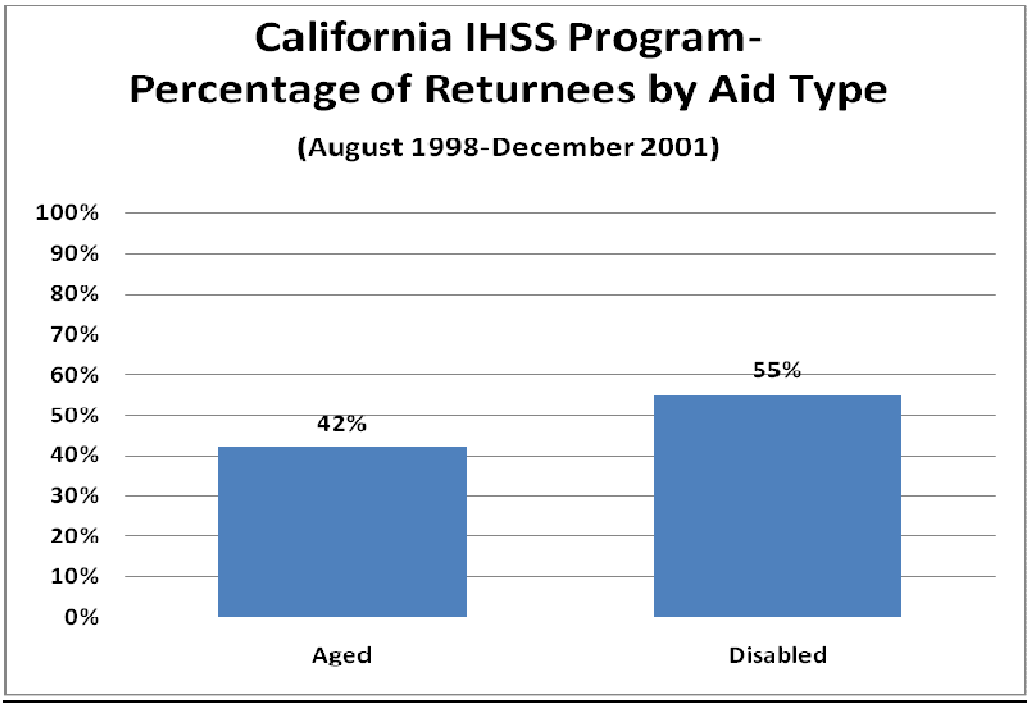
Table 1. Returning Recipients

Reason for Leaving	***Left Program for First Time***	***Number That Returned***	***Percentage That Returned***
Deceased	45,205	0	0%
Skilled Nursing Facility	13,969	1,597	11%
Out of Home Care	9,452	2,120	22%
Own Request	14,889	3,712	25%
Other Combined:	69,862	20,766	30%
Medi-Cal Eligibility Changes	8,684	2,089	24%
Miscellaneous	23,828	4,661	20%
Other Eligibility Changes	24,954	9,120	37%
Wherabouts Unknown	12,396	4,896	39%
Total Exits	**153,377**	**28,195**	**18%**
Total Possible Returnees*	**108,172**	**28,195**	**26%**

**Total possible returnees are the total exits minus deceased recipients.*

As Figure 3 shows, those that returned to the IHSS Program after exiting for the first time were more likely to be disabled than aged.

Figure 3.



VARIABLES THAT INFLUENCE IHSS CONSUMER OUTCOMES

There are a multitude of variables that should be considered when analyzing an IHSS recipient's ability to remain at home. Personal resources such as reliable family members and friends provide a greater opportunity for elderly to remain in their homes and communities. Whether this assistance stands alone or compliments professional services, National Alliance for Caregiving (NAC) and AARP (2004) found that 83% of care receivers identified their primary caregiver as relatives.

Financial resources also play a determining role. The relatively high costs of living and health care can have a detrimental impact for potential IHSS recipients. In 2004, 38.7% of Americans age 65 and over earned an annual income of approximately $18,527 or less (identified as poverty to low income). It is estimated that 40% of their earned income was spent on housing expenditures, leaving limited finances to pay for other necessary expenses. For example, health care was averaged to cost over $12,520 annually and approximately 27.8% of these costs are paid for out of pocket by the poor or near poor as described by the US Census Bureau (Federal Interagency Forum on Aging-Related Statistics, 2006).

The Alzheimer's Association reports that as many as 5 million U.S. citizens 65 and over are living with Alzheimer's disease. Cognitive decline or dysfunction is another challenge facing the elderly. Cognitive or thought disorders may include dementia, psychiatric related, or trauma related (e.g. traumatic brain injury or stroke). Caring for a

person with cognitive limitations can be challenging because, depending on the extent of limitation, it may be unsafe to leave the person alone for any amount of time. Wandering, poor judgment, and memory loss increases risks for ambulating into unsafe situations, over or under medicating, or forgetting about appliances increasing the risk of fires. Goudreau (2006) reported clients who have cognitive limitations are also likely to have difficulty retaining caregivers related to behaviors and difficulty managing the role of employer.

Additional challenges in determining the effectiveness of IHSS are related to the lack of a controlled comparison group. When assessing the determinants of out of home services, it is difficult if not impossible to narrow the contributing factors to one, IHSS. A person's level of physical and cognitive independence, progressive stages and symptoms of medical condition, and access to resources (e.g. transportation) are all determining variables.

HIGHLIGHTS FROM THE LITERATURE: CONSUMER-DIRECTED PERSONAL CARE SERVICES

Impact on Nursing Facility Utilization

1) Dale, SB & Brown R. (2006). Reducing Nursing Home Use through Consumer-Directed Personal Care Services. *Medical Care*, *44*(8), 760-767.

- **Context:** Personal care services (PCS) are intended to enable beneficiaries with physical or cognitive impairments to live safely at home rather than in nursing facilities. The quality and flexibility of these services, typically provided by home care agencies, may not be sufficient to allow some beneficiaries to continue living at home.
- **Objective:** Sought to test whether consumer direction of PCS under Arkansas's Cash and Counseling demonstration reduces nursing facility use and expenditures, compared with traditional Medicaid PCS, and how it affects total Medicaid cost.
- **Design:** Interested adult Medicaid beneficiaries in Arkansas who were eligible to receive Medicaid PCS were randomly assigned (1) to have the option to receive an allowance instead of PCS (the treatment group) or (2) to receive traditional PCS through an agency (the control group). Between December 1998 and April 2001, 2008 beneficiaries enrolled.
- **Measures:** Nursing facility use and costs, PCS costs, and total Medicaid costs (according to Medicaid claims data).
- **Results:** *Nursing facility use was 18% lower for the The Cash and Counseling program treatment group than for the control group during the three-year follow-up period. Similarly, only 11.5 percent of the treatment group spent more than 90 days in a nursing facility over the 3-year post-enrollment period, compared with 14.4 percent of the control group.*
- **Conclusions:** *Consumer-directed PCS in Arkansas reduces nursing facility use and costs more effectively than providing services in the traditional manner.* This favorable reduction in nursing facility costs was much more pronounced in Arkansas than in the other two states (New Jersey and Florida) where the Cash and Counseling demonstration was carried out.

Satisfaction with Care

2) Benjamin, A. E., Matthias, R., & Franke, T. M. (2000). Comparing consumer-directed and agency models for providing supportive services at home. *Health Services Research 35*(1), 351-66.

- **Context:** Intent was to conduct an experiment that would compare California consumer-directed models to agency models for providing supportive services at home. In contrast to the agency-directed model, the consumer-directed model of care, gives the clients control to recruit, train, hire, supervise, and fire the provider of care.
- **Method:** State law mandates that the IHSS program be offered in all 58 counties within California. However, 12 counties exercised an option that allowed them to contract with home care agencies to deliver services to persons judged inappropriate for consumer direction by case managers. Thus, a stratified random sample of 1,095 IHSS recipients was drawn from all 58 counties for the consumer-directed group and from the 12 counties for the agency-directed group.
- **Results:** Controlling for demographics and case mix, *the consumer-directed group was associated with increased consumer satisfaction along five different measures, an increase in a sense of security and a decrease in unmet IADL needs.* No statistical difference was found between the two groups in physical and psychological risk or unmet ADL needs. In addition, consumer-directed clients are at no greater risk than agency clients for worker abuse and neglect of clients (Matthias and Benjamin 2003). Finally, although the young old (65-74) embraced the consumer-directed model more readily than the old old (75+), most service outcomes showed no real differences by age (Benjamin and Matthias, 2001).

3) Carlson, B. Foster, L, Dale, S. Brown , R. (2007). Effects of Cash and Counseling on Personal Care and Well-Being. *Health Services Research, 42*(1), 2.

- **Context:** "Cash and Counseling" is an ongoing three-state demonstration project in which Medicaid enrollees receive a monthly cash allowance to purchase personal assistance and related goods and services. The evaluation of the cash and counseling demonstration has examined effectiveness and costs across the two groups.
- **Objective:** To examine how a new model of consumer-directed care changes the way that consumers with disabilities meet their personal care needs and, in turn, affects their well-being. An evaluation has been undertaken to examine the effects of the demonstration on consumers and their caregivers, public costs, and overall participation.
- **Design:** Eligible Medicaid beneficiaries at least 18 years of age in Arkansas, Florida, and New Jersey volunteered to participate in the demonstration and then these 2,008 enrollees were randomly assigned to to receive an allowance and direct their own Medicaid supportive services as Cash and Counseling consumers (the treatment group) or to rely on Medicaid services as usual (the control group). The demonstration included elderly and nonelderly adults in all three states and children in Florida.

- **Measures:** Telephone interviews administered 9 months after random assignment. Outcomes for the treatment and control group were compared, using regression analysis to control for consumers' baseline characteristics.
- **Principal Findings:** *Treatment group members were more likely to receive paid care, had greater satisfaction with their care, and had fewer unmet needs than control group members who were receiving agency-directed system in nearly every state and age group. The demonstration results from Arkansas indicate that specifically consumers were more satisfied with the timing and reliability of their care, less likely to feel neglected or rudely treated by paid caregivers, and more satisfied with the way paid caregivers performed their tasks. The program also reduced some unmet needs and greatly enhanced quality of life relative to agency-directed services. The program produced these improvements without discernibly compromising consumer health, functioning, or self-care. Within each state and age group, consumers were not more susceptible to adverse health outcomes or injuries under Cash and Counseling.*
- **Conclusions:** *Cash and Counseling substantially improves the lives of Medicaid beneficiaries of all ages if consumers actually receive the allowance that the program offers.*

4) Matthias and Benjamin. (2008). Paying Friends, Family Members, or Strangers to Be Home-Based Personal Assistants: How Satisfied Are Consumers. *Journal of Disability Policy Studies 18*(4), 205 -218.

- **Purpose:** This study describes consumers who hire friends, family members, or strangers as paid personal assistants and compares service satisfaction among the three groups.
- **Method:** Surveyed 511 consumers of self-directed home care services,
- **Results:** The authors found that :
  - Consumers who hire friends as workers are younger and more educated than consumers who hire family members and strangers, and they are more impaired than consumers with strangers as workers.
  - *The friend cohort experiences more stability with their personal assistants than does the stranger cohort but not as much stability as the family cohort.*
  - *Family members, who have some degree of obligation, are more stable workers over time.*
  - *For all three groups the level of satisfaction with care are generally quite high.* One reason may be that all of the home-based service consumers in this sample receive consumer-directed . They have control over hiring and firing their own personal assistants, so there is probably some degree of survival of the fittest among workers because consumers can fire those whom they find unsatisfactory.
- **Implications:** Findings indicate that in terms of service stability and consumer satisfaction, friends are the next best thing to family members as personal assistants. Using friends as paid workers is an important resource. Researchers and policy makers should further explore this approach because the need for home-based personal assistance continues to increase

Appropriateness for Consumers with Mental Illness

5) Shen, C., Smyer, M., Mahoney, K., Loughlin, D., Simon-Rusinowitz, L., & Mahoney, E. (2008). Does Mental Illness Affect Consumer Direction of Community-Based Care? Lessons from the Arkansas Cash and Counseling Program. *Gerontologist*, 48(1), 93-104.

- **Purpose:** Previous research from the Cash and Counseling Demonstration and Evaluation (CCDE) in Arkansas, New Jersey, and Florida suggests that giving consumers control over their personal care greatly increases their satisfaction and improves their outlook on life. Still, *some argue that consumer-directed care may not be appropriate for consumers with intellectual disabilities or mental health diagnoses.* This study examined how Cash and Counseling—a new option allowing consumers to manage an individualized budget equivalent to what agencies would have spent on their care—changes the way consumers with mental health diagnoses meet their personal care needs and how that affects their well-being.
- **Design and Methods:** Using the Arkansas CCDE baseline and the 9-month follow-up data for individuals in the treatment and control groups, compared and contrasted the experience of elderly consumers with and without mental health diagnoses.
- **Results:** Alter examining several outcome measures, including satisfaction with care arrangements and the paid caregiver's reliability and schedule, unmet needs, and satisfaction with the relationship with paid caregivers, this study found evidence that, from the perspective of consumers, *the Cash and Counseling program works well for participants with mental health diagnoses. The authors conclude emphatically that "if a client is mentally ill, it is better for him or her to be in Cash and Counseling than in traditional treatment."*
- **Implications:** Considering the growing need for long-term-care services and the limited resources available, *a consumer-directed option makes sense, and it can be a valuable alternative for persons with mental health needs.*

6) Alakeson, V. (2008). Self-Directed Care for Adults With Serious Mental Illness: The Barriers to Progress. *Psychiatric Services 59*, 792-794.

- There is little evidence about longer-term impacts, but *recent analysis of the program in Florida highlights a promising development: consumers who use self-directed care are more likely to make use of routine and early intervention services and to have less use of crisis units, compared with a matched sample of consumers who do not use self-directed care.*

Potential Limitations:

- **Benjamin, A. E. (2001)** concluded that while older persons are somewhat less enthusiastic about the benefits of self-direction, their expectations and experiences generally mirror those of their younger counterparts. While generational differences seem to be real, older persons are not much different when choices involve daily living, personal services, and home settings. Like others, they prefer to have a say in what is done, when, and how. *On average, however, older recipients may need more outside support in getting started and making consumer direction work.*
- **Murashima, S., & Asahara, K. (2003)** found that home care was effective in reducing the use of institutional long term care when complimented by additional

assistance via family or others. However, the study also found that *home care is limited in that there are some situations that no amount of home care can prevent institutionalization (e.g. poor support system, complicated medical condition).*

- **Horner, B. & Boldy, D. (2008)** found that *some elderly persons may put themselves at risk by trying to stay in there home and avoid care facilities for too long resulting in a need for higher level of care than they would have had they transitioned to a lower level of care facility earlier.* This study further stated that this results in a more difficult adjustment for the person when they did move to a facility.
- **Friedman. et. al. (2005)** found that the *strongest risk factor for being readmitted to a nursing home is following a long-term nursing home stay (30 days or more). Factors predicting institutionalization for community participants included age, instrumental activities of daily living (IADL) dependence, and bowel incontinence.*

CONCLUSION

During the research process various limitations emerged in determining the effectiveness of IHSS at preventing nursing home care. As this report outlines, prior to linking a recipient's transfer to a nursing home setting as a shortfall of the IHSS Program, several other variables need be considered, which at this point have not been adequately studied. While existing research does support that the IHSS Program improves consumer satisfaction, reduces unmet needs, and enhances quality of life, evidence is inadequate to substantiate the efficacy of the California IHSS program at preventing institutionalization. Other nationwide consumer-driven programs with similarities to the IHSS Program are reporting decreases in recipient utilization of skilled nursing facilities and hospitals, which point toward the potential for similar outcomes.

Enhanced data collection, accessibility and reporting systems for aging and disabled Californians needs to be implemented in order for the effectiveness of the IHSS program to be more accurately assessed. In addition, a more in-depth analysis of the emerging promising practices should be pursued (e.g. Cash and Counseling Program, Program of All-inclusive Care for the Elderly-PACE, Money Follows the Person, San Diego County AIS Long-term Care Integration Project). Further investigation of IHSS Program outcomes could lead to more informed program and policy-making, resulting in improved care for this vulnerable population.

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