Testimony for Lisa R. Shugarman, Ph.D.

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Little Hoover Commission

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About The SCAN Foundation: Established in 2008 with the mission to advance the development of a sustainable continuum of quality care for seniors, The SCAN Foundation is the only foundation with a mission focused exclusively on long-term care. The SCAN Foundation is dedicated to long-term care services that keep seniors independent, at home, and in the community. We are taking action to develop and support programmatic and policy-oriented recommendations and solutions that address the needs of seniors and influence public policy to improve the current system.

The SCAN Foundation has three funding priorities:

Funding Priority 1: Public Engagement – to elevate the establishment of a comprehensive continuum of care for seniors as a national priority, and as a state priority for California.

Funding Priority 2: Policy Development – to advance realistic policy options to establish and finance a comprehensive continuum of care for seniors.

Funding Priority 3: Promising Programs – to support the dissemination and assessment of promising new program models that can inform and strengthen long-term care policy development.

The following comments provide a broad overview of long-term care nationally.

What is long-term care?

Long-term care refers to a broad range of services provided by paid or unpaid providers that can support people who have limitations in their ability to care for themselves due to a physical, cognitive, or chronic health condition that is expected to continue for an extended period of time. These disabling conditions may arise from an underlying health condition as is most common among older adults, or can be the result of an inherited or acquired disabling condition among working-age adults, or due to a condition present at birth.

Generally, a person who needs long-term care services requires assistance with activities of daily living (ADLs) - including bathing, dressing, eating, transferring, walking; or instrumental activities of daily living (IADLs) - including meal preparation, house cleaning, medication management; regardless of the cause of their disability. The array of long-term care services may include human assistance, supervision, cueing, and standby assistance as well as assistive technologies and devices that can

substitute for human assistance. The installation of home modifications such as building ramps and grab bars may also be considered long-term care services. Long-term care services are often intertwined with but are generally considered to be distinct from medical care services.

Who uses long-term care?

The number of individuals who use long-term care varies by data source but as many as 12 million people nationally have a need for long-term care due to a physical impairment. This may under-represent the number who need long-term care due to a mental illness or cognitive impairment. Because chronic illness and other physical and cognitive impairments increase with age, older adults use long-term care services in higher proportions than those under 65. Over 60% of those who live in the community and have a need for long-term care are age 65 and older; in California, this proportion is almost 68%. Nationally, almost 82% of individuals residing in institutional settings are age 65 and older, and the proportion of individuals who are in institutional settings increases with age. Among those who need long-term care services and live in the community, approximately 24% are living alone. Women are more frequent users of long-term care, especially paid long-term care.

Growing demand for long-term care

Given that older adults, particularly those over age 85, are more likely to use long-term care services than younger people, we can expect that the population in need of long-term care will grow substantially in the coming years. In 2011, the largest generation in history – the baby boomers – will start turning 65, resulting in a rapid increase in the number of older Americans in the United States. In California, the number of individuals age 65 and older is projected to increase 90% in the next 20 years (from 4.64 million in 2010 to 8.84 million in 2030). The largest increase in the population of California seniors will be among those 85 and older; between 2010 and 2030, this population will increase by over 200%. Working age adults with disabilities in California currently number approximately 480,000; this population is anticipated to increase by 20% to 550,000 by 2030.

Where are long-term care services provided?

Long-term care services can be provided in a variety of settings including one's home (as with home care services), in the community (as with adult day care/adult day health care), in residential settings (as with assisted living or board and care homes), or in institutional settings (as with nursing homes). Although the definition of long-term care generally excludes medical care services, some highly technical services that were traditionally provided in the hospital may now be provided in the home or in the nursing home alongside the traditional support with ADLs and IADLs, which has resulted in the blurring of the line between long-term care and medical care.

Who provides long-term care?

Long-term care services can be provided by paid providers or unpaid caregivers, most often family members. Approximately 87% of those who need long-term care get that

care from unpaid caregivers. There are 65.7 million unpaid caregivers nationally; 43.5 million of these unpaid caregivers provide care to adults age 50 and older. In California, approximately 16% of all households contain at least one caregiver for someone age 50 and older. The majority of unpaid caregivers in California are family members (85%) and almost half of unpaid caregivers are caring for a parent.

Among community-residing individuals in need of long-term care, only 13% rely on care from paid helpers; older adults are much more likely to rely on paid helpers than younger adults (18% vs. 7.8%). Between 70% and 80% of paid long-term care is provided by direct care workers (DCWs); this includes nursing assistants, nursing aides, home health aides, personal aides, and home care aides. Approximately 46% of DCWs work in institutional settings, the remainder work in home and community settings.

Who pays for long-term care?

Total spending on long-term care was $231 billion nationally in 2006. Approximately 65% of all long-term care costs are publicly funded through either Medicaid (Medi-Cal in California) or Medicare. Medicaid is the largest payer of long-term care services; 43% of long-term care payments nationally were made by Medicaid. Medicare does not cover the costs of custodial long-term care. Still, Medicare post-acute care services may help individuals with long-term care needs, such as transitions from the hospital into a nursing facility or back into the home; 18% of long-term care spending (home health and skilled nursing home care) is covered by Medicare. It is critical to note that 8.8 million individuals nationwide are eligible for both Medicare and Medicaid services, complicating the payment picture for these "dual eligibles."

Approximately 35% of long-term care services are privately financed. Out-of-pocket payments by individuals and their families are second only to Medicaid at 28% of total long-term care payments. Private long-term care insurance covers a modest 7% of total long-term care payments. The value of unpaid caregiving is substantial – approximately $350 billion in 2006; if factored into total long-term care spending, the value of unpaid caregiving would increase the total cost of long-term care by 150%.

National policy environment

Historically, nursing homes have been the primary setting for long-term care services. Medicaid was and still is the dominant payor of custodial nursing home care. In fact, states are required to cover the costs of nursing home care for Medicaid beneficiaries but there is no similar requirement for states to cover home- and community-based services (HCBS). These services are considered optional benefits. Still, consumers prefer to remain in their homes and communities. Beginning in the 1980s, HCBS began growing as a proportion of Medicaid spending. Some benefits are offered through each state's Medicaid State Plan but the majority of HCBS spending growth occurred through Medicaid waivers.[1]

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[1] Medicaid waivers allow the state to limit services to specific Medicaid populations, limit services to specific geographic regions, or expand Medicaid eligibility to allow others to access services who would not be eligible under the State Plan benefits.

In 1999, the U.S. Supreme Court decision in *Olmstead v. L.C.* affirmed that people with disabilities should not be forced to reside in institutional settings and that they should have reasonable access to services in the least restrictive environment. Multiple responses to Olmstead have lead to increased access to HCBS across states. Among the federal efforts to improve access to HCBS are the Real Choice Systems Change Grants – the federal government has made over 300 grants across the states and territories to enable them to build the necessary infrastructure to improve HCBS.

Current challenges

System Fragmentation: One of the major challenges facing seniors and people with disabilities in the current health and long-term care systems is the fragmentation of funding and service delivery. For example, in California, among those dually eligible for both Medicare and Medi-Cal, Medicare covers hospital, medical, skilled nursing, pharmacy, and mental health benefits. Medi-Cal covers services that serve as a "wrap-around" to Medicare offerings, such as custodial nursing, and home- and community-based services. Home and community-based service offerings for Medi-Cal beneficiaries include In-Home Supportive Services (IHSS), Multipurpose Senior Services Program (MSSP), Adult Day Health Care, AIDS case management services, care management, and information and assistance services. Depending on the county in which a beneficiary resides, these services may be administered by a single agency (e.g., San Mateo's Aging and Adult Services) or located in different agencies.

The resulting fragmentation in financing, administration, and oversight of the myriad of services available inevitably leads to fragmentation in the care of Medi-Cal beneficiaries. Dual eligible beneficiaries (eligible for both Medi-Cal and Medicare) are even more challenged in navigating the various systems as the result of having to manage different payors of services.

Each payor and program has its own information system and the various home- and community-based services each have their own assessment system. Multiple assessments further burden beneficiaries and create significant challenges for care coordination across programs. The lack of a uniform assessment tool, which could be used to determine eligibility and care plans across programs, creates significant inefficiencies in the system. There is no easy way to understand who is being served across these programs, what are the total costs of care, and how best to plan for the needs of the long-term care population.

Challenges for the Middle Class: One of the other major system-wide challenges is access to a range of services for the near-poor and middle class, as eligibility to most programs is restricted to those with the lowest income levels. There are few good choices for the non-poor who need services and few tools other than LTC insurance to help prepare for long-term care needs. In the absence of comprehensive long-term care financing and the low utilization of often costly private long-term care insurance policies, many now middle-class baby boomers will be unable to pay for their long-term care. The few protections that do exist currently for the middle class are only available for those in nursing homes and not for those receiving HCBS.

What might a high-performing long-term care system look like?

Ultimately, the goal of the long-term care system is to enhance the well-being and quality of life of individuals who experience functional or cognitive limitations because of a chronic illness, accident, or other causes of disability. There are several characteristics of a state's long-term care system that can make it a "high-performing" system. These characteristics were identified by a panel of national long-term care policy experts and are something to strive for when considering public policies that affect the organization, delivery, and financing of long-term care services. We believe a high performing long-term care system is one that:

1. Is person-centered;

2. Is of high quality;

3. Is efficient and provides high-value care;

4. Supports family caregivers;

5. Ensures access to care for all who need it; and

6. Is integrated with the larger health care system.

Models and Opportunities to Integrate Medical and Long-Term Care Services

Examples of current efforts to improve the long-term care system focus on integrating services with medical care. This approach is vital for the most vulnerable population in the current fragmented system: dual eligible beneficiaries. Of the nearly 9 million dual eligibles in the country, over 1 million reside in California. Duals make up only 13% of all Medi-Cal enrollments but comprise 47% of Medi-Cal spending. Integrating care for dual eligibles offers an important opportunity to improve care and control health and long-term care costs for this population.

Selected Medicare Advantage plans known as Special Needs Plans (SNPs) offer an opportunity to coordinate care for dual eligibles paid for by Medicare and Medicaid along with other benefits. Minnesota (Minnesota Senior Health Options – MSHO) and Texas (Texas Star+Plus) serve as examples of SNP plans that integrate long-term care services with traditional Medicare and Medicaid services in a capitated system.

The Program for All-Inclusive Care for the Elderly (PACE) is yet another example of successful integration of Medicare and Medicaid funds and services for dually eligible adults who meet a nursing home level of care eligibility criteria. There are several PACE programs across California, with several more in various stages of planning and development.

Opportunities to improve linkages between medical and long-term care services are apparent in the current health care reform discussions. Models such as accountable care organizations, medical homes, pilots to bundle acute and post-acute services, and care coordination demonstration concepts offer promise to expand beyond a narrow medicalized scope of practice toward connecting older adults in need of long-term care to supportive services their community. These models also offer an opportunity to

expand care coordination efforts to improve health-related outcomes beyond the acute and immediate post-acute care episode by including active engagement with the HCBS provider community. Several programs around the country seek to coordinate delivery and financing of HCBS with medical services to help prevent health complications in older adults and mitigate common causes of costly re-hospitalizations. Supportive services could include Medicaid-funded personal care services and care management, services provided by Area Agencies on Aging and Aging and Disability Resource Centers, and/or services provided by faith-based organizations and other private entities.

For those in the middle class who are not eligible for Medicaid, the promising models of care described above may be out of reach. As mentioned previously, private long-term care insurance products may also be out of reach for the majority of the middle class. In addition to the elements described above, the current health care reform discussions also revolve around a new public long-term care insurance program (CLASS Act), which could keep those in the middle class from becoming impoverished in order to obtain needed long-term care services.

LTC Reform in California

The issues and challenges confronting California's LTC system are many, as will be outlined in the accompanying testimony by Sarah Steenhausen, also from The SCAN Foundation. Any effort to reform California's system needs to be understood in the broader national context. By understanding both the national and state-level issues that impact the LTC system, the Little Hoover Commission is well-positioned to examine options for reform and system improvement.

Project Summary: The Comprehensive Analysis of Home and Community-Based Services Project

Co-Funders:

JANUARY 2010

SUMMARY

The Comprehensive Analysis of Home and Community-Based Services (HCBS) in California is a 36-month project to conduct the first comprehensive review of all HCBS in California. Funded by The SCAN Foundation and the State of California Department of Health Care Services (DHCS), researchers with the California Medicaid Research Institute (CaMRI) located at the University of California San Francisco (UCSF) will conduct three research tasks:

(1) a review and summary of the published research on cost-effectiveness of home and community-based services;

(2) a comprehensive analysis of the utilization and cost information for Medi-Cal beneficiaries receiving home and community-based services in California; and

(3) an analysis of the costs and utility of home and community-based service benefits provided under Medi-Cal via federal waivers and the State Plan.

The research will inform HCBS-related policy by providing information on how HCBS: prevent or delay institutionalization, reduce the use of emergency rooms services and hospital admissions, and improve or maintain a person's quality of life. In addition, this project endeavors to provide insight on the cost-effectiveness of programs and services, identifying which of these are the most essential to consumers.

Research Task #1 - Literature Review

The initial phase of the project will include a systematic review of the published literature on the use of home and community-based services and effective practices in their delivery. A starting point for this review is the perspective that health care and long-term care services and practices constitute a continuum of care that is highly compartmentalized. These compartments are varyingly defined by the setting (e.g., hospital, nursing home), the provider (e.g., primary care physician, social worker), the body system or disease (e.g., dementia, congestive heart failure), or the severity of the conditions (e.g., levels of functional limitations, nursing home level of care thresholds, stages of chronic or terminal disease). Compartmentalization has been reinforced by policy makers for funding purposes and in turn has influenced the means of publicly financing and regulating these different levels and types of care.

The literature review, drawing on California and other state experiences as well as national demonstrations and evaluations, will describe recent trends in service delivery approaches and place them into the context of a continuum of care across the different services and settings considered. The researchers will also review the literature addressing the question of how to appropriately and safely transition individuals from

institutional settings back to the community. Finally, the review will identify examples of efficacious and cost-effective care as well as identify factors contributing to the failure of some approaches addressing the safe transition of individuals back into community settings.

Research Task #2 - Analysis of Utilization and Cost

The second phase of the project will examine health and long term care utilization and costs for Medi-Cal beneficiaries over a four-year period (January 2005-December 2008). The analysis will cover seniors and people with disabilities, but will be conducted separately for those over and under the age of 65. Within each age group, the research team will compare the utilization and costs of acute, primary, and long-term care and other services for those who are enrolled in HCBS waivers, In-Home Supportive Services (IHSS), and Adult Day Health Care (ADHC) with age-matched recipients who are not in enrolled in these programs. Using a merged dataset, CaMRI will conduct a series of analyses that will attempt to answer a range of questions about service use and outcomes, with a specific focus on cross-sectional and longitudinal comparisons.

Cross-Sectional Analysis of the Effectiveness of HCBS

Building on the descriptive information obtained in the analyses described above, this component of the project will examine the factors associated with health care and other Medi-Cal/Medicare expenditures. The specific goal of this component is to look across the range of programs and make comparisons between those persons receiving HCBS and those receiving institutional long-term care services (e.g., nursing homes).

Longitudinal Analysis of the Effectiveness of HCBS

This next component will be an analysis of four years of linked Medi-Cal and Medicare data to look at the outcomes over time for seniors and people with disabilities, across the programs and services they have used during specified time periods. This component of the project examines patterns of person-specific service use over time, and the extent to which these patterns are associated with HCBS participation.

Transitioning Beneficiaries from Nursing Homes Back to the Community

In this study component, CaMRI will evaluate data reflecting current practices for transitioning Medi-Cal nursing home residents back to the community appropriately and safely. The Department of Health Care Services will identify Medi-Cal beneficiaries who have been residents of long-term care facilities and who have successfully transitioned to home or community environments. Three programs provide the majority of transitions: the Assisted Living Waiver, the Nursing Facility/Acute Hospital waiver (Senate Bill 643, Chapter 551, Statutes of 2005), and the California Community Transitions "Money Follows the Person" demonstration. Initially, transitions between long-term care facilities have been rare, but it is expected that the incidence of these transitions has grown over the evaluation time period. Starting in the second year of the research project, linked Medi-Cal, Medicare and OSHPD data for seniors and people with disabilities will be conducted to identify the types, intensity and costs of services used while institutionalized, and during and after transition. The utilization data will be explored as possible sources of information for determining what services were most effective in securing and maintaining community living arrangements.

Research Task #3: Analysis of HCBS Benefits Packages

The goal of this task is to synthesize the results from the analyses as outlined above and to make recommendations informed by the data regarding service benefit packages that may reduce costly

utilization such as emergency room use and hospitalization.

Using data from the approved Medi-Cal HCBS waivers operated in California, the research team will analyze the benefits allowed under each waiver to determine differences and gaps between the waivers. This analysis will specifically attempt to determine whether benefit packages could become more standardized or whether they need to be modified. Researchers will also compare funding mechanisms, including the use of capitated payments, to understand their impact on cost and utilization. A fundamental question is whether the waivers could be streamlined or merged in ways that reduce complexity and increase cost savings while improving utilization, outcomes, and satisfaction.

POLICY DISCUSSION

The State of California DHCS developed a set of key policy questions to guide the CaMRI research. While not meant to be exhaustive, these questions reflect current policy concerns.

- What HCBS programs prevent or delay a person's placement in a long-term care facility?
- What HCBS programs reduce a person's use of emergency room services and hospital admissions?
- What HCBS programs improve or maintain a person's health status and lead to better health outcomes?
- What is the cost-effectiveness of HCBS programs?
- Given current budget constraints, what HCBS services or programs are most essential for supporting seniors and persons with disabilities in community environments? What HCBS services or programs are less essential?

In addition to the above overarching questions, CaMRI will explore specific programmatic and policy questions such as:

- Are there significant differences in the type, scope and duration of services provided depending upon the population served?
- Are these differences in service type, scope and duration based upon the level of need, availability of service providers, structure of the service delivery system, or other factors?
- Are there significant differences in health outcomes depending upon the population served? Upon the type, scope and duration of services provided? Upon the service delivery system?
- What are the factors that drive and influence health outcomes, and to what degree do they contribute to them?
- How well do the different programs and delivery systems for HCBS deliver services to specific populations? Are there differences based on geographical settings?
- Can a particular program or delivery system be successfully replicated to serve different populations? Can the success be replicated in different geographical areas?

State and local policy makers (such as boards of supervisors or city councils) and program administrators (such as the Area Agencies on Aging) are currently wrestling with these questions and trying to decide what level of HCBS service and payments they can continue to maintain given California's economic crisis. They are searching for and often not finding reliable data and analytical information to guide their decision making. As important as comprehensive data and analysis is to present-day decision making, it will be equally, if not more so, critical to future decisions about which HCBS programs or delivery systems should be restored and/or expanded at both the state and local

levels. This project will provide policy makers and program administrators with the breadth and depth of data and analytical information that they will need to face these challenging decisions well into the future.

Department of Developmental Services, Department of Mental Health, Department of Public Health, Department of Rehabilitation and the Department of Social Services.   www.chhs.ca.gov

ABOUT THE GRANTEE

The California Medicaid Research Institute (CaMRI) is a University of California multi-campus research program hosted at the University of California San Francisco (UCSF) and directed by Professor Andrew Bindman, MD. Through a multi-year interagency Master Agreement with the California Department of Health Care Services (DHCS), CaMRI provides research and analytic expertise to Medi-Cal that is grounded in data and focused on health policy. Negotiated projects between the University of California and DHCS are intended to strengthen Medi-Cal's analytical foundations for policy setting while advancing the University's research, training, and public service missions.

ABOUT THE PARTNERS

The California Health and Human Services Agency (CHHS) oversees twelve departments and one board that provide a range of health care services, social services, mental health services, alcohol and drug treatment services, income assistance and public health services to Californians from all walks of life. CHHS also directly manages the federally-funded California Community Choices project to promote systems change and better insure that seniors and people with disabilities are diverted from unnecessary institutionalization. While the Department of Health Care Services is the State's single Medicaid agency, many of the departments within CHHS administer Medi-Cal waivers that support home and community-based services for seniors and people with disabilities. These departments are also engaged with this study: California Department of Aging,

ABOUT THE FUNDERS

The SCAN Foundation, located in Long Beach, CA, is an independent nonprofit dedicated to advancing the development of a sustainable continuum of quality care for seniors that integrates medical treatment and human services in the settings most appropriate to their needs and with the greatest likelihood of a healthy, independent life. The SCAN Foundation supports programs that stimulate public engagement, develop realistic public policy and financing options, and disseminate promising care models and technologies. www.thescanfoundation.org

The Department of Health Care Services' (DHCS) mission is to preserve and improve the health status of all Californians. DHCS works closely with health care professionals, county governments and health plans to provide a health care safety net for California's low-income and persons with disabilities. www.dhcs.ca.gov

For more information on The Comprehensive Analysis of Home and Community-Based Services in California project, please contact Kali Peterson at (562) 308-2867, kpeterson@thescanfoundation.org or Paul Miller of the Department of Health Care Services at (916) 440-7534.