CONGRESS OF CALIFORNIA SENIORS

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Remarks of Gary Passmore to the Little Hoover Commission
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Thank you for the opportunity to participate in your timely review of long-term care in California.

My views are based on eight years of experience dealing with the issues and concerns of California seniors as Director of the Congress of California Seniors (CCS), a statewide advocacy and outreach organization in operation since 1977. Over the years, we have been engaged in a number of coalitions and legislative initiatives to create a strong, well-organized system for delivering long-term care to hundreds of thousands of seniors and people with disabilities. The work has been challenging and is, still, far from complete. During the 30+ years of CCS, public attitudes about long-term care have changed considerably, although there is still a widespread lack of understanding about what long-term care is and how it is financed.

A recent study by the SCAN Foundation revealed that a solid majority of Californians assume long-term care costs are covered by Medicare (which they are not) and that many will require long-term care services at some point in their lives. Conversely, fewer than ten percent of people have long-term care insurance to meet these costs. Most studies show that Californians have almost no understanding of the costs of long-term care and have never planned to pay for care. Most of us don't want to think about being old, especially being very old and dependent.

In my experience, most policymakers come to office with the same lack of knowledge as their constituents. Too often, they have a mental picture of a nursing home that is decades out of date…that of a "rest home" where people are often discarded and in isolation from their families and community. They have little understanding of the large number of assisted living arrangements that have emerged in recent years (which, by the way, are largely unregulated by the state). And they have unrealistic ideas about homecare services, believing that family members can and should care for their senior members.

Today, we are battling the notion that homecare should only be for people who are nursing home eligible. But this has little to do with the reality of today's nursing homes. The average stay in a nursing home is under three months and most nursing home stays are around thirty days. Nursing homes care for a few people in the very late stages of life, or provide rehabilitative services for people following a stroke, a hip replacement, or the like. Most long-term residents of skilled nursing facilities are those with very advanced Alzheimer's disease or dementia who need around-the-clock supervision. People who need assistance with daily living skills like dressing, bathing or cooking

meals… or help taking medications… do not belong in a nursing home, but will surely end up there if we narrow the scope of In-Home Supportive Services.

To argue that families need to care for dependent elders is to propose rolling back four decades of social and economic change in which nearly every household with two adults finds both of them working full time, some with more than one job. We all enjoyed “Father Knows Best,” but none of us live that way. California’s In-Home Care program has been an innovator in helping those family members who are able to stay in the home and draw a modest income by providing home-based care for a dependent family member. The majority of people with Alzheimer’s disease or dementia – between 70 and 80% – are cared for by family members and are not part of any public program. In my experience, most families who can, still do take care of dependent members, whether elderly or disabled.

The state has, in recent years, undertaken a thorough study to match needed services with appropriate time allocations, and set standards of service that are applied statewide, so people in San Diego get the same level of care as those in Butte County. We have implemented quality assurance measures to minimize waste. And reports of fraud are highly exaggerated.

Proposals for limiting service are an understandable response (if inappropriate) to the new demographic realities facing California and most other states in the coming decades. I am sure you have all been given the numbers: we will grow from 4.5 million seniors to over ten million seniors in the coming generation. These large numbers threaten to overwhelm our system and financial capacity. The fastest growing age cohort in California is people over 85, so the demands are increasing. We are dealing with the fact that medical science has been able to extend life by many years, but has not figured out how to make those additional years ones of self-sufficiency and independence. We live longer, but too often, only with assistance in daily living and support.

These demographic trends have collided with another, more recent, challenge. Between September 2007 and September 2009, California’s millions of baby boomers lost 49% of their wealth. They have lost retirement savings, they have lost home equity, and many are losing their jobs, their health care and their employer retirement benefits. Very few have sufficient years to rebuild. A recent report on line says that the big loser from this economic calamity is people’s retirement planning, which includes savings for long-term care.

So what do we do about long-term care? The state is broke. The number of people needing long-term care is getting ready to explode, most people have not prepared and those who did have seen their plans blown up.

I have five suggestions and we should probably do them all.

First, we need to strengthen the ability of families to continue to care for their dependent members. Actions by state government to cut or eliminate Caregiver Resource Centers or Alzheimer’s Day Care Resource Centers are short sighted and wrong headed. Care giving families need training, they need respite, and they need targeted help to keep doing this important job. The need will grow as the population grows and the old become older and more frail. Helping family caregivers is probably the most productive use of state funds there is. Although not direct caregiver support, the Adult Day

Health Care programs and the Adult Day Care services fall under this same rule…efficient support programs to help keep very vulnerable people in the community and out of costly care. We should not even think of eliminating these services…we should be expanding them. A recent report commissioned by CCS and conducted by the Lewin Group shows that the governor's plan to close down Adult Day Health Care wouldn't save a dime, but would rather cost taxpayers more than $50 million in new or shifted costs in the first year alone. The state should go further in helping family caregivers by looking at new tax credits to encourage and support such care.

Second, we need to take advantage of new opportunities to build community-based, long-term care services embodied in the recently enacted national health care reform legislation. The CLASS Act portions of the new law, which is the final great idea of the late Sen. Ted Kennedy, will create a voluntary program encouraging those not yet retired to invest in affordable long-term care assistance which can be client directed to a variety of community and institutional services. The program will be a costly new federal obligation, but it is voluntary and it will reflect the first significant federal investment in long-term care since Medicaid. The state should build mechanisms to promote worker savings in the new insurance, and build the revenues generated into future plans for financing long-term care. This insurance will not be available for at least five years which gives California time to plan to promote it and make it as widely available as possible.

Third, as the state recovers its financial footing, it needs to discover new ways to help more people meet the costs of long-term care. Today, most of the assistance is available through the Medi-Cal health insurance for low-income people. The new expansion of coverage of Medi-Cal authorized under health reform specifically excludes increasing the income eligibility for people over 64. California should begin the long process of convincing the federal government that more older people should be able to qualify for long-term care under an expanded Medi-Cal eligibility up to 133% of the federal poverty level. This would make billions more federal dollars available to help people who are just above poverty pay for long-term care.

Fourth, California should once again lead the nation in innovation in delivering long-term care and community support services. Under the newly proposed Medi-Cal 1115 Waiver, we will be mandating that seniors and persons with disabilities receive medical care through a system of managed care where that is available. There have been stakeholder discussions about how to extend this coverage to the 1.1 million seniors and people with disabilities who are dually eligible for Medicare and Medi-Cal. We believe that one essential ingredient that has been missing is creating stronger coordination between medical care and those psycho-social and behavioral services which many older people need.

We would hope to see the state innovate in creating seamless systems of acute and long-term care for senior and disabled people. This is often the reality as people in IHSS or nursing homes go in and out of the hospital and from home to doctor as health deteriorates or chronic diseases become more complex. Care managers of the entire care needs of this population should be put in place rather than have care offered and negotiated separately. An 85 year old woman with limited income, diabetes, and early-stage dementia should have her care and services coordinated in a way that recognizes all her needs, and is driven by a unique plan of care which she and her family believe can maximize her functioning and quality of life. She may need domestic care services as much as she needs her

diabetes medicine, and she may need to live in a setting where someone can manage her medicine and make sure her bills get paid on time.

Finally, we believe that we need to re-think how we organize to provide support for our dependent citizens. We believe that the fractured organizational structure of state services and programs impedes good decision making and coordination of services. Most citizens are overwhelmed trying to discover and coordinate all the services and eligibility requirements of programs. So, too, are policymakers who cannot see the full costs of serving the same population through the state budget with programs split among four of five state agencies. They do not realize that Adult Day Health Care programs are monitored by four separate state and regional agencies. Policymakers cannot make important judgments about the right balance between funding for income assistance, community care, community services, and institutional care. We should reorganize at the state level and at the local level.

Just as important, our private and non-profit providers need to move out of thirty-year-old structures and redesign themselves for the needs of the “silver tsunami.” We need to rethink licensure requirements and funding streams so nursing facilities can begin to meet the health care needs of people living in their communities. Some nursing homes in rural California should become the medical homes for seniors and people with disabilities in Medi-Cal. Some should operate Adult Day Health Care. People living at home should be able to go to a skilled nursing facility for physical therapy on an outpatient basis. Doing so would break down the fear and stigma about nursing homes and make more efficient use of provider resources.

I am in the first wave of baby boomers. When I entered public school, I don’t remember cutting back to three-day-per-week schools. I don’t remember calls to cut teacher pay to the minimum wage. I don’t remember policymakers calling for Hobson’s choices between children and their grandparents. I remember that we found the political will to build new schools, train new teachers in new colleges, and hiring more staff. We are the same people who entered school in the early 1950s and now we are entering a new phase where many will need quality, available and affordable long-term care. We need to find the same political will to meet this challenge that we always have.