

Aging safely at home? California's disabled elderly are barely holding on

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The network of public services that supports California's low-income, disabled elderly is fragile, affecting the ability of these vulnerable residents to live independent lives in their own homes, according to a new study from the UCLA Center for Health Policy Research.

This policy note reports the first findings from a yearlong effort to follow the lives and challenges encountered by several dozen representative older Californians in Los Angeles, San Diego, San Francisco and Santa Clara who are enrolled in [Medicare](#) and Medi-Cal and who receive in-home and community care.

The documentary project comes as California lawmakers consider additional cuts to a network of services that help seniors remain "safely in their homes" — the stated goal of these public programs and the way in which an overwhelming number of Americans say they want to age.

The policy note, "Holding On: Older Californians with Disabilities Rely on Public Services to Remain Independent," shows seniors struggling to live functional lives in the face of already reduced caregiving hours. For example:

Caring for the caregivers

Sara cares for her disabled son and husband, whose heart disease, diabetes, incontinence and limited mobility require 24-hour care. There's

help from In-Home Supportive Services (IHSS) and other family members, but Sara is the primary caregiver. Now, her back is acting up. She's been delaying seeing a doctor to take care of her own needs — who will care for her family if she's hospitalized?

Delicate balance

Paralyzed by polio, Mary breathes with the help of a ventilator and gets around in a wheelchair. She needs help to dress, bathe, use the toilet and eat. She's created an elaborate system to meet her needs, using maximum IHSS hours of support and offering room and board to another caregiver in return for care. Mary's happy with her life and rates her health as "excellent," but she knows that even a small change in the delicate balance of her care system will send her to a nursing home.

His choice

Incapacitated by stroke and diabetes and confined to a wheelchair, Jack spent time in a nursing home a couple of years ago, and he's not in a hurry to go back. In the nursing home, he felt unsafe and more isolated than he does in his own house with support from IHSS. Jack's a realist. He knows a nursing home may be in his future again, but he wants to choose when and where he'll go.

According to the researchers, all participants in the study are aware that the networks of care they've cobbled together could easily unravel, and most say they'd rather "make do" by eating less often, letting their homes become less safe or allowing their medical conditions to worsen than give up their independence and go to a nursing home — the likely scenario if they lose the in-home services they now rely upon.

"These seniors are using every sort of innovation and self-deprivation to

make do," said Steven P. Wallace, the study's senior author and associate director of the UCLA Center for [Health Policy Research](#). "They have nowhere to turn if their fragile care systems are further undermined.

"Policymakers need to see the faces of these vulnerable Californians as they crunch the numbers in budget discussions," Wallace added.

"Further cuts are an assault on their independence. Slashing in-home and community care will also increase total health care costs as these seniors increasingly use emergency room care, are hospitalized or enter institutions — under conditions that could have been prevented."

Budget cuts looming

California, which is home to the largest number of older adults in the country, has several programs funded by federal, state and local dollars to assist low-income adults with disabilities. Proponents of these programs say that while such care isn't perfect, it is far less expensive and more humane than the alternative — placing seniors in publicly financed [nursing homes](#).

Yet, IHSS program-hours were trimmed by 3.6 percent in January 2011, and they face further across-the-board cuts of 8.4 percent, plus additional targeted reductions in the governor's proposed budget. Adult day health care centers are slated for elimination, and supplemental security income cash benefits are to be reduced for single low-income aged and disabled individuals.

All the older adults in the study receive IHSS support, ranging from 20 hours of in-home help each month to the maximum of 283 hours per month. Most need help with household tasks, such as cleaning and cooking, and personal tasks like getting dressed or taking medications. Many require help getting in and out of bed, bathing and using the toilet. Some who might benefit from adult day health care or other supportive

programs are unable to participate because of limited mobility or lack of transportation.

"California's current system to support old and young adults with disabilities at home operates in silos and is not person-centered," said Bruce Chernof, M.D., president and CEO of the SCAN Foundation, which is funding the study. "The Brown administration has an important opportunity to design a more stable, integrated, efficient and person-centered system that can meet the needs of these vulnerable residents throughout the state."

Provided by University of California - Los Angeles

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