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Holding On: Older Californians with Disabilities Rely on Public Services to Remain Independent

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SUMMARY: Low-income older adults with disabilities in California depend on a variety of public programs to help them remain in their own homes. Last year's state budget reduced the amount of support provided by these programs,¹ and the proposed 2011–12 budget reduces them further.² This policy note provides the first findings from a study that is following a group of California seniors who depend on fragile arrangements of paid and unpaid help to maintain their independence. The analysis finds that the disability needs of these older adults are often unstable, with both their physical and mental health status sometimes changing day to day. Many of these older adults with disabilities have nowhere else to turn for assistance if their public services are cut. Interviews with people in this group have shown that they are commonly in poor physical and/or psychological condition and are just barely managing to live safely in their homes. At the same time, all of them share the common goal of remaining in their homes and maintaining their independence. Public services serve as a crucial link in the support networks of these individuals.

California is home to the largest number of older adults in the country. A sizeable number have incomes so low that they qualify for Medi-Cal and also have disabilities severe enough that they need assistance in order to live safely at home. Several programs assist low-income older adults who have disabilities. Among the largest of these programs are the In-Home Supportive Services Program (IHSS), which pays for personal care assistance, and Adult Day Health Care (ADHC), which provides therapeutic services for seniors and respite for their families, the Multipurpose Senior Services Program (MSSP), which provides enhanced case management and supplemental services, and Meals on Wheels, which provides home-delivered meals.

This policy note provides the first findings from a study of low-income older adults in California who receive Medicare and Medi-Cal, have disabilities, and receive at least IHSS services. The study, Helping Older-adults Maintain Independence (HOME), is designed to investigate the ways in which low-income older Californians use home and community-based services (HCBS) to remain “safely in their own homes” – the stated goal of HCBS services. Our initial analysis of in-depth interviews with older care recipients, their paid caregivers, and their family members shows that the needs of older adults with disabilities are often unstable and changing, that many still have unmet needs, and that most have nowhere else to turn in the absence of government programs. This policy note documents those key findings and discusses their implications for public policy.

Disabled Older Adults Often Have Highly Changeable Needs for Assistance

All the older adults in this study have been assessed by professional IHSS social workers and determined to need assistance in order to live safely at home. These individuals represent the full range of those receiving IHSS services, from those receiving only 10 hours of paid in-home help per month to those at or near the maximum of 283 hours per month. Clearly, their needs vary widely. Most of the people in this study need help with household tasks, such as cleaning and cooking; some also need assistance with personal care tasks, such as getting dressed or taking medications; and the most disabled among them need help with basic activities, such as getting in and out of bed, bathing, and toileting.

While some in the study describe their situation as better than it has been in years due to medical treatment and to the in-home support they now receive, most are on a downward trajectory. Their health problems – such as diabetes, heart disease, arthritis, and other chronic conditions – will never be cured, and the passage of time is likely to lead to additional complications and increased dependency. In spite of these challenges, virtually all of these seniors express a great desire to continue to live independently at home.

But I would rather be in my own home, even if I have to be in pain to do it, I'll manage, you know. There's nothing like being in your own home. Nothing... [Beatrice, 80 years old]

Describing a “normal” day for these older adults is difficult, since most of them have good days and bad days. Formal (paid) services are typically authorized and provided on a fixed schedule, and as a result they are not always adaptable to the care recipients’ fluctuating needs. Chronic illnesses can flare up at any time. For example, the pain from arthritis may spike suddenly and intensely, making movement around the house difficult. Changing needs may also result from an unexpected acute illness, such as the flu, that increases the amount and intensity of care a person requires. For some seniors, depression, anxiety, or mental illness may contribute significantly to variability in their need for care and can unpredictably interfere with daily life, even when properly treated.

For the frailest seniors – most often those suffering from chronic illness, pain, or fatigue – getting their care needs met takes an enormous effort on their part. For example, the energy such individuals must expend just to visit the doctor for a routine appointment may exhaust them so much that they need the entire next day to recover. Such efforts contribute to the instability of their care needs, since their needs are different on routine days than on “recovery” days.

I'm like a lot of people – on good days, I do too much, I wear myself out. On bad days, I don't do anything. And so you really have to learn to pace yourself... It's really hard for me, I need a day to recover... [Mitch, 65 years old]

Additionally, some older adults are further taxed by the effort it takes for them to manage and direct their care providers, or even simply to visit with a friend at their home. The often changing needs of these older adults with disabilities makes the consumer-directed care design of IHSS critical, since the senior is able to adjust the care they receive to the highest priority needs each day.

Following a stroke two years ago, Jack, a diabetic who is now 78 years old, spent a couple of months in a nursing home. He says he feels safer in his own home, where he is well-supported and cared for by Carol, his IHSS provider. He expresses ambivalence around the perception of his need for care, stating: “*I’m not senile, but people assume I’m senile or totally helpless. I am helpless ... Oh, God.*” While not ruling out the possibility of moving into a nursing home in the future, he wants to be the one to make that decision.

Many Low-Income Older Adults with Disabilities Have Unmet Needs

Due to their serious physical, psychological, and social needs, most of these seniors are highly dependent on support from others. While all seniors in this study receive some form of public support, in many cases these services fall short of fully addressing their complex care needs.

Some are not receiving the type of care that would be most responsive to their needs, while others are simply not receiving enough help and would benefit from additional hours of care.

Many of the older adults in this study find it difficult to assess the full extent of their care needs. Others report that they do not need help beyond what they are currently receiving, yet at the same time they acknowledge that any reduction in the care they receive would be problematic. Some have lowered their expectations for care over time and therefore understate the presence of unmet needs. Most have been coping for quite some time with chronic health conditions and their attendant symptoms, such as pain, inflammation, or fatigue.

Public services are designed to respond to a specific list of basic needs, and do not always respond effectively to the more holistic and nuanced needs of these vulnerable elders. Public programs such as IHSS typically evaluate and target physical needs – for example, help with dressing or bathing. Such programs are indispensable to older adults, yet the assistance provided is in many cases incomplete, failing to account for such care components as moral support, companionship, and a connection to meaningful activities that contribute to a person’s quality of life – all as essential as physical care to the health and well-being of this population.

The desire to stay at home and live independently is a strong and common goal expressed by these seniors: most would rather remain in their homes, even if some needs were left unmet, than go into an institutional setting. While a combination of denial and resilience may help these older adults protect and maintain their independence, their tendency to understate their care needs may, at times, work against their interests by making it more difficult for them to obtain the in-home help they need to remain independent in the long-term.

Social and Mental Health Needs May Be Overlooked

Social isolation and a variety of mental health problems complicate the caregiving needs of a substantial portion of this group of older adults. While these conditions intensify overall care needs, they also tend to be less visible

The food situation is probably the biggest issue with Jack and it’s not necessarily because he doesn’t have access to the food, although he does not get meals delivered on the weekends. They’ve cut back. Meals on Wheels used to deliver extra meals that would go in the freezer and they’d be for the weekends. I’ve noticed that...periodically they’re showing up again... But, for the most part he doesn’t get those anymore.

[Carol, 38 year old paid caregiver]

than other assistance needs and are therefore not always addressed by the services provided. The extent of social isolation observed within this group is profound and has implications for the mental health and well-being of these individuals. Public programs such as ADHC and senior centers offer the opportunity to respond to this need. Many seniors are not able to participate in these programs because of problems with physical mobility, whether due to functional impairment, a lack of viable transportation options, or both. Many report that public transportation is not reliable, and that in any case it is challenging – if not impossible – for them to manage on their own. And while some live in senior housing units that organize social activities and events, just getting out of one’s room or apartment to go elsewhere in the building can at times simply present too much of a physical or emotional challenge.

The majority of older adults in this study receive care within the confines of their own homes. Because their living situations restrict opportunities for social interaction, the visits from care providers can alleviate some of the isolation of these seniors. Although the care is not explicitly intended for this purpose, companionship is a natural byproduct of the physical care provided through HCBS. For some seniors, the opportunity to connect socially is as important as the physical assistance they receive. Paid caregivers often assist older adults in getting out of the house and engaging in activities, such as shopping or going to medical appointments. While these are not usually perceived as social activities, for many seniors they represent the only social connections made outside the home in the course of a typical week.

In addition to the companionship provided by a paid caregiver, the physical presence of the caregiver in the home often contributes to an increased sense of safety and security for the older person. Many seniors report the reassurance they feel when someone is standing nearby, especially at times when they are feeling weak or unsteady or are planning to take a bath or shower. While this monitoring role is a more passive form of care, it often helps assuage the fear or anxiety of older adults and increases their sense of well-being, in this way facilitating their ability to care for themselves.

Low-Income Disabled Elders Who Rely on Public Services Have Few or No Other Options

Low-income older adults with disabilities who receive personal care assistance from the IHSS program may hire anyone they choose to provide the assistance. In more than half the cases statewide, the paid caregiver is a family member, and the rest are unrelated. Whether or not the paid caregiver is a family member, some of the older adults have additional, unpaid family members involved in their care. However, this help is most often limited because of the unpaid relative’s other obligations (e.g., employment or child care demands).

Whether paid or unpaid as caregivers, family members are not always the most appropriate candidates to provide supplemental care. Long-standing parent-child conflicts, possible physical or mental health problems of the caregiver, or mismatches between an older adult’s needs and a caregiver’s abilities – for instance, lifting is required, but the caregiver is of small stature – can make the caregiving match less than optimal. In other family caregiving situations, however, the relationship is warm and loving, and elder needs and caregiver abilities are perfectly matched. Some families assume all of the care responsibilities, and while paid through IHSS for part of the care they provide, family members of the older adult frequently provide additional and often substantial amounts of unpaid care. Many of these family caregivers say that they are just doing “what families do,” with the belief that a caregiver who is a family member will be best able to respond to the preferences of the older

adult. At the same time, some of these family caregivers forgo certain opportunities for themselves, such as paid employment or education, which would be investments in their own futures.

Exhibit 1: Case Study of Home & Community-Based Services With Family Support

Sara is a family caregiver for her husband and disabled youngest son, both of whom have IHSS. Her husband, Martin, had a heart attack about a year ago, which resulted in his need of constant care. He also has diabetes, incontinence, and limited motor skills. Most of Martin’s care is provided for by his wife and by his oldest son. Martin’s oldest son is in charge of the labor-intensive housework, shopping and errands, driving his father to all medical appointments, picking up prescriptions and diabetes supplies, as well as giving his father insulin shots. Sara provides assistance with cooking, light housecleaning, and personal care for Martin, such as bathing, dressing, and incontinence care.

Sara’s life has changed since she became a caregiver for her husband. She spends much of her day at home since someone must be with her husband at all times. She is constantly tending to the needs of her husband and disabled son, with much of the day spent being there “*just in case*” something is needed. Her disabled son attends adult day health care several times a week, which gives her extra time to care for her husband and herself. Sara, however, is also worried about her own health. She is 72 years old and is beginning to have health problems of her own. Her fear is that there will be no one to care for her husband and son if she were to fall ill and need to be hospitalized. While there is help from IHSS and other family members, Sara is the coordinator and the one who can provide assistance night and day.

Some family members, particularly those who work full time or do not live near the older adult, arrange and oversee the provision of the hands-on care that is delivered by a non-family IHSS provider. In still other cases, particularly those that involve seniors with very high levels of complex needs, families work in tandem with formal providers, with each member of the “team” taking a distinctive role and specific caregiving tasks to ensure that the older adult receives the comprehensive care required. In these situations, limited resources often mean that the essential components of care are “patched together” and provide just enough to meet the older person’s basic care needs. If any one element is changed or removed, the delicate balance is upset.

Other recipients of personal care services have no family members available to help with any aspect of care. Older adults in this group are thus especially dependent on the paid care they receive and they must be much more active in managing their own care. Some seniors demonstrate great resilience when faced with the challenges of securing the services and obtaining the care they need; as a result, these individuals are frequently very enterprising and quite successful in building and managing a care network.

Changing Needs and Limited Options Result in a Fragile Network of Care

All of the older adults in this study receive at least IHSS caregiver assistance, if not other types of care as well. Some receive a broad array of home and community-based services, including case management, home-delivered meals, in-home physical therapy, adaptive equipment, home modifications, and emergency call

systems. Most, however, are not receiving the full range of services they need in order for their complex care needs to be adequately met. In some cases, as noted above, unpaid family members are already part of the care network and do their best to fill in the gaps in services. In other cases, non-family providers report that they work more hours than they get paid, just to “get the job done.” Older adults without this extra, voluntary help from family and caregivers may simply go without having certain of their care needs met at all.

Exhibit 2: Case Study of Home and Community Based Services Where There Is No Family Support

Stricken with polio as a child, Mary is paralyzed and confined to a wheelchair. She cannot feed, dress, bathe, or toilet herself, and she relies on a ventilator to help her breathe. Surprisingly, however, Mary describes her health as “*excellent*.” Despite her need for 24-hour care, Mary is able to live at home safely and is an active participant in her church and community because of the care that her IHSS worker provides.

A widow in her seventies, Mary has no relatives in the area. Although she currently receives the maximum number of IHSS hours, this amount does not fully cover her care needs. As a result, Mary has chosen to offer free room and board in exchange for the additional hours of assistance she requires. Mary is acutely aware of the fragility of her care network. She says that without the IHSS workers she has had over the years, she would have no other option but to enter a nursing home. But Mary is optimistic about the future because of the care that she receives. She plans to finish her college degree and is looking forward to becoming a “*grandmother*” to her IHSS worker’s children who are “*joining her family*.”

The most common characteristic of the long-term care network is its fragility. The activities and supports provided are not independent of one another, but they are not always well coordinated. Coordination of care can take quite an effort, with different members of the care network assuming different roles and providing different facets of care. Programs like MSSP can provide social workers to help with such efforts. Although quite variable and often ill-defined, the networks of care that are constructed can represent the difference between seniors living independently in their own homes and having to move into an institutional care setting.

Housing arrangements are a critical concern for some seniors— if they lose their subsidized rental housing or their homes are foreclosed, they do not know where they will go. These low-income individuals cannot afford market rents, and they typically lack family members who can assist with space or rent money. The greatest fear of these older adults is that losing their apartment or home will lead to institutionalization. Similar to the case of Mary, in Exhibit 2, part of the patchwork of care services might involve shared living arrangements, with the contribution of a renter helping the older person remain in the home. The added benefits of companionship and an increased sense of security could help meet some of the senior’s other care needs.

The composition of the support network and the intensity and quality of care provided are unique for each individual in this study. There are variations in the level of need, the amount of formal support provided, the degree of family involvement, and the availability of other resources. Other variations result from the changeable nature of chronic health care needs and the types of care that are available.

Policy Implications

Supportive services for older adults and the disabled have been targets of state budget cuts for the past several years.¹ The 2011-12 budget proposals continue the trend of targeting reductions in services for older adults with disabilities who wish to remain in the community.² IHSS program hours were trimmed by 3.6 percent in January 2011; they face another 8.4 percent across-the-board cut, plus additional targeted reductions in the governor's proposed budget. ADHC and MSSP are slated for elimination, and Supplemental Security Income (SSI) cash benefits are to be reduced for single, low-income aged and disabled people. The initial findings in this policy note document that recipients of these programs are often already in precarious situations and that undermining their care networks will place them at risk of worsened health and institutionalization.

The importance of consumer-directed care. Debates about spending on IHSS in recent years have overlooked the intentional design of the program as “consumer directed.” Some proposals have directed cuts in specific activities that comprise part of the total package of care hours, such as the current proposal to eliminate hours for domestic services for those living with their IHSS caregivers, most of whom are family members. But consumer direction means that older adults with disabilities are given the autonomy to supervise the actions of their caregivers, and it assumes that disabled individuals know best about how their basic needs should be met. Given the unique mix of other formal and informal care that each older adult manages, along with the changing availability of those supports, it is important that consumers retain control over how they use their IHSS hours so that they can obtain the assistance they need most.

Gaps need to be filled, not widened. The economic climate is not conducive to filling unmet needs, but it is important not to lose sight of gaps in care faced by many older adults with disabilities. In particular, the psychosocial needs of these individuals are often not taken into account by most programs when care needs are determined, to the detriment of the overall health and well-being of these seniors. Policies and programs that provide wraparound mental health and social supportive services can better address the social isolation, mental distress/illness, and continuity-of-care needs of these older adults. In addition, it is evident from these interviews that housing and transportation programs need to be considered as core health programs that can enable older adults to live independently. Cutting cash assistance as well as direct services, as currently proposed, will serve to further widen these gaps.

Service cuts will undermine the ability to remain safely at home for many older adults who depend on community-based services. The tenuous nature of the support network documented in these interviews indicates that most low-income older adults with disabilities have few options to replace reductions in services, even when family members are part of the care network. Some have been quite creative in assembling a network of friends, family, and paid caregivers to meet their basic needs. Those individuals have already tapped out their networks to fulfill their needs, leaving little room for service reductions that seem certain to impact their ability to remain safely at home. Others are largely reliant on a single paid caregiver, and their situations have even less margin to allow for a reordering of priorities and assistance. When asked what they would do if their in-home care hours were reduced or eliminated, many consumers indicated that they would “make do”: in other words, they would rather struggle – perhaps eat less often, let their homes become less safe, and allow their medical conditions to worsen – than lose their homes and independence and go into institutionalized settings. This explains findings from other states documenting increased use of emergency rooms and hospitals

by those who have experienced reductions in their in-home care.³ Some will not be able to make do for long, and will require institutionalization.

Policy debates often focus on budget numbers, but it is important for policymakers to also keep a focus on the lives of the real people affected when programs are cut. The data and analysis in this policy note provide new information on how crucial the network of public programs is for older adults with disabilities. Listening to the voices of those likely to be the target of budget reductions is crucial to understand the full impact of those cuts.

Methods

This policy note presents the initial findings from analyses of in-depth, face-to-face interviews with 33 older adults (age 65 and over) who are consumers of public programs that provide long-term in-home care services and supports in four large California counties. Interviews were usually with the older adult and his or her paid caregiver (who could be related, or not), as well as with an unpaid family member when possible.

All of the older adults received at least Medicare, Medi-Cal, and IHSS services. Respondents were randomly selected and invited via postcard. They represent a diverse group that varies by gender, ethnic/racial background, and level of assessed need. Data were collected in English and Spanish from September through December 2010. Certain identifying information included with the quotes and case studies provided in this policy note (e.g., name, age, and/or gender) has been changed to safeguard the confidentiality of study participants.

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² The SCAN Foundation. 2011. Fact Sheet Highlighting Cuts Affecting Seniors in California's 2011-12 Proposed Budget. January 13. www.thescanfoundation.org/sites/default/files/California_2011-2012_Proposed_Budget_Fact_Sheet_No_16.pdf

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