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A Portrait of Older Californians With Disabilities Who Rely on Public Services to Remain Independent

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Abstract

Low-income older adults with disabilities in California depend on a variety of public programs to help them remain in their own homes. The availability of those services has been in flux since 2009 because of cuts caused by the recession. This article reports on a qualitative study of 33 California seniors who depend on fragile arrangements of paid and unpaid assistance. Thematic analyses of in-depth interviews conducted with these older adults and their caregivers indicate that the disability needs of these individuals are often unstable, with both physical and mental health status sometimes changing day to day. Most have nowhere else to turn for help if their public services are cut. All share the common goal of staying at home and maintaining their independence. Public services serve as a crucial link in the support networks of these individuals.

Keywords

care networks; home- and community-based care; long-term care services and supports; older adults; public programs; state budgets

INTRODUCTION

In recent years, gerontologists, health care professionals, policy makers, consumers, and families have raised concerns about the adequacy, quality, and sustainability of our long-term care system. There is increasing recognition that we have a fragmented system of

health and social care which offers a range of services that is difficult to navigate and which does a poor job of adequately meeting the comprehensive and complex care needs of older adults (Komisar, Feder, & Kasper, 2005; U.S. Government Accountability Office, 2005). As the demand for long-term care services and supports (LTSS) grows, the supply of both informal and formal care providers is shrinking (Robine, Michel, & Herrmann, 2007). Furthermore, public reimbursement continues to be biased toward institutional care, even while the overwhelming majority of Americans with chronic care needs prefers to be cared for at home (Harrington, Ng, Kaye, & Newcomer, 2009).

In California, efforts over the years have been made to shift some of the provision of health and social care away from institutions and back to the community. As a result, the state ranks sixth nationally in the balance of Medicaid dollars spent on care in the community versus institutional care (Reinhard, Kassner, Houser, & Mollica, 2011). Yet, recent reductions in public financing for LTSS in California are eroding a critical source of care for older adults who, with these supports, are able to continue to live independently at home. Cutbacks to the LTSS safety-net raise concerns about how, in the absence of adequate supportive services, we will be able to effectively meet the needs of the most vulnerable and frail elderly (Kietzman, Durazo, Torres, Choi, & Wallace, 2011).

The current study investigates the ways in which LTSS are being used in California by “dual eligible” older adults—i.e., those who qualify for both Medicare and Medi-Cal (California’s Medicaid program)—to remain “safely in their own homes” (the stated goal of LTSS services in the state).¹ Study participants were consumers of In-Home Supportive Services (IHSS)—a consumer-directed Medi-Cal personal assistance program—and their paid IHSS caregivers or unpaid family caregivers when available. IHSS is especially important to low-income elderly and their families, many of whom are members of historically disadvantaged ethnic/racial minority groups. Most IHSS consumers are ensconced in a complex network of informal and formal care, and rely on a variety of supports provided through a mix of public programs and voluntary help from family members, friends, and other members of the community. This study offers a portrait of the care networks that frail elderly and their caregivers construct to meet their needs while residing independently in the home and community.

Background

Increased longevity, a projected increase in chronic disease and disability in future cohorts of older adults, and the aging of the Baby Boomer generation—the large cohort of Americans born between 1946 and 1964—are all factors contributing to an expected increase in the demand for LTSS (Martin, Freedman, Schoeni, & Andreski, 2009). By 2050, it is estimated that more than 88 million Americans will be age 65 and older (U.S. Census Bureau, 2009). While in recent years the proportion of older adults with disability has decreased (Crimmins, 2004), a projected increase in chronic illness among Baby Boomers portends the reversal of these recent declines in rates of morbidity and disability (Martin et al., 2009).

The immediate economic crisis in the United States—referred to by many as “the Great Recession”—is intensifying the ongoing challenge of effectively meeting the long-term care needs of older adults and has serious implications for the sustainability of supportive public programs at both the national and state level. A look at recent budgets in the State of

¹The California Department of Social Services (<http://www.dss.cahwnet.gov/cdssweb/PG139.htm>): While the “safe” dimension of remaining at home is not explicitly defined in state statute or elsewhere, here it is conceptualized as involving an adequate level of care that is appropriate to the needs and desires of the older adult and where the risks from remaining at home of severe injury or complications of illnesses do not exceed what a “reasonable person” would find acceptable.

California brings these issues into sharp relief, providing a stark illustration of the potential effects of reducing public programs for low-income frail and disabled older adults. The initial 2010–2011 California state budget proposed reducing support for many LTSS, including IHSS and Adult Day Health Care (ADHC). ADHC provides therapeutic services and supervision to adults with physical or cognitive impairments during the day and respite to their caregivers (Wallace et al., 2010; Wallace et al., 2009). As finally enacted, the budget reduces these and other supportive programs even further, including Supplemental Security Income (SSI) and enhanced case management under the Multipurpose Senior Services Program (MSSP) which provides social and health care management for Medi-Cal eligible frail elderly clients who are certifiable for placement in a nursing facility (The SCAN Foundation, 2011; Wallace et al., 2009).

In California, the IHSS program has proven to be an integral component of gradual but continuous efforts to shift institutional-based care to the home and community. The IHSS program provides personal assistance services to over 400,000 low-income adults and children² who are Medi-Cal eligible and meet specified levels of disability (California Association of Public Authorities, 2012). Services include personal care (e.g., bathing, dressing, and feeding), domestic and related chores (e.g., laundry, cooking, cleaning, and shopping), paramedical services (e.g., injections, catheters, foley bags, feeding tubes), protective supervision, and transportation to medical appointments. IHSS is a consumer-directed program that gives Medi-Cal eligible care recipients the opportunity to manage their own care by directly hiring a caregiver of their choice, including family members or friends (Wallace et al., 2009). The program has been credited with empowering participants, providing a source of financial support for family caregivers, and a source of employment for an unskilled workforce (Benjamin & Matthias, 2000; Delp & Quan, 2002).

Previous studies of IHSS and other consumer-directed home care programs (e.g., The Cash & Counseling Demonstration Evaluation) provide evidence of care recipient and caregiver satisfaction (Benjamin, Matthias, & Franke, 2000; Benjamin & Matthias, 2004) and demonstrate a number of positive outcomes for both care recipient and caregiver (see, e.g., Foster, Brown, Phillips, Schore, & Carlson, 2003). While these studies highlight the promise of consumer-directed personal assistance programs, there is much yet to learn about the long-range effects of these and other LTSS programs.

The recent cuts made to LTSS services in California may result in more rapid rates of functional decline and increased acute care needs among the frail and disabled elderly. Numerous studies have shown multiple adverse outcomes—including increased rates of hospitalization, emergency room use, nursing home placement, and caregiver burden—following the reduction (or elimination) of resources for home care (D'Souza, James, Szafara, & Fries, 2009; Jacobs et al., 2007; LaPlante, Kaye, Kang, & Harrington, 2004; McCall, Korb, Petersons, & Moore, 2002; Sands et al., 2006; Schlenker, Powell, & Goodrich, 2005). As such, the reductions made to LTSS services in California invoke a sense of urgency and provide an opportunity to investigate how consumers use IHSS and other programs to continue to live safely and independently in the community.

To date, no study has used primary data collected from IHSS consumers to look across publicly and privately funded programs and voluntary sources of support to identify and define a comprehensive network of care. Further, there have been no studies that track the

²There are 56 Public Authority IHSS agencies throughout California's 58 counties (<http://www.capaihss.org>). As of January 10, 2011, they served approximately 422,644 consumers and 357,849 caregivers. The following report (<http://www.dss.cahwnet.gov/research/res/pdf/dapreports/IHSSRecipientRpt.pdf>) from 2001 indicates that two thirds of IHSS consumers age 65+ were female; among consumers of all ages, 44% were White, 22% Latino, 17% African American, 16% Asian, and 1% were American Indian.

outcomes of California's IHSS program participants and their caregivers over time. This study offers the opportunity to learn about the broader support network that IHSS care recipients avail themselves of to maintain their status of living independently in the community. The consumer experience described here can inform future efforts to identify and measure outcomes of importance to this LTSS population.

The primary research goals of this study are:

- to develop a detailed understanding of how California's dual-eligible (Medicare-MediCal) older adults patch together public and private services to remain safely in their homes;
- to identify unmet needs among dual-eligible older adults receiving public services;
- to describe how changing needs and resources affect these older adults and their caregivers.

METHODS

Sample

Prospective study participants were recruited from IHSS program participant lists in four large California counties that were purposively selected to reflect statewide demographics and geography. The researchers established cooperative relationships with counties' public authorities and program administrators who were positioned to provide information and assist with recruitment.

Participants had to be age 65 or over, receive at least Medicare, MediCal, and IHSS services, and be able to effectively communicate in English or Spanish. Respondents who exhibited signs of moderate to severe cognitive decline or dementia during the screening process were excluded. Those who were successfully screened and verbally consented to participate were asked to refer their primary IHSS and/or family caregiver (CG) who was actively involved with providing for their care needs, so that they too could be invited to participate.

Program administrators in the four counties sent a total of 1,524 invitation postcards to IHSS consumers who met the eligibility requirements for this study. Of the 130 individuals who responded by calling a toll-free number, 86 completed a screening interview, 65 consented to participate, and a final sample of 55 was interviewed. Of the consumers who were screened but not included in the final sample, several did not meet the eligibility criteria, others declined because they were too ill to participate, while the remainder was lost to follow-up. Several caregiver participants declined due to time constraints, others were recently hired and said they did not know the consumer well enough, while others were lost to follow-up.

Data Collection

Between September and December 2010, face-to-face interviews were conducted in English and Spanish with 55 study participants (representing 33 IHSS consumer "cases"). Participants were informed that the primary goal of the study was to learn more about the type and quality of programs and supports that older Californians with disabilities rely on to continue to live safely in their own homes.

In-depth interviews were conducted to solicit data on the full range of care needs and sources of formal and informal assistance received (or provided) and to learn more about the processes by which care recipients (CRs) access and manage available sources of support. The interview guide included open-ended questions and prompts, to be used as needed, to

clarify the intent of the question. Questions were organized by the following major topic areas: current needs; current sources of support; safety and independence; impact of IHSS and other sources of support; interaction with health care systems; initiation of IHSS care; quality of life; the future (i.e., anticipated changes in needs, services, and supports). 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 caregiver when possible. The inclusion of data collected from CRs and from different categories of CGs (i.e., paid and unpaid, related and unrelated) provided different perspectives of the CR's care network while also allowing for the triangulation of CR self-report data.

All study protocols, including subject recruitment and screening, and data collection instruments and protocols, were approved by the UCLA Office for the Protection of Human Subjects.

Data Analysis

Data were stored and managed in ATLAS.ti, version 6.2 (ATLAS.ti GmbH, Berlin, Germany), a qualitative data analysis software program. All interviews were audiotaped and transcribed verbatim.³ The university-based and interdisciplinary research team of seven included two senior faculty, three junior faculty—all with PhDs—and two doctoral students; and represented the fields of public health, sociology, political science, history, and social work. Researchers used a constructivist grounded theory approach to analyze data (Charmaz, 2006; Glaser & Strauss, 1967). Grounded theory is an inductive method that employs an iterative and rigorous process of constant comparison of data collected from different people, at different points in time, within and across different categories (Glaser & Strauss, 1967). A constructivist approach emphasizes the emergent characteristics of knowledge that is generated as a product of the exchange between the interviewer and the interviewed (Charmaz, 2003).

Members of the research team first read transcripts and drafted memos to summarize highlights and note their early analytical impressions of the interviews. Researchers were then paired up to independently and systematically review and label interesting and relevant text segments and quotations with “in vivo” codes—i.e., labels or reference points that most closely represent the study participant's perspective and choice of words. After an initial round of coding, the team met to review and compare the codes generated from these baseline data. Through team review and discussion, a master code list was created and refined. The code list was used to ground an iterative analytical process that involved multiple rounds of review and coding of transcripts and memos. Codes were then grouped into categories and recurrent patterns and themes were identified.

RESULTS

Table 1 displays a care recipient (CR) sample of 33 older adults who represent a diverse group that varies by ethnic/racial background and by level of assessed need.⁴ The 22 CR participants range from 65 to 90 years of age and more than three quarters are female. Less than half of CRs are White, close to one third are Latino, four are African American; while the remaining four include one American Indian, one Chinese, one Filipino, and one biracial (African American and American Indian) participant. About one fifth of CRs were assessed at high levels of need, close to two fifths were assessed at moderate levels, and five were

³With the exception of two participants who declined to be audiotaped; in these cases, memos were drafted by the interviewer immediately following the interview and later coded as a transcript.

⁴Certain identifying information included with the quotes and case studies provided in this article (e.g., name, age, and/or gender) has been changed to safeguard the confidentiality of study participants.

assessed at low levels of need.⁵ More than two thirds of CRs indicate that they have been receiving IHSS care for more than 3 years. Most IHSS consumers reported multiple chronic conditions—including diabetes, heart disease, neurological disorders, and depression (not displayed). The number of Activities of Daily Living (ADLs—e.g., bathing, dressing, feeding) with which they report needing assistance range from 0 to 7, the number of Instrumental Activities of Daily Living (IADLs—e.g., laundry, shopping, cooking) range from 2 to 9.

Table 2 shows that the majority of caregiver (CG) study participants are female and Latino. Half of CGs report they are related to the CR with one third providing care for less than one year, and one quarter providing care between one and three years.

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 older adults 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. Beatrice, who is 80 years old, comments: “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....”

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, even though consumer directed, there are limits to what single workers and family members can do to respond to unscheduled 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. Eileen is 76 and suffers from chronic pain. When we asked whether she could bathe or shower on her own, she responded: “Right now, yes. But I’ve checked it out with her [the IHSS caregiver] on the interview, because I certainly can’t take a shower by myself when my back goes out.”

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

⁵Assessed level of need was determined by IHSS social workers. Information about level of need was unavailable for 24% of the sample.

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. Mitch, who is 65 years old, relates the following:

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.

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.

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. For example, Jack is a 78-year-old man with diabetes and a history of strokes who uses a wheelchair for mobility. He began using IHSS services 11 years ago, when he realized that he was unable to clean and maintain his home by himself. He relies solely on his IHSS caregiver Carol, who provides 40 hours of assistance each week. Carol reports:

The food situation is probably the biggest issue with Jack...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.

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.

Jill is 72 and suffers from several conditions—including depression, early stage dementia, and a neurological disorder that causes fatigue, pain, and repeated falls. In recent months, Jill has become increasingly disorganized. She reports having trouble finding a psychiatrist who can prescribe the right medication. Although her depression has become quite severe, because of the expense, she only recently made an appointment with a therapist. Jill states: “I just started it last week as a matter of fact.... Yeah, ‘cause I have so little income and I wait until I’m so bad before I do anything, you know.” Jill’s family worries that she is not getting all the help she needs. According to Jill:

My daughter gets upset because she says “Mom, you minimize, everybody maximizes things, and you minimize what’s going on with you and you project that so people don’t really know what’s going on with you.”

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.

Social and Mental Health Needs May Be Overlooked

The majority of older adults in this study receive care within the confines of their own homes. 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 than other assistance needs and are therefore not always addressed by the services provided.

Teresa is 65 years old, has bipolar disorder, and recently went through knee replacement surgery. She talks about her struggles with leaving the house:

I'm looking also at getting around out of the house and whether that means psychological or physical. Physically I can get around outside of the house to some degree. Still, there are times that I can't get around outside of the house psychologically. I can't get out and I need her [the IHSS caregiver] to go with me.

Public programs such as ADHC and senior centers offer the opportunity to respond to this need. While some of our study participants use these programs, many are not able to participate because of problems with physical mobility—whether due to functional impairment, a lack of viable transportation options, or both. Several 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.

Ana, a 53-year-old IHSS caregiver, cares for her mother, Maria, who has dementia, hypertension, and osteoporosis. She regularly attempts to get her mother out of the house. Here she describes efforts to take her to the beach:

I thought, I got to bring my mom here, you know, so she can see what life is. She thinks life is inside her house. No, come on, there's a lot of things to do outside. And she could, maybe she would enjoy with her chair going up and down. But, she doesn't want to go.

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 by-product of the physical care provided through community-based LTSS. 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. Rosa, who is 79 years old and recovering from hip replacement surgery, explains:

I manage it on my own but I try to make sure somebody's here uh, when I do shower.... It all depends on how I feel. If I feel kind of weak, I won't take the shower until somebody is here.

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 sometimes limited in their ability 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.

Recipients of personal care services who have no family members available to help are especially dependent on the paid care they receive and 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, as exemplified by Mary.

Vignette 1: Case Study of LTSS Consumer with 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 70s, 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.”

Family Caregivers Can Be a Critical Component of the Consumer Care Network

In other caregiving situations, families assume all of the care responsibilities, and while some are partially paid through IHSS, 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 and, like Sara (Vignette 2), may neglect their own health needs.

Vignette 2: Case study of LTSS consumer with family support—Sara is an unpaid 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 for constant care. Most of Martin's care is provided for by his wife and by his oldest son who is paid through IHSS. Martin's oldest son is in charge of the labor-intensive housework, shopping

and errands, driving his father to all medical appointments, 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, 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 fill in for the care she provides her husband and son if she were to fall ill and need to be hospitalized.

In some cases, family members 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 something close to the range of 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 may be upset.

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 community-based LTSS—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 paid caregivers may simply go without having certain of their care needs met at all. For many, family members are just not available. Bertha, 78 years old, recounts the following:

I have a daughter that's real sweet. But she works, she works every day and so she's not around to help me. You know, she works and she gets off in the evening sometimes at 6:30, 7 o'clock. So, she's not available.

Jack's 38-year-old paid caregiver, Carol, speaks candidly about a recent and precarious health event he experienced, noting the fragility of his care network:

He called me, he had a medicine error...and he didn't know what to do with it.... I'm the only one that's there for him.... There's no family. There's no other providers. So, to have someone else, really, I don't think anybody should rely solely on one person.

Housing arrangements are a critical concern for some of the seniors we interviewed—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 rate rents, and they typically lack family members who can assist with space or rent money.

Fran, 84, was going through a bank foreclosure on her home of 40 years when we first interviewed her. She expressed her anxiety and dismay as she faced the uncertainty of whether she would be able to find an affordable housing option:

Because the bank foreclosed on my house, I don't even know where I'm going now.... [I have to move] as soon as possible, but I don't have the ability to do it.... I'm looking for senior housing in Section 8. But that takes 7 years to wait. So where I go, I don't know.... You have to do it yourself. Nobody comes to you.

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 Vignette 1, 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.

DISCUSSION

The sustainability of the system of LTSS in California is challenged by the current fiscal climate in the state and across the nation. This lends a sense of urgency to policy and program efforts to sustain and improve a system of home and community-based care which, while imperfect, is overwhelmingly preferred by consumers.

This study offers an analysis of the lives of low-income older adults living with complex chronic conditions and disabilities who have variable needs for assistance. It illustrates their experiences navigating a fragmented system of care and highlights the role of public programs that support their ability to live independently. Although the existing system of LTSS is tenuous, for some older adults it is the sole source of care upon which they rely. The personal assistance services provided by IHSS caregivers represent the core of their support system. Many use it as a base from which they manage to construct a more responsive network of care using a combination of formal (paid) and informal (unpaid) support.

The in-depth interviews conducted with LTSS consumers reveal the complexity of their care needs and the uncertainty that many face regarding how their needs will be met from one day to the next. The findings represent the voices of consumers whose narratives capture the fragility of the care networks they rely on and provide insight into the combination of supports they need—and are able to access and use—to continue to live at home.

In addition to immediate physical health needs, these older adult consumers have a broad array of social and psychological needs. The nature of these diverse needs often requires that treatment or services are provided through a combination of informal and formal supports. While each component makes an important contribution to a more holistic package of care, the interdependency of these supports reveals the fragility of these care networks. If any care component is taken away, the effect on the overall support system can be quite profound. Often it is the delicate combination of multiple sources of support that facilitate the ability of the older adult to continue to live safely and independently.

These findings support the case for developing more effectively integrated systems of long-term care. While much attention has been given to integrated and coordinated care in the context of acute and primary medical care systems (Dove, Weaver, & Lewin, 2009), until recently, relatively little effort has been made to promote integrated supportive care for community-dwelling older adults with chronic care needs (The SCAN Foundation, 2012).

By definition, the integration of long-term care services and supports necessitates coordinating care between health and social care providers. As we envision restructuring our systems of health and social care, we have an opportunity to think more broadly about what that might entail and to extend such thinking beyond the confines of institutionally based health care. For instance, we need to consider the social determinants of health occurring in both the physical and social environment and affected by community design and infrastructure (Felix, Burdine, Wendel, & Alaniz, 2010). This effort would entail considering components of care that extend beyond acute medical care and span the spectrum of supports—including housing, income support, social care, psychological care, and transportation services (Gitlin, Szanton, & DuGoff, 2011).

Effective integrated systems of long-term care will also need to account for socioeconomic, racial, ethnic, and cultural diversity among consumers. Considering the needs of low-income care recipients takes this discussion to a different level, and is imminently relevant given the recent policy decision in California to begin to transition the dual eligible population into managed health care plans (<http://www.CalDuals.org>). This decision provides the opportunity to examine how well integrated care fares in the context of a low-income, physically vulnerable, and frail elderly service population. The potential for improved health and quality of care outcomes for this population at a time of economic downturn may be even more profound.

Recent discussions and numerous provisions included in the Affordable Care Act provide an opportunity to advance integrated care and extend it beyond the realm of institutionally based medical care (Reinhard, Kassner, & Houser, 2011). There is broad consensus about the sensibility of improving communication and the exchange of service information to, in turn, improve quality of care, reduce emergency room visits and hospital readmissions, and reduce health care costs (Berwick, Nolan, & Whittington, 2008).

Limitations

This article presents cross-sectional and retrospective data and does not reflect the changes expected to be seen prospectively among this sample of IHSS consumers and caregivers over time. Respondent self-reporting may introduce a bias, especially in the context of questions asked about challenges associated with chronic care needs or about the demands of care-giving. While not eliminating the risk for bias, some of these concerns are addressed through the triangulation of data collected from both consumers and caregivers. Further, those who elected to respond to the invitation and participate in this study may have certain shared characteristics that have the potential to bias the findings.

As a qualitative study with a modest sample size, the findings cannot be generalized to the entire statewide population of LTSS consumers. However, the depth of the data allows us to provide detailed descriptions of situations, linkages between events, and categories of needs/outcomes that accurately portray the range of situations experienced by most state-funded LTSS consumers. While the findings may provide useful information for other states grappling with similar challenges to provide LTSS for their aging population, the data gathered here are specific to the system of care operating in California under current state budget constraints.

CONCLUSION

The findings of this study offer important information about the experiences of low-income older adults who rely on public programs to continue to live safely and independently at home. These analyses can help us think beyond the internal mechanisms and delivery of any one service or program and think instead *across* these sources of support. In so doing, we

can begin to identify common guidelines and principles for integrated LTSS for older adults, as well as promising strategies for their implementation and broad scale dissemination.

In the short run, the results can inform the decision making of state policy makers positioned to either reinstate funding to these programs or support the restructuring of their design and delivery to provide an alternative public benefit. This is especially important given that national and state budget deficits threaten to undermine the continued provision of these publicly funded LTSS services at the same time that household budgets and employment opportunities are dwindling. In the long run, the findings may be used to inform policy decisions about how to better plan for and respond to the care needs of elderly frail and disabled in the community; in particular, the California experience may offer lessons to other states facing similar challenges in planning and implementing adequate and sustainable systems of long-term services and supports for their older adult populations, especially low-income older adults, and especially during times of economic downturn.

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TABLE 1

Care Recipient Characteristics

	<i>n</i> = 33
Age (range)	<i>M</i> = 75 (65–90 years)
Gender (female)	26
Race/Ethnicity	
White	15
Latino	10
African American	4
American Indian	1
African American/American Indian	1
Chinese	1
Filipino	1
Education (<i>n</i> = 26)	
More than high school	15
High school graduate	4
Less than high school	7
Level of assessed need	
1 (low)	5
2 (moderate)	13
3 (high)	7
Unknown	8
Years receiving IHSS care	
Less than 1	2
1–3	8
3–5	8
5+	15
Number of ADLs	
0	12
1–3	13
4–6	5
7–8	3
Number of IADLs	
0–1	0
2–3	8
4–6	20
7–9	5
Self-reported health	
Excellent	1
Very Good	4
Good	8
Fair	5

<i>n</i> = 33	
Poor	8

Note. IHSS = In-Home Supportive Services; ADLs = activities of daily living; IADLs = instrumental activities of daily living.

TABLE 2

Caregiver Characteristics

	<i>n</i> = 22
Age (range)	<i>M</i> = 48 (23–74 years)
Gender (female)	17
Race/Ethnicity	
Latino	14
White	4
African American	2
Vietnamese	2
Education	
More than high school	11
High school graduate	5
Less than high school	6
Relation to care recipient	
Not related IHSS provider	11
Related IHSS provider	9
Family caregiver (not IHSS)	2
Years providing care to CR (<i>n</i> = 20)	
Less than 1	7
1–3	5
3–5	1
5+	7

Note. IHSS = In-Home Supportive Services; CR = care recipient.