



# From Hospital to Home: Improving Transitional Care for Older Adults



HEALTH RESEARCH FOR  
**Action**  
UC Berkeley



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Improving Transitional Care  
for Older Adults**

*April 2006*



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## About Health Research for Action

*H*Health Research for Action—formerly the Center for Community Wellness—is located in the UC Berkeley School of Public Health. Our mission is to conduct research and translate findings from that research into policies, products, and programs that reduce health disparities and create healthier, more empowered communities. All of our work is conducted in partnership with the people living in these communities.

**Applied research and evaluation.** The center's research explores the key factors that affect individual and community health for children, teens, parents, and elders. Our special focus is racial/ethnic minorities, recent immigrants, people with disabilities, people with low literacy skills, and other underserved groups. We work closely with these groups to design and evaluate effective policies and interventions.

**Interventions to reduce health disparities.** Meeting the needs of diverse groups is critical to reducing health disparities. The center's *Wellness Guide*, available in English, Spanish, and Chinese, responds to the needs of families from pregnancy through old age. Our *Parents Guide*, available in English, Spanish, Chinese, Korean, and Vietnamese, includes important information for parents and multigenerational households, and our HMO guides, available in English and Spanish, and related materials help consumers navigate health systems. A falls prevention workbook and training program for low-income seniors in Pennsylvania is intended to reduce falls and improve mobility. The center is also leading a statewide initiative to improve the readability and usability of information for health care consumers, and has initiated school-based programs to support under-represented minority students in achieving academic success and pursuing health careers.

**Policy development.** Our staff is involved in policy analysis and advancement at the local, state, and national levels. Areas of policy development include maternal and child health, eldercare and senior health, health access, health communication, e-health, and environmental health.

## Acknowledgments

*T*he work of this project was greatly enhanced by the expert guidance of our Advisory Board, which included professionals in aging from all of our study counties, as well as seniors and family caregivers. Their assistance in identifying and encouraging the involvement of community members was invaluable. We also wish to acknowledge the critical work of our community partners who spent many hours recruiting subjects, facilitating and translating for our focus groups, and identifying key informants for interviews. Staff from the American Society on Aging—especially Patrick Cullinane—contributed importantly to all phases of the project and convened focus groups with providers knowledgeable about discharge planning. Colleagues at UC Berkeley's Data Archive & Technical Assistance (UC DATA) in the Survey Research Center provided generous assistance with data analysis. Finally, we thank the Gordon and Betty Moore Foundation for their support and assistance with this project.

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## Executive Summary

This project is one of the most comprehensive assessments to date of issues related to hospital-to-home transitions for seniors. The project comprised analyses of peer-reviewed studies and secondary data, focus groups with caregivers and providers in diverse communities, interviews with providers and policymakers, and case studies with families and isolated seniors. We have identified many important actions to improve transitional care through interventions to empower seniors and their caregivers with information about and access to community resources, through specialized training of providers to enhance their ability to serve vulnerable seniors in diverse communities, and through system- and policy-level changes. The project was funded by the Gordon and Betty Moore Foundation.

### KEY FINDINGS

**Care transitions are an increasingly critical health and social problem for seniors and their caregivers.** Hospitalization can be a turning point in the lives of seniors, whose physical and mental health often deteriorate after discharge. Many older adults experience breakdowns in care during the transition from hospital to home. This results in high rates of poor outcomes and rehospitalization. Patients and caregivers are on the receiving end of a badly fragmented system of care, and both medical and caregiving support during the hospital-to-home transition are inadequate.

**We are failing to meet the needs of vulnerable populations.** Some seniors are at very high risk for rehospitalization and increased morbidity and mortality after discharge. Elders with multiple medical problems, functional deficits, cognitive impairment, emotional problems, and poor general health are at particular risk during this transition. Racial/ethnic minorities, non-English speakers, immigrants, and older adults living alone and in poverty are also at high risk. Informal caregivers also face health risks and increased mortality from providing complex care. A one-size-fits-all approach to transitional care is not sufficient, given the ethnic and economic makeup of the Bay Area and most areas of the United States.

**Seniors and caregivers are not prepared.** As hospital stays have been shortened and health care costs have risen, discharge planning has decreased in many hospitals. Patients are discharged “quicker

and sicker,” with little or no information on care in the home. Patients and caregivers—especially non-English speakers—have difficulty finding information about condition-specific and home care, where or how to get help, eligibility for home and community-based services, home modification, and caregiver support. Informal caregivers (family, friends, and neighbors) play vital roles in assisting elders after discharge, but they are seldom included in discharge planning and receive little or no training in home care or support for their roles.

**Training of professionals serving seniors does not adequately address discharge planning and home care.** Inadequate training for discharge planners is a key reason why informal caregivers are not receiving the information and training they need. Most discharge planners, whether nurses or social workers, do not know the services available in their communities, and they cannot therefore relay that information to patients and their families. Physicians, nurses, social workers, and other providers serving seniors need specialized training to understand the needs of older patients.

**Care in the community is fragmented.** Home and community-based service providers operate independently of each other in their communities, a consequence of being administered and funded by a patchwork of state and local agencies. In addition, lack of availability, underfunding and conflicting eligibility requirements for services result in waiting lists, delayed care, and unmet needs. The episodic,

acute, and institutional focus of current long-term care policies and funding is outdated. A policy shift needs to occur emphasizing preventive care and chronic care management in the home rather than in skilled nursing facilities. In addition, more attention needs to be given to the continuity and coordination of care and to integrated delivery systems that extend beyond medical care to incorporate health and social services and caregiver training and support.

## RECOMMENDED ACTIONS

Our findings suggest the need for a wide range of actions targeting seniors and informal caregivers, providers, and health systems, as well as policy changes to support effective transitional care. Key recommended actions include the following:

1. Implement effective care coordination across sites, and leverage the potential of both providers and peer volunteers to help seniors recover safely at home.
2. Promote family-centered care to recognize the vital role of family and informal caregivers in helping seniors after a hospital stay, and the critical importance of assessing the caregiver's own needs for information and support to assure quality care in the home.
3. Implement risk/needs assessment at several stages: before a hospitalization, upon admission and prior to discharge from the hospital, within 72 hours after discharge, and at later stages.
4. Develop educational materials for seniors and caregivers to help them navigate the system of care and provide condition-specific and direct assistance during and after a hospital stay.
5. Train health care providers in effective discharge planning and transitional care.
6. Improve the cultural, linguistic, and literacy competencies of all providers.
7. Define transitional care as an explicit priority of professional associations, health systems, and governmental organizations.
8. Change policies to improve the availability and quality of transitional care. Recommended policy changes include the following:
  - Promote policy and program changes to Medicare, Medicaid, the Older Americans Act, and In-Home Supportive Services and increase funding for community services through these programs to support effective discharge planning and transitional care.
  - Simplify program eligibility. Expand care integration models that create single points of access to determine eligibility and connect seniors to multiple services.
  - Support and evaluate demonstration projects in enhanced discharge planning and transitional care, including in-home services.
  - Develop new privacy/confidentiality policies so that information can be shared across care settings with informed patient consent.
  - Reward physicians and hospitals that improve patient outcomes and reduce rehospitalization.
  - Amend state and federal family leave laws to give workers the right to more flexible schedules so that they can provide care while continuing to work.
  - Undertake home assessments, and invest in home modifications and durable medical equipment, to ensure safe recovery in the home.
  - Expand eligibility for public programs to meet the needs of the growing number of vulnerable seniors.

## Background

People ages 65 and older are the fastest-growing segment of the U.S. population. In California alone, the population over age 65 is projected to increase by more than 200% over the next 50 years. As this demographic trend continues, a much larger number of older adults are expected to use in-patient health care. While some will not be able to return to the community because of a debilitating injury or illness, most will be discharged to home. The transition from hospital to home is a crucial stage in the recovery of elders from injury or illness, and for some family members, it is the first point at which they assume a caregiving role. Consequently, attention to hospital discharge to home or hospice care should be a key component of health and long-term care planning.

A primary goal of short- and long-term care in the community is to help seniors function at the highest possible level and maintain independence for as long as possible. However, it is becoming increasingly difficult for discharge planners to help patients meet this goal. As older adults continue to be released from the hospital after shorter stays and in weaker condition, there is a greater need for post-discharge services at home. Research has repeatedly shown that such services are currently insufficient, unaffordable, and difficult to maintain. This increases the burdens on informal caregivers and puts discharged seniors at considerable risk for poor health outcomes.

Some seniors are at especially high risk following a hospitalization (e.g., those with multiple medical problems, dementia, depression or other mental health problems, isolated seniors who have no informal caregivers, non-English speakers, immigrants and refugees, and those in poverty or the near poor). Research also shows that informal caregivers are at greater risk for health problems and increased mortality as a result of the demands of caregiving. According to the Caregiver Health Effects Study, caregivers who report mental or emotional strain associated with caregiving are more likely to die than non-caregiving controls.<sup>1</sup>

Low literacy, and especially low health literacy, is also a serious problem among seniors moving through the health care system. The U.S. Healthy People 2010 defines health literacy as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.” Although there are no overall estimates yet of the health literacy of the U.S. population or of seniors, there are assessments of selected populations. One study of Medicare beneficiaries age 65 and above in selected managed health care plans in four states found that inadequate or marginal health literacy ranged from 27% to 44% for English speakers and from 40% to 76% for Spanish speakers, with significantly higher rates of inadequate or marginal literacy among those 85 and older.<sup>2</sup> Another study of public hospital patients found very low health literacy among participants age 60 and older; these patients had difficulty reading medication instructions and other advice concerning their health care.<sup>3</sup>

<sup>1</sup> Schulz, R., Beach, S. (1999). Caregiving as a Risk Factor for Mortality: The Caregiver Health Effects Study. *Journal of the American Medical Association* 282(23): 2215–2219.

<sup>2</sup> Gazmararian, J., Baker, D., Williams, M., Parker, R., Scott, T., Green, D., Fehrenback, S., Ren, J., and Kaplan, J. (1999). Health Literacy Among Medicare Enrollees in a Managed Care Organization. *Journal of the American Medical Association* 281(6): 545–551.

<sup>3</sup> Williams, M., Parker, R., Baker, D., Parikh, N., Pitkin, K., Coates, W., Nurss, J. (1995). Inadequate Functional Health Literacy among Patients at Two Public Hospitals. *Journal of the American Medical Association* 274(21): 1677–1682.

Another important consideration for populations with low health literacy is whether it affects their utilization of health care services and results in higher medical costs. Studies have shown that patients with low health literacy receive fewer preventive services, frequently fail to follow medication instructions, have worse health outcomes, and are more likely to have higher utilization of services. A recent study of seniors enrolled in Medicare managed care plans found that emergency room costs are significantly higher for seniors with low health literacy than for seniors with adequate health literacy.<sup>4</sup>

For seniors and caregivers with low health literacy, the transition from the hospital to home presents an added risk. These groups usually receive little information at discharge to help with recovery at home, and the information that is provided is not written at accessible reading levels or in culturally and linguistically appropriate formats. Even when literacy is not a barrier, seniors and caregivers are given information that does not address their specific conditions and care needs and that does not help them obtain the services they need. Few caregivers receive any training before their care recipient leaves the hospital.

Is the Bay Area prepared to respond to the growing need for improved discharge planning and transitional home care services? Where are the gaps in services, and who is at greatest risk? What changes will improve patient safety and prevent readmission? With support from the Gordon and Betty Moore Foundation, this project, *From Hospital to Home: A Strategic Assessment of Eldercare in the San Francisco Bay Area*, has sought to answer these questions and to provide a comprehensive understanding of the transitional care needs of Bay Area seniors and their caregivers.

Seniors are a growing and increasingly diverse part of our communities. The policies we set now can affect the well-being of seniors and their families for decades to come.



<sup>4</sup> Howard, D., Gazmararian, J., Parker, R. (2005). The Impact of Low Health Literacy on the Medical Costs of Medicare Managed Care Enrollees. *The American Journal of Medicine* 118 (4): 371–377.

## Demographic Projections of the Older Population

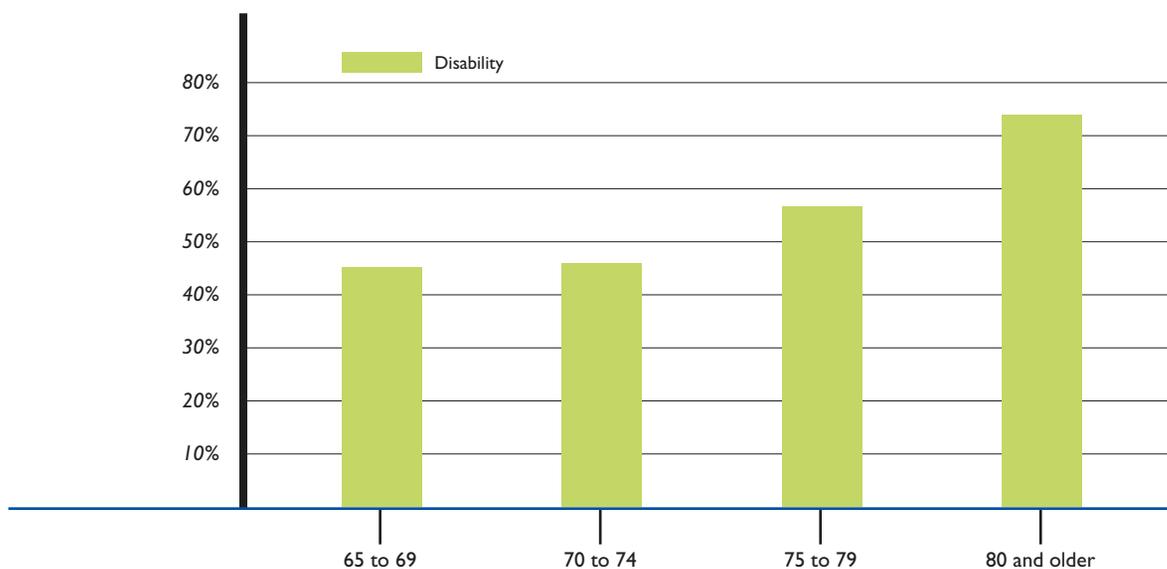
The number of California's seniors is expected to more than double by 2050. California now has 3.5 million people over age 65. This number is expected to increase to more than 7 million over the next 45 years. The greatest growth will be among those age 85 and older, whose numbers are projected to grow over 300%.

Acute and chronic health problems will increase as the population ages. Among persons age 65 and older, more than half have some form of disability; the rate of reported disability increases with age. African-Americans and Hispanics age 65 and older report higher rates of disability than non-Hispanic Whites.

Older Californians will be more ethnically diverse in the future. By 2050, it is estimated that Whites will make up only 31.2% of the over-65 age group, while the proportion of Hispanics and Asians will increase dramatically to 41.3% and 17.9%, respectively. Socioeconomic, racial/ethnic, and cultural factors, as well as language and literacy, will be increasingly important to consider in designing support systems for aging Californians and their caregivers.

**Figure 1**

*Disability Prevalence by Age*



Source: U.S. Census Bureau. (2001). From *Americans with Disabilities: Household Economic Studies, 1997*.

## Project Scope and Methods

The goal of the Hospital-to-Home study was to advance the understanding of the needs of older adults transitioning home after a hospital stay, including the needs of patients (care recipients) and their caregivers before, during, and after discharge. The objectives were to:

- Assess the services available in each of four study counties in Northern California (Alameda, San Francisco, San Mateo, and Santa Clara) for patients and caregivers during this transition.
- Assess unmet needs of patients and caregivers in each county during this transition.
- Identify populations that are especially vulnerable during this transition and assess the special needs of these populations.
- Identify potential interventions to increase access to services for patients and their caregivers during the transition from hospital to home.

The project analyzed the transition experiences of seniors and their informal caregivers (family, friends, and neighbors who are not paid to provide care) in the above four San Francisco Bay Area counties. The study team identified potential interventions and recommendations through a review of the scientific literature and through case studies, focus groups, and interviews with seniors, caregivers, providers, and policymakers (including project Advisory Board members and national experts).

Our research shows that some intervention strategies have helped to address significant gaps in post-hospital care. A variety of these evaluated interventions are described in the *Review of Literature*. The literature review also identifies approaches to improving discharge planning, post-discharge care, and on-going care for chronic conditions. Promising strategies include the following:

- Assessing, at admission, the needs for home-based services improves hospital-based discharge planning.
- Discharge planning supported by an interdisciplinary team, follow-up services, and monitoring helps to reduce rehospitalization.
- Empowering patients to navigate the health care system through use of a personal health record in collaboration with a transition coach—typically a geriatric nurse practitioner—helps to identify and respond to patients' questions (e.g., identifying signs of a worsening condition, obtaining needed information, and understanding reasons for taking medications). Outcomes included significantly reduced rates of rehospitalization.
- Post-acute or transitional-care services (often delivered by advanced-practice nurses or social workers as part of interdisciplinary teams) that continue for some period following discharge can help providers detect early changes in patient condition, change treatment plans as needed, and provide support to caregivers.
- Hospice services, which are commonly provided in the home and support both the patient and the caregiver, serve as a model for care that could improve outcomes for many older adults living with chronic, unstable, but long-lasting medical conditions, such as heart disease, chronic lung disease, cancer, and HIV. A wider application of the hospice model might allow older adults who currently end up in long-term care facilities to remain in the community.

## Project Scope and Methods

The strategic assessment included the following components:

1. **A comprehensive literature review:** This encompassed the hospital-to-home needs of seniors and their caregivers and included an examination of peer-reviewed studies both within and outside the United States, including interventions that were formally evaluated.<sup>5</sup>
2. **Qualitative research:** Services, problems and unmet needs, and information resources affecting patients and caregivers during the hospital-to-home transition were examined. Research components included the following:
  - 20 caregiver focus groups (in multiple languages and involving 166 participants, including health literacy assessments of 37 English-speaking caregivers)
  - 4 provider focus groups (nurses and social workers)
  - 45 key-informant interviews with service providers
  - 17 key-informant interviews with policymakers
  - 16 interviews with project Advisory Board members
  - 36 care-recipient health literacy interviews
  - 5 in-depth longitudinal case studies of recently hospitalized seniors
3. **Secondary data analysis:**
  - An assessment of discharge data for the four study counties from the Office of Statewide Health Planning and Development (OSHPD), California's statewide hospital discharge database, to examine the most common medical conditions at discharge in this area compared with national data from the 2001 National Hospital Discharge Survey.
  - Development and analysis of a caregiving module in the "Golden Bear Omnibus" statewide random-digit-dial telephone survey of California residents in August 2005. A subset of respondents who identified as unpaid caregivers were asked a series of questions about caring for an older adult.
  - Analysis of aging, caregiving, and depression data from the longitudinal Study of Physical Performance and Age-Related Changes in Sonomans (SPPARCS).

<sup>5</sup> See the companion report *From Hospital to Home: A Strategic Assessment of Eldercare in the San Francisco Bay Area, Review of Literature* for complete results.

## Key Findings and Recommended Actions

*Absolutely, we were totally in the dark, we knew there were some services that can be available . . . we really didn't know where to find [them]. . . . My mom's social worker was very hard to reach and we kept leaving messages, and finally we just came to know from a friend who happened to tell us how to approach them and how to get the required papers.*

–Caregiver

*Family members are untrained in how to care for people. People are discharged because they don't meet hospital criteria. Caregivers are not trained in level-of-care needs, especially transfer skills; and caregivers get hurt.*

–Provider

*Discharge planning is nonexistent. It occurs in the last hour of the hospital stay. It's not integrated, and no time is spent on it in the hospital.*

–Policymaker

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The key findings presented in this report were strongly supported from many sources, including older patients, caregivers, discharge planners and other hospital staff, home and community-based service providers, and policymakers, and are consistent with studies examined in our literature review.<sup>6</sup>

The report is structured to focus on eight findings, with accompanying recommendations and action steps. While there is necessary overlap among these key findings, we selected this way of presenting the findings to give a more comprehensive perspective on each issue and recommended action.

Recommendations to improve transitional care are targeted to seniors and informal caregivers, to professional service providers and health systems, and to federal and state policymakers. However, the critical problems we have identified in our study would be best addressed through concurrent implementation of these recommendations. While working to change policies that inhibit hospital discharge planning and community-based post-acute care, we also need to enhance the training of providers in more culturally competent care and effective discharge planning, and to educate seniors and their informal caregivers about obtaining community services and providing safe care in the home.

<sup>6</sup> See the *Review of Literature*.

## Key Findings and Recommended Actions

### FINDING 1

*Care transitions are an increasingly critical health and social problem for seniors and their caregivers.*

In our review of nearly 100 studies reported between 1985 and 2001, we found that the transition of

elders from hospital to home was associated with high rates of poor outcomes after discharge, including rehospitalization.

Caregivers in our focus groups reported being unprepared because their care recipient was discharged from the hospital prematurely. Many felt that their care recipient was rushed out of the hospital. They felt that premature discharge, often with inadequate information,

put the patient at risk for complications and the caregiver at risk for health problems associated with

the caregiving role. While specific actions are needed to better prepare seniors and informal caregivers for hospital discharge, as described in Findings 4 and 5, there is also a need for much broader awareness of the potential risks associated with care transitions.

### RECOMMENDATION 1.1

**Increase public awareness of transitional care issues for seniors.**

#### ▶ ACTION 1.1.1

Launch a public information campaign to educate seniors and their families about issues associated with hospitalization and the transition from hospital to home and other care sites. Emphasize personal stories to dramatize potential problems following a hospitalization.



Rehospitalization is one of the poor outcomes frequently associated with inadequate discharge planning and support.

### FINDING 2

*Some seniors are at very high risk for rehospitalization and increased morbidity and mortality after discharge.*

Elders with multiple medical problems, functional deficits, cognitive impairment, emotional problems, and poor general health are at particular risk during this transition. Provider and policy key informants reported that we are failing to meet the needs of vulnerable seniors, and emphasized that a one-size-fits-all approach to transition services is simply not sufficient, given the ethnic and economic makeup of the San Francisco Bay Area.

Diverse populations are at high risk:

**Non-English speakers, racial and ethnic minorities, and recent immigrants** face language and cultural barriers and often do not understand verbal and written communication.

*Non-English speakers are isolated from services.*

*They don't know how to ask for services.*

—Provider

*I really wasn't prepared for it and emotionally I felt terrible because I arrived to this country alone with my husband. My two . . . children are in El Salvador, so I felt I had no support from anyone.*

—Caregiver

## Problems with Hospital-to-Home Transitions

Discharge planning is inadequate.  
 Transitional care is not coordinated across sites.  
 Eligibility is inconsistent.

Patients lack caregivers or other advocates.  
 Resources are limited, especially for those facing language and cultural barriers.  
 The system is biased toward institutional care.



### Problems/barriers in the hospital:

Little or no discharge planning  
 Limitations of nursing paradigm/medical model  
 No home assessment before discharge  
 Poorly trained discharge planners  
 Providers not trained in geriatrics or culturally competent care  
 Caregiver not included in unit of care  
 Lack of incentives for good transitional care



### Problems/barriers at home:

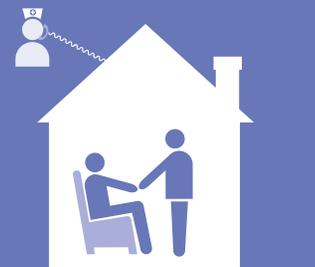
No post-discharge follow-up  
 Lack of caregiver training and support  
 Inaccessible information (due to language/literacy barriers)  
 Unrealistic expectations of caregivers' abilities



## COMMUNITY-BASED SERVICES

### Problems/barriers with CBS:

Lack of referrals to needed services  
 No information to help families compare quality of services  
 Lack of centralized services, requiring visits to many sites  
 Delays in accessing services  
 Cost and unavailability  
 Inadequate training/high turnover of workforce  
 Lack of transportation



## Key Findings and Recommended Actions

*Hospitals discriminate against the [poor] and more so if you're Latino. For example, there were an American and a Latino [at the hospital] and always they'll give preferential treatment to the American and will leave the Latino aside, even if the Latino person arrived first. To me, that's discrimination. . . . I can't even speak just thinking about it.*

—Caregiver

According to the California Statewide Survey of Caregivers (CSSC), caregivers reported two barriers to the use of services: providers not speaking their language, and services not being offered by people similar to them.<sup>7</sup>

**Isolated seniors** have no one to act as their advocate when they are ill or hospitalized and no one to help with post-hospital caregiving needs and planning. They are especially at risk when the short-term services covered by insurance plans run out, because isolated seniors have no informal caregivers to provide care.

At discharge, many seniors are weakened and disoriented. For those without caregivers, the post discharge risks are high.



*After I came home from the hospital, I had a [home health aide] for a few weeks who helped me take a shower. Two weeks ago they cancelled her because they said my insurance didn't cover it. I haven't washed my hair in two weeks.*

*Can you imagine?*

—Isolated Senior

**Middle-income seniors** do not qualify for public programs yet often lack the financial resources to purchase the care they need. The CSSC also found that high cost was a common barrier to service use.<sup>8</sup>

*I find that so many of the agencies . . . they'll do all kinds of things as long as you're poor, but if you have any kind of resources, they're not helpful. I mean if you're willing to pay for them, it's not easy to know where to go.*

—Caregiver

**Low-income seniors** suffer a range of hardships associated with living in poverty. Key informants pointed out that, unlike middle-income seniors, low-income seniors do at least qualify for public programs. However, impoverished seniors face many other barriers to care, such as lack of transportation and other social supports and access to care facilities.

**The uninsured** have very limited access to services and lack the resources to pay for services.

**High-income seniors** are not immune to the impact of diseases with a high burden of caregiving, such as Alzheimer's, even though they may be able to purchase services. Having the money to pay for care takes away one source of stress but does not eliminate the emotional impact of having a debilitating condition or being the caregiver for someone who does. Even seniors who can afford to pay for services have difficulty finding services of acceptable quality.<sup>9</sup>

**People with depression** also have an important risk factor. Depression is associated with a variety of health and functional problems and has health implications for both care recipients and caregivers. Caregiver depression may worsen with the additional strain of caregiving. In particular, a husband's health status may increase the wife's risk for depression.

<sup>7</sup>Scharlach, A., Dal Santo, T., Lehning, A., Gustavson, K., Lee, S., Auh, E., Fox, P., Chow, J., & Hung, W. (2005). *Family Caregiver Support Project Summary of Activities: Year One*. Berkeley, CA: University of California, Center for the Advanced Study of Aging Services.

<sup>8</sup>Ibid.

<sup>9</sup>Ibid.

## RECOMMENDATION 2.1

Improve cultural, linguistic, and literacy competencies of providers.

### ▶ ACTION 2.1.1

Improve cultural and linguistic training of health professionals in hospitals and home and community-based services.

- Examine existing training models (such as those developed by the American Society on Aging) for wider application.
- Include cultural and linguistic competencies in the training of future health professionals.
- Identify opportunities for ongoing training and for reinforcing this training (e.g., through mandatory certification of unlicensed workers and state licensing requirements for clinical professionals).

- Offer financial incentives for health care organizations to enhance and expand bilingual staff competency. Ensure that hospitals can gain access to some type of federal or state funding to meet federally mandated language accessibility requirements.

### ▶ ACTION 2.1.2

Increase the degree to which health care professionals interact with and learn about the communities they serve.

- Require medical and nursing students to perform rotations in community clinics that are known to effectively serve seniors with diverse racial/ethnic/language backgrounds and literacy levels.
- Bring community representatives to speak at staff meetings in hospitals and home and community-based services, to provide information and training relevant to the care of specific local communities.



Improving the cultural competencies of the workforce will help us reach diverse seniors more affectively.

## FINDING 3

*Transitions can be dangerous for seniors, and their care is seldom coordinated.*

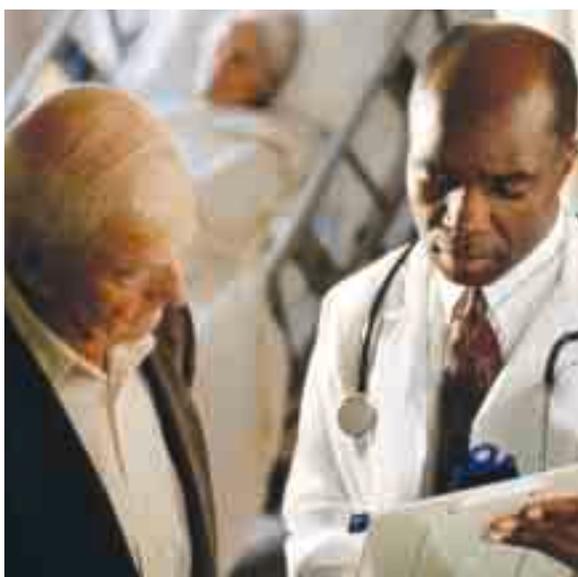
Discharge from hospitals to home care can be dangerous for seniors. In addition, seniors often make several transitions after leaving the hospital (e.g., to skilled nursing facilities for rehabilitative care, then to home), yet no single provider monitors the patient across care sites. The result is inefficient care coordination and mistakes in care, such as multiple physicians prescribing medications that are contraindicated for the patient. Even when public or private case-management programs are utilized, they are often not brought into the discharge planning process until after the patient has arrived home.

Providers and policymakers stressed poor communication between hospitals and home and community-based services, poor education of hospital personnel on community resources, and language barriers as major problems placing seniors at risk.

## Key Findings and Recommended Actions

*The receiving provider gets inadequate information. . . . There is a lack of information flow from the hospital to discharge planning, community care managers, therapists, family members.*

–Policymaker



*Information doesn't follow the person in a timely way. . . . Orders like rehab can take a week. Services stop and start. Or the therapist shows up and doesn't know what the patient had done previously in another setting.*

–Policymaker

Discharge planning should begin well before the patient leaves the hospital, and family caregivers, such as this husband, should be involved.

There is also a need for an ongoing contact person to assess services, assist with financial and coverage determinations, and provide support. However, with the exception of those who can afford private case management and the small number of disabled and frail elders who qualify for case management programs funded by Medi-Cal, care coordination is rarely available to community residents. The lack of in-hospital, post-discharge planning means that patients' needs are not identified or addressed until they have already arrived home. Services may not start for days or weeks, particularly if programs have waiting lists.

*When the patient leaves the hospital setting and goes home and there are questions, there's no one person they can turn to for information.*

–Policymaker

*We need some sort of advocate, perhaps trained volunteers, who can follow the patient from the discharge into their home to confirm that the homecare services are implemented. This person would have the authority to make calls and arrange services if there is a problem. We need this bridge to restart services and confirm [that] the services that should be in place are in fact in place.*

–Provider

### RECOMMENDATION 3.1

**Improve discharge planning and transitional care across sites, and begin discharge planning before hospitalization.**

#### ▶ ACTION 3.1.1

Create a consent mechanism that enables patients to approve sharing of information among providers (and volunteers) at inpatient, outpatient, and post-discharge care sites.

- Use a “Durable Power of Attorney” model or add a space on the HIPAA form.
- Begin this process before hospitalization, if possible, to get a head start.
- Provide consent forms in several languages and in low-literacy formats, and explain the purpose and importance of this consent.
- Include informed consent to share information in both electronic and non-electronic health records.

#### ▶ ACTION 3.1.2

Assign responsibility to hospital staff or volunteers to follow up with patients after discharge, to ensure that they are getting needed services. (See Action 3.2.1 for recommendations on follow-up as part of risk assessment.)

### ▶ ACTION 3.1.3

Increase the use of care coordination positions to monitor and support patients after discharge.



Patients often leave the hospital with new prescriptions and inadequate instructions. There are potentially dangerous interactions with medications the patient is already taking.

- Eliminate the influence of adverse financial incentives (i.e., for hospitals to discharge patients before the diagnosis-related group [DRG] average length of stay is exceeded) by establishing care coordinator positions in local community organizations that are independent of the hospital.
- Have care coordinators educate hospital discharge planners on transitional care needs and resources.

- Link care coordinators with peer advocates and caregiver support programs.
- Create a feedback loop with caregivers to share information about care.

### ▶ ACTION 3.1.4

Encourage broader adoption of financial incentives that link cross-institutional performance to provider pay—such as the pay-for-performance demonstrations begun under the Centers for Medicare & Medicaid Services (CMS). Examine the process for unintended consequences of health system changes, such as the risk shifting that occurred with the implementation of DRGs.

## RECOMMENDATION 3.2

**Implement risk assessment of seniors and caregivers.**

### ▶ ACTION 3.2.1

Develop a framework that could be used at or before admission to assess seniors' risks for post-discharge problems. Risk tools should assess medical, psychological, social, and environmental factors for patients and caregivers (including health status, proximity of caregiver to patient, and ability of caregiver to provide care in the home). Conduct risk assessments

before admission when possible, at admission, before discharge, within 72 hours after discharge, and at intervals up to six months after discharge.

- Determine who will conduct the risk assessment(s). Coordinate this responsibility with discharge planning and post-discharge care coordination. Identify financial incentives to compensate parties for assuming this responsibility and to ensure that risk assessment is followed up with services after discharge.
- Assess the risks for and signs of depression and other mental or behavioral problems in both care recipients and caregivers. Ensure that services are available if needed.
- Develop a set of standards for risk assessment and begin by assessing the highest-risk groups; expand the scope of assessment as models demonstrate good results.
- Link measures to evaluate the efficacy of risk assessment, such as tracking hospital readmission rates and changes in care costs.

### ▶ ACTION 3.2.2

Identify existing and emerging risk assessment models (e.g., caregiver assessment principles and guidelines being developed through a national effort by the Family Caregiver Alliance), and review use of risk assessments in other efforts (e.g., California's Acute and Long-Term Care Integration Program). Assess the potential of adopting these models.

### ▶ ACTION 3.2.3

Work with health care systems to incorporate risk assessment into the discharge planning process; integrate risk tools and information into electronic health records as these systems develop under federal mandates or to meet a system's own goals.

### ▶ ACTION 3.2.4

Assign responsibility to hospital staff or volunteers to follow up with patients after discharge in order to ensure that needed services have been obtained.

### RECOMMENDATION 3.3

**Reward hospitals that incorporate longitudinal risk assessments to capture changing health status and needs.**

#### ► ACTION 3.3.1

Use prospective payment systems under which facilities could be paid more if they use risk assessments to improve patient outcomes, to reduce re-hospitalization (and reduce more expensive skilled nursing care within integrated health systems), and to better secure needed in-home services after discharge.

### RECOMMENDATION 3.4

**Develop peer-support programs that use seniors as volunteers.**

#### ► ACTION 3.4.1

Implement and evaluate a pilot program that trains seniors as volunteer peer advocates who assist other seniors and their caregivers during the hospital-to-home transition.

- Examine and adapt existing peer-advocacy models such as the Health Insurance Counseling and Advocacy Program (HICAP) and Civic

Venture's Experience Corps and work with organizations that have experience promoting community involvement by seniors (e.g., Planning for Elders in the Central City in San Francisco, UC Berkeley's Senior Leaders Project, and the Neighbor-Helping-Neighbor Program developed by Jewish Family & Children's Service in West Palm Beach, Florida).

- Provide resources for seniors to use in advocating for their peers.
- Expand existing hospital-based programs and create new ones to train seniors volunteering in hospitals to provide follow-up calls to discharged patients.



The peer-helper model, used in Meals on Wheels and HICAP, could help bridge the gap between the current state of post-discharge support for seniors and what is needed.

## FINDING 4

***Hospitals do not prepare patients and caregivers adequately for discharge.***

Largely as a result of reimbursement policies based on diagnosis-related groups (DRGs), patients are discharged “quicker and sicker.” As hospital stays have been shortened and health care costs have risen, many hospitals have minimized discharge planning. Discharge planners are poorly trained; they are overwhelmed by large caseloads and do not have time to provide adequate services to patients.

Data from the California Statewide Survey of Caregivers show that informal caregiver use of education and training services in 2002 was associated with preventing the movement of the care recipient into long-term care.<sup>10</sup> However, in our study, patients and caregivers reported receiving little or no training in home care. The result is a devastating breakdown in continuity of care; patients and caregivers must fend for themselves after discharge.

<sup>10</sup>Scharlach, et al., 2005.

*Even my dentist since I had some dental work done . . . called that evening and said, “How you are doing? Has your bleeding stopped?” And then you go into the hospital and have major surgery and you go home. You don’t hear from these people. You know, you are in pain. They might tell you, uh, you see redness . . . come back or give us a call, come to the emergency room. That’s the extent of discharge information or instructions.*

–Caregiver

## RECOMMENDATION 4.1

Provide training for patients and their family caregivers.

### ▶ ACTION 4.1.1

Form partnerships with existing caregiver organizations to develop and distribute specific information for caregivers on post-acute care tasks, including bathing, lifting, and injections, as well as self-care for caregivers.

*Discharge planners don’t have enough time to dedicate to planning since the patient turnaround is so quick. We need a system for discharge planners to engage community partners in the planning.*

–Provider

### ▶ ACTION 4.1.2

Develop hospital and home-based patient and informal caregiver training modules specific to the medical needs and conditions of diverse patients after discharge.

### ▶ ACTION 4.1.3

Create Care Support Centers in hospitals for education and training, where patients and family caregivers can watch videos and DVDs, find print and online resources, connect with volunteers, and be referred to community-based caregiver support programs and in-home services.

## RECOMMENDATION 4.2

Involve clinicians more fully in the discharge process and training.

### ▶ ACTION 4.2.1

Develop checklists with specific information by medical condition. Have physicians and nurses use the checklists to tailor their attention and guidance to the specific needs of patients during the transition to home. Encourage professionals to use checklists when reviewing issues and home care needs with patients and when providing patients with take-home copies. Develop and promote the use of practice guidelines supporting the use of care checklists, and seek adoption of these guidelines by medical associations.



Caregivers are often faced with daunting medical care tasks after discharge. Training for caregivers is an essential part of effective transitional care.

## Key Findings and Recommended Actions

### RECOMMENDATION 4.3

Support and evaluate implementation of new JCAHO indicators on hospital discharge planning and transitional care as part of the hospital accreditation process.

#### ▶ ACTION 4.3.1

In response to implementation by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) of additional indicators to assess the effectiveness of discharge planning and transitional care, recommend that an independent study be funded to assess compliance with new JCAHO requirements. The study will ideally include several health care organizations, and be structured to ensure the anonymity of organizations to encourage their participation and identify problems that might be impeding compliance with new criteria. Consider at an early stage imposing no penalties for compliance problems so that hospitals can get feedback without fear of losing accreditation.

### RECOMMENDATION 4.4

Incorporate transitional care into the program priorities of relevant federal organizations.

#### ▶ ACTION 4.4.1

Share these research findings with relevant government agencies and recommend that they include transitional care as a priority within their areas of oversight (e.g., ensuring cultural competency of health care providers and providing high-quality care to underserved populations). Include the Administration on Aging, the National Institute on Aging, and the U.S. Department of Health and Human Services' Office of Disability, Aging, and Long-Term Care Policy, as well as the Health Resources and Services Administration's Bureau of Health Professions and Bureau of Primary Health Care.

## FINDING 5

*Seniors and caregivers are not informed or trained in critical home-care needs after a hospitalization.*

Patients and caregivers lack the information and training critical to ensuring safe recovery at home. They have difficulty finding information about a myriad of issues, including medical problems; home care; care for specific conditions; where to go and whom to call for help both during and after a hospital stay; eligibility for home and community-based services and how to arrange them; home modification; caregiver emotional and physical self-care; and information in the patient's and caregiver's language(s). According to the California Statewide Survey of Caregivers, information, education and training were the services most commonly used by informal caregivers, but information was also one of the services most frequently reported not to meet caregivers' needs.<sup>11</sup>

Caregivers in our study reported that the information the hospitals provided was inadequate, incomplete, or uncoordinated. They did not know what information to look for, and they found hospital staff—especially physicians—unhelpful. They needed individualized information in multiple forms: verbal, written, and video. These issues were intensified for non-English speaking patients and caregivers.

*I didn't know what questions to ask or what information to even look for. What is important for me was to have someone that had a family member who went through the similar issues basically that their parents went through . . . surgeries or an illness. Basically, they would tell me what questions to ask the doctor, what questions to ask the social*

<sup>11</sup> Scharlach, et al., 2005.

worker or the nurse . . . find out what information to ask for. I didn't know where to get a lot of information to begin with, but I didn't even know what to ask.

–Caregiver

## RECOMMENDATION 5.1

**Develop and distribute new resources and increase awareness of existing resources.**

### ► ACTION 5.1.1

Produce educational materials and related resources to address the pre- and post-discharge needs of diverse seniors and caregivers. The resources should provide integrated, easy-to-use, and culturally appropriate guidance in the following areas for readers with a range of literacy levels.

1. Information to empower patients and promote advocacy by the care recipient:
  - How to talk to your doctor
  - Your rights while in the hospital
  - How to navigate and negotiate the system

2. Resource guides and referrals that promote better access to home and community-based services:

- Information on community services (AAAs, Medicare, Medicaid/Medi-Cal, senior centers, volunteers, paratransit, etc., with key contacts highlighted)
- Eligibility criteria for services
- Facilitated referrals
- Caregiver support programs

3. 24-hour telephone support through advice and information lines, especially about where to get help when problems arise at home or with in-home services

4. Individualized, condition-specific information (in multimedia formats, including print, DVD/video, and Internet):

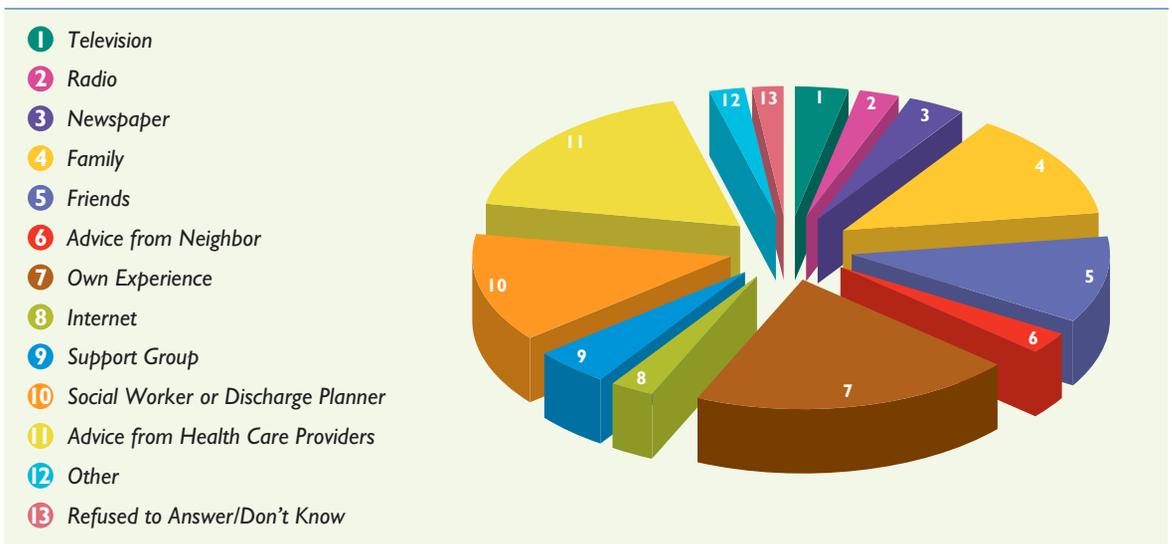
- Information tailored to the patient's and family's needs
- Care advice, danger signs, and phone numbers for getting help

The person going home and their family have no idea and understanding of what it takes to manage at home. . . . If they aren't aware of services, they don't know how to try to get them.

–Provider

**Figure 2**

Information Sources Used by Caregivers



## Key Findings and Recommended Actions

### ▶ ACTION 5.1.2

Increase the awareness and availability of existing resources that help seniors and caregivers with the hospital-to-home transition. Form partnerships to distribute resources before, during, and after hospitalization through:

- Physician groups and health systems
- Organizations that serve seniors, such as AAAs, senior centers, and adult day health centers
- Organizations that serve caregivers, such as Family Caregiver Alliance and the Alzheimer's Association

- Organizations that train and offer continuing education to providers, such as the American Society on Aging
- Employee assistance and eldercare programs, such as those offered by large employers

### ▶ ACTION 5.1.3

Adapt existing information models for use in transitional care. For example, adapt hospice materials for use in post-discharge home care, and adapt information to multimedia formats to enhance usability and improve access to people with low health literacy.

## FINDING 6

***Professionals serving seniors are not adequately trained in effective discharge planning, post-discharge home care, and transitions across care sites.***

Inadequate training for discharge planners is a key reason why informal caregivers are not receiving information about appropriate services and training on how to provide care. Most discharge planners, whether nurses or social workers, do not know the services available in their communities.

*This [home health aide] who had 12 years of experience was very loving to my mother. But she couldn't read a thermometer. She couldn't take blood pressure. She couldn't keep the blood pressure cuff on. She didn't know how. I told her exactly how to transfer my mother and she let her fall the first time by not following any of the directions that I gave her.*

–Caregiver

Physicians, nurses, social workers, and other providers also need specialized training to understand the needs of their older patients and to enhance their cultural competency to better serve

patients and caregivers from diverse backgrounds and with limited English language skills. Research shows that differences in language and culture can have major impacts on the quality and safety of care, and that disparities in health services and outcomes are associated with race, ethnicity, and language.

*The doctor yelled at us because nobody was able to communicate with him. He said in a very angry tone that an interpreter was badly needed at that time and [asked] why my daughter who understands English left. He yelled at us that he didn't need people like us around, what he needed was an interpreter.*

–Caregiver

*People don't know about services that are available, and the hospital doesn't tell them. Among hospital discharge planners, RNs don't know about home and community-based services and resources.*

*Social workers are a little better.*

–Provider

## RECOMMENDATION 6.1

### Enhance training and education of providers.

#### ▶ ACTION 6.1.1

Develop professional training modules on discharge planning and transitional care.

- Incorporate the modules into academic training programs and continuing education for providers.
- Include modules on family issues for patients with Alzheimer's and other dementias, high-risk conditions, and mental health problems.

#### ▶ ACTION 6.1.2

Create opportunities for cross-disciplinary and cross-site education and training.

- Develop mandatory cross-disciplinary training (e.g., including social workers and physicians in training modules for nursing students).
- Include paraprofessionals in cross-disciplinary team training.
- Establish ongoing, multidisciplinary meetings of staff from hospitals and from home and community-based services to encourage shared planning and care management and communication across care sites.

#### ▶ ACTION 6.1.3

Provide information resources for providers to use with patients and informal caregivers in discharge planning and home care, and train providers on use of these materials.

- Develop and provide information on local resources, with attention to the cultural and linguistic needs of patients.
- Implement this recommendation to support the new communication requirements of the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) and to improve compliance with current federal mandates for linguistically accessible health communications.

(Effective January 1, 2006, revisions made to Information Management standard IM.6.20 require hospitals to collect information on the language and communication needs of patients.)

#### ▶ ACTION 6.1.4

Partner with leading professional associations (e.g., the American Medical Association, the American Nurses Association, the National Association of Social Workers, the Council on Social Work Education, the American Society on Aging, and the American Geriatrics Society) to promote implementation of transitional-care training across academic disciplines, as part of continuing education for certification or licensing and as tracks at professional conferences and meetings.

#### ▶ ACTION 6.1.5

Recommend to government and professional regulatory bodies (e.g., the Medical Board of California, the California Board of Registered Nursing, California's Board of Behavioral Sciences, the American Board of Medical Specialties, the National Association of Social Workers and others) that they include training on transitional care as part of their requirements for professional board certification and licensing.

#### ▶ ACTION 6.1.6

Develop new certification processes and care standards for training paraprofessionals so that they can perform some tasks now allowed only by nurses or social workers, such as administering medications, monitoring respirators, treating wounds, assessing ADLs (activities of daily living), and conducting home assessments.

#### ▶ ACTION 6.1.7

Provide in-service training to paraprofessionals (e.g., In-Home Supportive Services [IHSS] workers and others who provide personal care), who currently have fewer existing mechanisms for training. For example, include no-cost or low-cost tracks for workers at conferences sponsored by professional associations. Work with IHSS Public Authorities to implement such training.

*Many medical care providers are not trained to work with geriatric populations, especially when it comes to cultural competence.*

—Provider

## Recommended Improvements in Hospital-to-Home Transitions

HOSPITAL

### **Seniors/Caregivers**

- Increase public awareness of transitional-care issues.*
- Provide empowering information and training for patients and caregivers.*
- Provide information about local resources.*
- Ensure that information is comprehensive, easy-to-use, and appropriate for patients with different cultural backgrounds, languages, and literacy levels.*
- Include caregivers in discharge planning.*
- Create care support centers in hospitals.*
- Develop peer advocacy programs using seniors as volunteers.*
- Provide advice and information through 24-hour phone support.*

### **Providers/Health Systems**

- Begin discharge planning before hospitalization.*
- Train providers on effective discharge planning and care for seniors.*
- Assess risks/needs of both patients and caregivers.*
- Train providers on culturally competent care.*
- Develop informed consent for information flow across sites.*
- Coordinate care and case management across sites.*
- Provide in-home follow-up.*
- Evaluate facility compliance with new JCAHO transitional care measures.*

### **Policy**

- Make transitional care an explicit public policy priority.*
- Change regulations and laws to improve transitional care.*
- Pilot enhanced transitional care, based on the hospice model.*
- Modify the Medicare hospice benefit to cover serious chronic illness and transitional care.*
- Link cross-institutional performance to provider pay.*
- Amend family leave laws to accommodate family caregiving needs.*
- Change reimbursement policies that create a bias toward institutional care.*
- Allow/fund IHSS workers to assess needs before discharge and conduct home assessments.*
- Cover costs of minor home modifications that would ensure patients' recovery at home.*
- Increase funding under the Older Americans Act and Medicare for home and community-based services and case management during transitions.*
- Make transitional care, not just skilled care for homebound patients, a Medicare benefit.*

HOME

### FINDING 7

*The medical system does not consider or support the critical role of informal (unpaid) caregivers.*

Family caregivers play vital roles in assisting elders after hospital discharge. One-fourth of caregivers

report that there is no one else who could help their care recipient if they were unable to do so. They do not receive adequate education and information about home care and community resources. Further, the medical and social service systems do not acknowledge the role of caregivers in discharge

planning and therefore do not assess, train, and support them in their caregiving roles.

Family members provide over two-thirds of home care, and caregivers report that informal support from family and friends is the most common source of help in the home. Yet, in the words of one key informant, “Caregivers are nowhere on the map.” According to one study, 75% of caregivers said they received no teaching or discharge planning during the patient’s hospitalization; only 25% reported feeling included in discharge planning. They are not seen as part of the unit of care and therefore neither caregivers nor the home environment are assessed during the discharge process. As a result, the abilities, resources, and skills of informal caregivers are often overestimated.

*Family members are untrained in how to care for people. People are discharged because they don’t meet hospital criteria. For example, the patient needs two-person assist and colostomy change. Caregivers are not*

*trained in that level of care needs, especially transfer skills; and caregivers get hurt.*

–Provider

*Can they give shots? Here is a real example: a husband with dementia who is resistant to care. The wife has macular degeneration, and she has to give shots because Medicare cut this back. Medicare says there is a caregiver and she can do it. What is the ability of the caregiver?*

–Policymaker

Training for caregivers is not part of discharge planning or follow-up. This is particularly disturbing because home care is increasingly complex and patients are often discharged with complex care needs.

Caregivers themselves reported increased physical and emotional problems as a result of caregiving, as well as a negative impact on their work and finances. Maintaining the physical and emotional health of caregivers, and especially long-term caregivers, is a priority need.

*I lost my job—I had to stay there with her, helping her out. I was fired because I missed a few days of work, so this made it more difficult for me to take care of her.*

–Caregiver

*I want to make it so clear that the role of being a caregiver affects your finances, your job if you have one, your family life, your own health, your emotional well-being, your mental well-being.*

–Caregiver



Family members often want to help, but the medical system must meet them halfway, with recognition of and support for their crucial roles.

## Key Findings and Recommended Actions

### RECOMMENDATION 7.1

#### Enhance caregiver support.

##### ▶ ACTION 7.1.1

Recognize and integrate caregivers as part of the unit of care and as an integral part of the care team. For seniors who do not have informal caregivers, identify an individual, such as a peer volunteer, who can act as a “care buddy” and advocate on the senior’s behalf throughout the hospital discharge process and transition to home.

##### ▶ ACTION 7.1.2

Encourage the development and evaluation of innovative models in team caregiving, in which family, volunteer, and/or professional caregivers partner to assist with caregiving responsibilities. For example, the Share The Care program organizes family members, friends, neighbors, and colleagues to assist with caregiving tasks identified by the patient and family. Help can include personal care as well as day-to-day tasks such as transportation to appointments, childcare, grocery shopping, meal preparation, and pet care.

##### ▶ ACTION 7.1.3

Increase the awareness and expand the availability of caregiver resources and support groups (such as those of the Family Caregiver Alliance through their

National Center on Caregiving) and other support services (such as telephone or online programs) to provide emotional assistance and respite for caregivers and information on providing and obtaining home care.

##### ▶ ACTION 7.1.4

Encourage the development and evaluation of caregiver assessment protocols in hospitals to systematically identify and assess the caregiver’s own needs for information and support before the care recipient is discharged. (See also Recommendation 3.2 regarding implementing risk assessment of seniors and informal caregivers.)

### RECOMMENDATION 7.2

#### Expand current laws to give family caregivers more leeway and flexibility to support their caregiving roles.

##### ▶ ACTION 7.2.1

Amend the federal and California family and medical leave laws, which currently allow periods of accrued or unpaid (federal) and paid (California) leave for caregiving, to also require employers to allow workers more flexibility in their schedules and other conditions of employment in order to provide care for a family member while continuing to work. Expand eligibility to include care recipients other than spouses, parents, and children.



Assessment of the patient’s—and the caregiver’s—risks and needs should take place before discharge from the hospital.

## FINDING 8

### *The system of care for seniors is badly fragmented and outdated.*

Public and nonprofit home and community-based services are often administered and funded by a patchwork of state and local agencies, resulting in a confusing array of services with differing eligibility requirements. Further, lack of funding results in limited availability of services, waiting lists, delayed

care, and unmet needs. In addition, publicly funded and private services operate independently of each other and provide only selected services, which generates confusion among seniors and informal caregivers who need a range of post-acute care services at home.

The episodic, acute, and institutional focus of current long-term care policies and funding is outdated. A policy shift needs to occur toward preventive care, chronic care management, continuity and coordination of care, and integrated delivery systems that incorporate medical and social services as well as caregiver training and support. Policymaker key informants shared policy, fiscal, and/or regulatory causes for hospital-to-home transition problems. Their responses focused on the following four problem areas:

- **Limitations of current financing and reimbursement mechanisms** don't allow many of the services that consumers, discharge planners, and providers identify as missing or unavailable.
- **Lack of funding** for services that exist or that need to be developed to address current service problems, gaps, and unmet needs.
- **Fragmented and disjointed funding streams and administrative authority**—coupled with rigid and outdated regulatory requirements—impede access, continuity, and coordination of care.
- **Inadequate data flow and privacy/confidentiality policies** prevent information from following patients across care settings.

The policymaker key informants were asked to identify specific programs and funding streams that are associated with the problems patients and caregivers encounter. The most frequently mentioned programs were Medicare, Medi-Cal (California's Medicaid program), case management, In-Home Supportive Services (IHSS), and the Older Americans Act (OAA).

**Medicare** was seen as a good program for acute and skilled care. However, it does not adequately address the preventive and chronic care needs of seniors now and in the future.

*Medicare is an amazing program for skilled needs for a large population and meets acute care needs. But what about after? People don't qualify. . . . Medicare has stayed where it was in the 60s. How do we design a system to address chronic needs? . . . When Medicare stops, there's no there there, but people are only [physically] at 70% of where they were before they needed care. How do we fill the gap? Medicare needs to be updated and revamped.*

—Policymaker

Problems associated with Medicare include the following:

- Lack of a non-institutional long-term care benefit, including transitional services, case management and home and community-based services for chronically ill seniors
- Limits on services
- Rules of use that lead to cost shifting
- Inadequate discharge planning and premature discharge

**Medi-Cal** was most commonly criticized for its priority on reimbursing nursing home care rather than home and community-based services, as well as for eligibility criteria that require users of both institutional and community-based long-term care services to be frail elders who need skilled care. Medi-Cal case management is limited to this population through home and community-based waiver programs like the Multipurpose Senior Services Program (MSSP), Programs for All-Inclusive Care for the Elderly (PACE), and the Linkages Program. These waiver programs serve small numbers of people but are the only route to non-institutional care. Further, there is no case management available for chronic care needs that could delay or prevent the need for skilled care. Medi-Cal's low provider reimbursement rates and lack of an assisted-living benefit were also concerns.

## Key Findings and Recommended Actions

*Lack of integrated payment systems makes it hard to put money into home and community-based services. Providers see nursing homes as the default. By policy, Medi-Cal funds skilled nursing facilities and not home and community-based services except through waivers. There is institutional bias that's hard to change at all levels of government.*

–Policymaker

**Medi-Cal model case-management programs such as MSSP and PACE** serve only the frail elderly

(those needing a skilled level of care), can enroll only a small number of people in each county, and are available only to people who require nursing home-level care.

*Medicare is an amazing program for skilled needs for a large population and meets acute needs. But what about after?*

–Policymaker

Case management for the population not served by Medi-Cal is available only on a fee-for-service basis, paid for by the patient and family. The cost is prohibitive for the near poor and for many middle-income patients.

*Research shows that case management reduces mortality. It needs to be consumer-driven and reported. Throwing tons of services at people doesn't work. . . . There are case-management models that work.*

–Policymaker

**In-Home Supportive Services (IHSS)** is a program for Medi-Cal beneficiaries. It allows consumers to find and hire workers to assist with personal care, homemaking, chores, and transportation. IHSS workers can be family members. While beneficiaries can receive as many as 283 hours of assistance per month, they rarely receive more than 100 hours. The number of allowed hours each month is based

on an assessment of the beneficiary's ability to perform activities of daily living (such as eating, bathing, and dressing independently).

IHSS problems include: cost (which more than doubled from \$1.39 billion in FY 1998–1999 to \$2.8 billion in 2002–2003 with a 52% increase in caseload); fiscal sustainability given anticipated increases in demand; and the long delay from application to receipt of services. In addition, there are program restrictions that limit IHSS's adaptability, for example, participants sharing an apartment cannot share an IHSS worker's time.

**The Older Americans Act (OAA)** funds Area Agencies on Aging programs throughout the U.S. as well as the National Family Caregiver Support Program. Problems with OAA programs identified by the key informants included funding limitations and restrictions, entrenched local funding processes, and eligibility criteria, including age.

### RECOMMENDATION 8.1

**Promote policy changes that support efforts already under way to improve the transitional care process and the accessibility and quality of community services. Expand the participation of providers in these efforts.**

#### ▶ ACTION 8.1.1

Support the expansion of One-e-App—a Web-based system being developed in California by the California HealthCare Foundation and The California Endowment that streamlines enrollment in a range of publicly funded health and human service programs—to improve access by seniors to appropriate services. Encourage broad adoption of this streamlined eligibility process by hospitals, home care agencies, and other home and community-based service providers in California, and advocate for similar changes nationwide.

### ► ACTION 8.1.2

Support California's acute and long-term care integration efforts, which include streamlining eligibility criteria and application processes for home and community-based services to avoid the need for multiple application forms, differing time frames for determining eligibility, and varying waiting periods. Promote similar changes nationally.

### ► ACTION 8.1.3

Encourage broader adoption of financial incentives (such as pay-for-performance incentives beginning to be implemented by the Centers for Medicare & Medicaid Services) for physicians who demonstrate successful, long-term reductions in rehospitalization for specific high-cost diagnoses by promoting effective transitional and in-home care.

### ► ACTION 8.1.4

Encourage implementation of an Electronic Health Record pilot or demonstration project that encompasses the hospitalization, discharge planning, and hospital-to-home transition periods.

### ► ACTION 8.1.5

Evaluate and recommend expanded implementation of legislative initiatives that improve care and services relevant to transitions:

- “Care navigator” proposals, such as California SB 953 and AB 10, that establish pilot programs to help seniors and caregivers identify and access long-term care services
- The Lifespan Respite Care Act (HR 3248 and S 1283) that enhances and expands respite care programs nationally
- The Improving Long-Term Care Choice Act of 2005 (S 1602) that allows expansion of home and community-based services through changes to state Medicaid plans rather than requiring waivers

## RECOMMENDATION 8.2

**Promote major Medicare, Medicaid/Medi-Cal, and Older Americans Act policy and program changes to support and adequately fund effective discharge planning and transitional care and encourage in-home rather than institutional care.**

### ► ACTION 8.2.1

Expand funding under the Older Americans Act for services provided to seniors in the home and community by Area Agencies on Aging, and services for informal caregivers through the National Family Caregiver Support Program.

### ► ACTION 8.2.2

Change Medicare's “75% rule” to cover rehabilitation in acute inpatient facilities for a wider range of conditions. Currently under this rule, inpatient rehabilitation facilities (IRFs) must prove that 75% of their patients have 1 of only 13 diagnoses or the facility risks losing Medicare reimbursement for all hospital admissions to the IRF in that fiscal year.



Courtesy of the PA Department of Aging

### ► ACTION 8.2.3

Change In-Home Supportive Services (IHSS) policy and procedures and increase program funding to encourage and train IHSS representatives to conduct pre-discharge determination of eligibility and home assessments so they can provide IHSS services in the home immediately after discharge.



Services like in-home assistance and paratransit help seniors stay in their homes and communities. However, many public policies still favor institutional care.

## Key Findings and Recommended Actions

### ▶ ACTION 8.2.4

To implement the *Olmstead*<sup>12</sup> decision effectively, eliminate/minimize reimbursement policies that create a bias toward putting patients in institutions after hospital discharge. Change reimbursement incentives so that more funds are available for home and community-based services. Assess the feasibility and cost-effectiveness of providing care in the home instead of in skilled nursing facilities and other institutions in the post-discharge period. Make home and community-based services priority entitlements, since they are less expensive than nursing facility care.

### ▶ ACTION 8.2.5

Cover costs of home modifications as well as durable medical equipment, since both have been demonstrated to enhance recovery in the home and reduce rehospitalization.

### ▶ ACTION 8.2.6

Pay for in-hospital visits from home health workers (use cost savings generated by reduced need for post-hospital visits) to begin assessing patients' needs and arrange for community services to be in place upon discharge.

### ▶ ACTION 8.2.7

Explicitly cover transitional care as part of the package of benefits provided under insurance plans. (Investment in better discharge planning and transitional care would lower overall costs for Medicare, Medicaid, and other insurers.)

## RECOMMENDATION 8.3

**Support demonstration projects and other initiatives in transitional care.**

### ▶ ACTION 8.3.1

Adapt the hospice model of family-focused and community-based care to transitional care. Recommend that the Centers for Medicare & Medicaid Services fund community organizations to provide transitional care and evaluate their programs in case management and in-home services (e.g., the Homecoming Services program at the San Francisco Senior Center). (Similar models being evaluated for long-term care, such as PACE, are showing good results; these and results from other Medicare demonstrations in progress could be extended to transitional care.)

### ▶ ACTION 8.3.2

Fund and evaluate local demonstration projects for the following:

- Care coordination and early-supported discharge
- Home-based caregiver training
- Team caregiving models, such as those developed by Share The Care

### ▶ ACTION 8.3.3

Design evaluations that have a high level of scientific rigor. Include longitudinal measures of hospital readmission rates, changes in care costs, and quality of life.

### ▶ ACTION 8.3.4

Monitor evaluation results of a pilot program under Medicare to fund adult day care services to enhance in-home recovery after a hospitalization. Review



Services like physical therapy can help people recover at home. However, many public policies still favor institutional care.

<sup>12</sup> In 1999, the U.S. Supreme Court ruled in *Olmstead v. L.C.* [*Olmstead v. L.C.*, (98–536) 527 U.S. 581 (1999) 138 F.3d 893] that Title II of the Americans with Disabilities Act prohibits the unnecessary institutionalization of persons with disabilities. The *Olmstead* decision has been interpreted to extend to people in nursing homes and other institutional settings and to those who live in the community and are at risk of institutionalization. The ruling requires states to make reasonable modifications to policies and programs that will enable individuals with disabilities to remain living independently through access to community-based care.

services to be covered in the demonstrations and recommend other essential transitional care services if gaps are identified. Recommend expansion if pilot results are positive.

► **ACTION 8.3.5**

Disseminate findings of promising interventions to various audiences, and identify opportunities for broader implementation.

**RECOMMENDATION 8.4**

**Following implementation and evaluation of system improvements in transitional care, seek to expand eligibility for public programs to meet the needs of the growing number of seniors.**

People consulted during the course of this research, including the project Advisory Board, identified the significant problem of individuals with low but above-poverty-level incomes being at high risk for

poor outcomes following hospital discharge. These individuals do not qualify for public services but cannot afford to pay for essential services out of pocket. However, the Advisory Board suggested that the highest priority recommendations are to improve the existing system and services related to discharge planning and post-discharge care and later to identify opportunities to expand eligibility for these improved services when their efficacy has been demonstrated. Included below are *longer-term* recommendations resulting from the research.

► **ACTION 8.4.1**

Raise the income threshold (i.e., to 200% of the federal poverty level) so that the near-poor elderly are eligible for additional home and community-based services under Medicaid/Medi-Cal.

► **ACTION 8.4.2**

Modify the Medicare hospice benefit to cover serious chronic conditions even if they are not diagnosed as terminal, and extend coverage of palliative care.

► **ACTION 8.4.3**

Make care/case management a reimbursable benefit under Medicare regardless of whether the patient is eligible for nursing home care. Some demonstrations are in progress and may offer workable models.

► **ACTION 8.4.4**

Expand Medicare coverage so that home care benefits (including personal assistance) are available for short-term transitional care and for chronic conditions, and not just when skilled care is needed for homebound patients.



Support for seniors and their caregivers should be a goal of public policies. Enhanced support can help frail seniors remain in their homes and stay involved.

## Conclusions

Seniors and informal caregivers, especially those in the most vulnerable communities, are currently at very high risk for poor outcomes following a hospitalization. Our analysis of hospital-to-home transitions of seniors shows that (1) such transitions are an increasingly critical health and social problem for older people and their caregivers, and that some seniors are at very high risk for rehospitalization and increased morbidity and mortality after discharge; (2) current training of professionals serving seniors does not adequately address issues such as effective discharge planning and critical home-care needs of seniors post-hospitalization; (3) seniors and their caregivers do not receive adequate education and information about caregiving at home and availability of community resources, and (4) to date, transitional care has not been identified as a significant priority by government agencies or philanthropic organizations. We have identified many important opportunities to improve such transitions through training of providers (nurses, physicians, social workers, and home health aides), interventions to provide seniors and their caregivers with information and linkages to community resources, and ideas for system- and policy-level change.



## Appendix A: Project Advisory Board

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## Appendix B: Community Partners

The following organizations assisted the Hospital-to-Home Project:

### **Alameda County**

Alta Bates Summit Medical Center: Ethnic Health Institute and Health Ministry Parish Nurse Program, Berkeley/Oakland  
Asian Health Services, Oakland  
Berkeley Primary Care Access Clinic, Berkeley  
Family Bridges, Inc., Oakland  
Hong Fook Adult Day Health Care Center, Oakland  
Jewish Family and Children's Services of the East Bay, Albany  
North Berkeley Senior Center, Berkeley  
Over 60 Health Center, Berkeley  
South Berkeley Senior Center, Berkeley  
Vietnamese Community Development, Inc., Oakland

### **San Francisco City/County**

Bayview Hunter's Point Adult Day Health Center  
Chinese Newcomers Service Center  
Institute on Aging Ruth Ann Rosenberg Adult Day Health Care Center  
Jewish Family and Children's Services of San Francisco  
Laguna Honda Hospital  
New Leaf Outreach to Elders  
On Lok SeniorHealth, 30th Street Center  
San Francisco Senior Center  
San Francisco LGBT Community Center  
Self-Help for the Elderly  
Newcomer's Health Program  
University of California, San Francisco Medical Center

### **San Mateo County**

El Concilio de San Mateo County, Burlingame  
Fair Oaks Community Center–Senior Services, Redwood City  
The Magnolia of Millbrae, Inc., Millbrae  
Self-Help for the Elderly, Daly City

### **Santa Clara County**

American Cancer Society, Northern California Chinese Unit, Fremont  
Avenidas Senior Center, Palo Alto  
India Community Center, Milpitas  
India Community Center, Sunnyvale  
Southeast Asian Community Center, San Jose  
Older Adult and Family Center, Stanford University School of Medicine/Department of Veteran's Affairs (VA) Palo Alto Health Care System





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