

# Health Affairs

At the Intersection of Health, Health Care and Policy

Cite this article as:

Carol Levine, Deborah Halper, Ariella Peist and David A. Gould  
Bridging Troubled Waters: Family Caregivers, Transitions, And Long-Term Care  
*Health Affairs*, 29, no.1 (2010):116-124

doi: 10.1377/hlthaff.2009.0520

The online version of this article, along with updated information and services, is available at:

<http://content.healthaffairs.org/content/29/1/116.full.html>

**For Reprints, Links & Permissions:**

[http://healthaffairs.org/1340\\_reprints.php](http://healthaffairs.org/1340_reprints.php)

**E-mail Alerts :** <http://content.healthaffairs.org/subscriptions/etoc.dtl>

**To Subscribe:** <http://content.healthaffairs.org/subscriptions/online.shtml>

*Health Affairs* is published monthly by Project HOPE at 7500 Old Georgetown Road, Suite 600, Bethesda, MD 20814-6133. Copyright © 2010 by Project HOPE - The People-to-People Health Foundation. As provided by United States copyright law (Title 17, U.S. Code), no part of *Health Affairs* may be reproduced, displayed, or transmitted in any form or by any means, electronic or mechanical, including photocopying or by information storage or retrieval systems, without prior written permission from the Publisher. All rights reserved.

Not for commercial use or unauthorized distribution

# Bridging Troubled Waters: Family Caregivers, Transitions, And Long-Term Care

**Carol Levine** (clevine@uhfnyc.org) directs the Families and Health Care Project at the United Hospital Fund in New York City.

**Deborah Halper** is vice president and director of the Division of Education and Program Initiatives at the United Hospital Fund.

**Ariella Peist** was senior program manager of the Families and Health Care Project at the United Hospital Fund until August 2009.

**David A. Gould** is senior vice president for program at the United Hospital Fund and is the principal staff person responsible for program development and grant making.

**ABSTRACT** Families are the bedrock of long-term care, but policymakers have traditionally considered them “informal” caregivers, as they are not part of the formal paid caregiving workforce. As chronic and long-term care systems have become more complex and as more demanding tasks have been shifted to families, this view is no longer sustainable. The care transition process offers a critical opportunity to treat family caregivers as important care partners. Enhancing their involvement, training, and support will contribute to reducing unnecessary rehospitalizations and improving patient outcomes. The contributions and experiences of family caregivers should be considered in gathering information to shape policies and practice; training health care professionals; developing programs; and reforming financing.

**I**nformal caregivers are “the backbone of the long-term care system in the U.S. today.”<sup>1</sup> Some variant of this statement, often using “bedrock,” prefaces nearly every discussion of long-term care. But do family caregivers receive commensurate recognition in analyses of long-term care? Beyond the initial statement, the usual mention of family caregiving goes something like this: In the United States, an estimated thirty-four million family caregivers, the majority of them women, provide 75–80 percent of long-term care in the community; the estimated value of their unpaid labor is \$375 billion a year—an unpaid contribution not calculated in the costs of long-term or health care.<sup>2</sup>

Having given an obligatory nod in the direction of family caregivers, policy analysts rapidly move on to address other issues such as financing, workforce shortages, long-term care insurance, consumer-directed care, and home and community-based care alternatives to institutional care. Like the bedrock to which it is compared, unpaid family care is invaluable but only occasionally visible.

In its 2008 report *Retooling for an Aging America: Building the Health Care Workforce*, the

Institute of Medicine (IOM) called for a new perspective on family caregivers: “The definition of the health care workforce must be expanded to include everyone involved in a patient’s care: health care professionals, direct-care workers, informal caregivers (usually family and friends), and patients themselves. All of these individuals must have the essential data, knowledge, and tools to provide high-quality care.” However, the committee noted, “Exactly when and how providers need to incorporate the family into the health care process is not yet well understood, but such incorporation is relevant across the full spectrum of institutional, ambulatory, and residential patient-care settings.”<sup>3</sup>

This paper provides a framework for collaboration with family caregivers by describing the complex roles family caregivers already play and their untapped potential to contribute to solving the problems of fragmentation, discontinuity, and poor-quality care. But, based on our experience, we also know that bringing family caregivers into the mainstream of policy and practice agendas is a daunting challenge that requires breaking through longstanding attitudinal, behavioral, financial, and professional barriers.

# In a fragmented system, where providers change with unsettling regularity, family caregivers are often the only people who have experienced the entire trajectory of their family member's illness.

The first section of this paper defines concepts and context. The second explores the reasons family caregivers have not been central to policy discussions. The third describes several innovative transitional care programs in the vanguard of change, including the United Hospital Fund's Next Step in Care campaign. The paper concludes with policy recommendations.

## Definitions And Context

Recognizing the reality of family life today, we define *family caregiver* broadly, to include not only relatives but also partners, friends, neighbors, and others who provide or manage the care of a person with a serious illness or disability. Although most practitioners and policymakers agree that long-term care encompasses both institutional and noninstitutional care, they generally focus on a specific sector. The whole is often eclipsed by its separate parts.

By definition, chronic care *is* long-term care. Yet it is often seen as falling outside the policy arena of long-term care because many people with chronic conditions live independently and manage their own health care. This paper focuses on the more severe end of the spectrum: people who cannot manage on their own. What counts as "ordinary" in a healthy person's life—getting out of bed, going to the toilet, getting dressed, eating a meal, shopping, and using the telephone—become major challenges when a person is seriously ill, physically disabled, or cognitively impaired. Beyond these needs, high-risk patients with multiple chronic conditions are likely to "rely heavily on their [family]

caregivers to provide help with taking medications, making appointments for and getting to physician visits, and understanding medical advice."<sup>4</sup>

Incremental changes in the health care economy, service delivery, medical practice, and consumer preference have created a patchwork of services characterized by frequent and often rapid changes in setting and providers. A study of patterns of 30-day posthospital care transitions for 700 Medicare beneficiaries found 46 distinct types of transfers, and a third of all transitions were deemed medically complicated.<sup>5</sup>

People with serious chronic illnesses typically go to an emergency department or hospital numerous times, may have several stays in subacute units in skilled nursing facilities, and receive short-term services from a home care agency. Eventually, they are likely to die in a facility—hospital or nursing home—where hospice or palliative care services, which consider family as the unit of care, are more likely the exception than the rule.

Almost unnoticed, health care providers have shifted to family caregivers more demanding and complex kinds of care that last longer periods—sometimes for decades.<sup>6</sup> In a fragmented system, where providers change with unsettling regularity, family caregivers are often the only people who have experienced the entire trajectory of their family member's illness.

Hospitals, nursing homes, and home care agencies are changing as well. Patients who are admitted to hospitals are likely to be more acutely ill and discharged with more complex ongoing needs than they were ten or twenty years ago. Many primary care doctors no longer make hospital visits. Hospitalists—doctors who are specially trained to take care of acute illnesses in the hospital setting—now provide much inpatient care.<sup>7</sup> And although hospitalists' greater availability and expertise are valuable, continuity of care has suffered.<sup>8</sup> Hospital patients might not know who is in charge of their care or even remember any of their doctors' names.<sup>9</sup> Because of concern about the potential for error, families have found it necessary—and have been encouraged by physicians<sup>10</sup> and quality improvement agencies<sup>11</sup>—to be present at all times to monitor medications, make sure tests are carried out and results received, sound the rapid-response-team alarm,<sup>12</sup> and be the patient's advocate.

Nursing homes are increasingly serving two populations: short-term rehabilitation patients and the traditional long-term residents.<sup>13</sup> To maximize Medicare and commercial insurance payments, nursing homes actively seek short-stay patients for their subacute rehabilitation

services.<sup>14</sup> Most residents in long-stay units are now older, sicker, and more cognitively impaired than they were a generation ago.

Much of the advice given to family caregivers about what to consider when choosing a nursing home comes too late; that initial choice is likely to be made by a hospital discharge planner, often with little notice. Even if family caregivers have indicated a nursing home preference, if a bed in a different nursing home becomes available, families are often made to feel that they cannot refuse. And although they may have had little input into the selection process, once their relative is admitted, family caregivers play an important role in short-term rehabilitation settings, encouraging and supporting therapeutic goals, providing comfort and reassurance, and participating in decisions about coming home or moving to a long-stay unit. In both short- and long-term settings, family caregivers become care monitors and advocates.

The chronic care patient's preferred destination is usually home, sometimes with a referral for home care services. Yet home health care services are also evolving—shorter duration; fewer visits; and more likely to include the trappings of a hospital, including hospital beds, IV infusions, injections, wound care, and oxygen. Some patients come home from the hospital with feeding tubes and even mechanical ventilators.<sup>15</sup> Although these devices may not seem “high-tech” to experienced clinicians, whose training was probably in a setting with backup and support, family caregivers who are home alone with their loved one report feeling terrified and overwhelmed.

Medication management, which is considered a routine part of caregiving, can be fraught with complications and potential for error when the person takes multiple prescription and over-the-counter drugs. Yet home care agencies cannot take the responsibility for a complicated case unless a family caregiver is present to provide most of the care. Our study of stroke caregivers found that even when agency services were in place, families provided 70 percent of the care.<sup>16</sup> These trends assume a continued level of family caregiving that may be impossible to sustain in individual cases and in the aggregate. A policy response is clearly needed. The next section examines what that response has been so far.

### **Why Have Family Caregivers Been Neglected In Long-Term Care Policy?**

According to the IOM report, “Public policy has traditionally viewed informal caregivers’ service as a personal, moral obligation, and not as an extension of the workforce.”<sup>17</sup> Bruce Vladeck, a

## **Rebalancing long-term care away from institutions and toward home and community-based services is a policy goal shared by older adults and their family caregivers.**

---

former administrator of the Health Care Financing Administration (now the Centers for Medicare and Medicaid Services), is more pointed: “Policymakers have perceived the problem as one of trying to avoid paying for something they have become accustomed to getting for free.”<sup>18</sup>

Public policy around long-term care has focused on controlling expenditures on nursing homes, because 64 percent of those costs are covered by Medicaid. States have limited the number of nursing home beds, which has remained stable at about 1.6 million since 1999, as has the occupancy rate, which was 86 percent in 2004.<sup>19</sup>

Government efforts to support family caregivers stem largely from a shortage of paid workers and a fear that if family members burn out, their relatives will end up in nursing homes at public expense. Making sure public funds are spent wisely is a cardinal responsibility for government officials. Still, the growing emphasis on saving money tends to overshadow the positive impacts of efforts to assist and support caregivers—known as “caregiver interventions”—on family caregivers’ mental and physical health and their family members’ quality of life. Increasingly, arguments for such interventions are couched in cost-efficiency language. For example, a recent literature review concluded that “failure to fund effective caregiver interventions may be fiscally unsound.”<sup>20</sup>

Rebalancing long-term care away from institutions and toward home and community-based services is a policy goal shared by older adults and their family caregivers, albeit for different reasons. Under the provisions of the 1999 Supreme Court decision in *Olmstead v. L.C.*,<sup>21</sup> states

are using federal funds to help people in nursing homes return to the community. Equally high on the policy agenda is keeping people out of nursing homes.

Yet as Edward Miller, Susan Allen, and Vincent Mor point out, the “underlying assumption that families of severely impaired individuals will be able to sustain that care over the long haul...is questionable.” They describe a patchwork of home and community-based services, located in multiple programs, which “tend to cover different types of services and also tend to be administered under different rules by different authorities at the federal, state, and local levels.”<sup>22</sup> These services assume that family members will provide most of the care. This assumption is clearly stated in the title—Family Care—of the Medicaid waiver program in Wisconsin. Yet the program’s Web site fails to mention family caregiver support.<sup>23</sup>

Existing federal caregiver services are important first steps but poorly funded. The National Family Caregiver Support program, the first federal initiative directly addressing family caregivers, was established in 2000.<sup>24</sup> Authorized by the Older Americans Act (Section 371, Title IIIIE), and administered through grants to state and local Area Agencies on Aging, this program provides information and referral, counseling, respite, and some other services. The budget for fiscal year 2008 was \$153.4 million, including set-asides for Native American tribes and grandparents caring for grandchildren.

The only other federal program, Lifespan Respite, was enacted in 2006 (PL 109-442) but was not funded until President Barack Obama signed the fiscal year 2009 appropriations bill, which allocated \$2.5 million to the program. Full funding in fiscal year 2010 would be \$71 million, to be awarded to states through a competitive grants process.<sup>25</sup> Comparing these figures to the estimated \$375 billion that family caregivers contribute to the health care system is a good marker of their bedrock—that is, underground—status.

Some states—notably California, New Jersey, and Pennsylvania—have well-established family caregiver support programs. But in many states, waiting lists are common and prolonged. State programs vary in quality, accessibility, and implementation, and are particularly vulnerable to budget cuts, which have already taken a toll.<sup>26</sup>

Money is only a symbol of deeper assumptions and attitudes. The very language policymakers use is revealing. Family caregivers are called “informal” caregivers to distinguish them from paid caregivers like nurses and aides. The term *informal* suggests casual, unstructured, unofficial care—pleasant but not essential. This is hardly an appropriate description of caregivers who

carry out medical tasks that if performed by a nurse would be considered skilled care.

The categories describing family caregiver tasks perpetuate the comfortable illusion of informality. Patients’ functional needs are described in terms of “activities of daily living” (ADLs, such as bathing and feeding) or “instrumental activities of daily living” (IADLs, such as making phone calls and arranging transportation). Yet, as Susan Reinhard, director of the AARP Public Policy Institute, points out, “When family caregiver research began in earnest in the 1980s, researchers applied the ADL and IADL scales to caregivers, on the assumption that what caregivers provided was the mirror image of the functional limitations of the care recipient. While this approach has intuitive appeal, it fails to consider many aspects of caregiving.”<sup>27</sup> The categorization ignores demanding medical tasks, frequent lack of cooperation from care recipients with dementia, constant strain of managing behavioral disturbances, timing of tasks (every four hours, unpredictable, repeatedly), as well as the financial and managerial challenges of caregiving over long periods of time.<sup>28</sup> At the end of the day, for caregivers in these demanding situations, there is no end of the day.

Policymakers, practitioners, and analysts employ a set of assumptions and standards that may have seemed appropriate in the 1970s and 1980s but no longer fit long-term care. As long as family caregiving is described and measured as if it were only domestic chores—the traditional view of women’s work—it will not be appropriately valued and integrated into the IOM’s vision of the workforce.

While policymakers worry about demographic and societal trends that may diminish family care, some health care practitioners, equally but differently dependent, may dread it. Certainly many physicians, nurses, and social workers communicate fully and freely with family members, helping them navigate the troubled waters of chronic care. However, there is another side that must be acknowledged. Especially in busy institutional settings, families are sometimes perceived as troublesome, interfering with proper care, fighting among themselves, challenging physicians’ or nurses’ authority, and generally behaving badly. When Connie Zuckerman, a health law attorney, asked forty-two hospital counsel and medical staff at New York City hospitals what created the most difficult situations in end-of-life care, nearly everyone responded: “Families.” A typical physician response was: “They don’t understand. They’re too emotional.”<sup>29</sup> Experienced physicians have written about their own difficulties getting information and managing care for their

relatives.<sup>30,31</sup>

The interests of family members are seen almost by definition as conflicting with the patient's best interests (as understood by professionals). Even a patient's concern about the impact of illness on his or her family can be viewed with suspicion.<sup>32</sup> Professionals often acknowledge that families are overwhelmed. And yet, when it comes time to send patients home, they are handed off to these same families for continued care.

### Transitional Care As The Vanguard Of Change

Transitions between care settings—in which family members play an important role—bring the varied elements of health and long-term care together for a fleeting but critical moment. Poorly planned and implemented transitions are prone to miscommunication, medication errors, and other lapses in patient safety. In turn these lapses can lead to costly and traumatic rehospitalizations, and repeated cycles of transitions to rapid deterioration and even death.<sup>33</sup>

Care coordination has assumed new urgency in the “perilous journey” through multiple providers, complex regimens of care, and rapid transitions.<sup>34</sup> Most care coordination programs assume that professionals know how to coordinate care and just need more time and money to do it. But the results of the extensive Medicare care coordination demonstrations were disappointing. The demonstrations, while costly, were not particularly innovative. They relied heavily on telephone follow-up, which in the absence of other supports is unlikely to make a difference. Programs that had some in-person follow-up reported somewhat better outcomes. None specifically involved family caregivers, which might have made a difference.<sup>35</sup> More time and money are certainly important incentives to support care coordination, but new models and staff training are critical.

Several innovative models have been designed to address transitions, but only a few of them directly involve family caregivers. Most, such as the Society for Hospital Medicine's Project BOOST<sup>36</sup> and the CMS-funded Transition Care Projects being conducted by fourteen state Quality Improvement Organizations,<sup>37</sup> focus on provider-to-provider communication and patient self-management. Others such as Project RED (Re-engineered Discharge) at Boston University focus on improving the hospital discharge planning process.<sup>38</sup> Although family caregivers are referenced in these models in the term “patient/family,” the models do not distinguish between the two, or pay specific attention to the

## More time and money are important incentives to support care coordination, but new models and staff training are critical.

needs of family caregivers.

Three other models—the Transition Care Model (TCM) at the University of Pennsylvania, the Care Transitions Program at the University of Colorado, and Guided Care at Johns Hopkins University—more directly include family caregivers and have already shown improved outcomes in randomized controlled trials (Exhibit 1).

The United Hospital Fund's Next Step in Care (NSIC) campaign shares the same goals as these programs but differs in important ways. It is an innovative quality improvement effort, not a research study, and it employs different implementation and evaluation methods. Not a program in itself, Next Step in Care provides a framework and an extensive series of practical tools for family caregivers and health care providers that can be used routinely in hospitals, nursing homes, and home care agencies.

Next Step in Care's goal is to change ordinary interactions—such as explaining medications, discussing care plans, and organizing discharges and admissions—in ways that acknowledge the special contributions and needs of family caregivers. The other programs focus largely on transitions from hospital to home. They are nurse- or doctor-led and deploy a specially trained professional. In contrast, Next Step in Care engages hospitals, rehabilitation units in nursing homes, and home care agencies. Its interdisciplinary structure enables and encourages every professional to participate in enhanced transitional care.

Next Step in Care is the culmination of thirteen years of research, analysis, publication, and advocacy.<sup>39,40</sup> Over the past three years we worked with institutional and agency partners as well as with clinical and system consultants (including Mary Naylor at the University of Pennsylvania and Eric Coleman at the University of Colorado) and a health literacy expert to create a series of eighteen guides and checklists for family care-

**EXHIBIT 1**

**Transitional Care Programs, 2009**

Program name	Description	Outcomes	Costs
Transitional Care Model, U. Pennsylvania; Mary Naylor, director <sup>a</sup>	Transitional care nurse (TCN) assesses patient in hospital, identifies priority needs, and collaborates with hospital team in developing care plan; TCN visits patient and family caregiver at home within 24–48 hours after discharge, once a week thereafter, and semimonthly for 3 months; TCN may accompany patient and family caregiver to first primary care physician appointment and is available by phone	In randomized controlled trial (RCT) of patients with congestive heart failure, improved short-term physical health, functional status, and quality of life; reduced preventable hospital readmissions	At one year, mean costs per patient lower in intervention group (\$7,636) than for control group (\$12,481)
Care Transitions Program, U. Colorado, Eric Coleman, director <sup>b</sup>	Transition coaches follow patients and family caregivers from hospital to home or rehab facility; coaches do not provide care but teach patients and family caregivers how to set goals, recognize red flags, and manage care; duration generally 14 days	In RCT of older adults with 1 of 11 conditions, intervention patients had lower rehospitalization rates at 30 and 90 days	At 180 days, mean hospital costs lower for intervention patients (\$2,058) than for control group (\$2,546)
Guided Care, Johns Hopkins University, Chad Boulton, director <sup>c</sup>	Based in primary care practice of several physicians; guided care nurse creates electronic health record, facilitates transitions between sites and providers; Guided Care Program for Families and Friends arranges family caregiver meetings, coaching sessions, and referrals to community resources <sup>d</sup>	Pilot study appeared to improve quality of care; reduced stress for family caregivers	Preliminary (8-month) report from 2-year RCT showed average of 24% fewer hospital days, and savings of \$1,364 per patient

**SOURCES** See below. <sup>a</sup>Naylor MD, Brooten DA, Campbell RL, Maislin G, McCauley KM, Schwartz JS. Transitional care of older adults hospitalized with heart failure: a randomized, controlled trial. *J Am Geriatr Soc.* 2004;52(5):675–84. <sup>b</sup>Coleman EA, Perry C, Chalmers S, Sung-joon M. The Care Transitions Intervention: results of a randomized controlled trial. *Arch Intern Med.* 2006;166(17):1822–8. <sup>c</sup>Leff B, Reider L, Frick KD, Scharfstein DO, Boyd CM, Frey K, et al. Guided Care and the cost of complex healthcare: a preliminary report. *Am J Manag Care.* 2009;15(8):555–9. <sup>d</sup>Wolff JL, Rand-Giovanetti E, Palmer S, Wegener S, Reider L, Frey K, et al. Caregiving and chronic care: the Guided Care Program for Families and Friends. *J Gerontol A Biol Sci Med Sci.* 2009;64(7):785–91.

givers (now translated into Spanish and Chinese). Three guides are addressed to professionals. The guides cover admission, planning for discharge, and discharge in the three settings. Some, such as medication management, explain provider instructions in terms family caregivers can understand and follow. Some are new ideas. A family caregiver’s self-assessment tool, for example, helps that person identify which tasks he or she already knows how to do; which ones could be done with some training; and which are impossible to do because of the family caregiver’s own health problems, full-time employment, or other reason.

The guides were pilot-tested to confirm accuracy, acceptability, and feasibility of distribution in ten New York City sites. A Web site, <http://www.nextstepincare.org>, was developed to house and widely disseminate the free tools and other resources.

Next Step in Care is a work in progress. A Collaborative Design Group of fourteen provider organizations was convened in July 2009 to develop an eighteen-to-twenty-four-month quality

improvement collaborative that will enroll forty to fifty teams from the New York City area early in 2010. The goal is to develop and test ways to integrate Next Step in Care materials and other tools into routine practice.

Unlike a randomized controlled trial, which has a detailed protocol, consistent interventions, and results published only after the study is completed, quality improvement collaboratives have flexible designs and aim to achieve significant changes in practice in a short time. A recent review article found that it takes seventeen years, on average, for research evidence to reach clinical practice.<sup>41</sup> In contrast, quality improvement takes place in practice settings, with all their idiosyncrasies and variabilities; adaptations are made while the process is going on; and practice changes that work in a particular environment can be spread within the organization and adapted to other settings.

Provider teams in the Collaborative Design Group are working with one or more partner organizations with which it routinely shares patients. They have tracked and mapped the flow of

patients and encounters with family caregivers across care transitions to identify problem areas. They report that this experience has been sobering and has given them new insights into how they might improve transitions. They are devising new procedures and protocols to be tested through the plan-do-study-act cycle popularized by the Institute for Healthcare Improvement.<sup>42</sup> Over six months they and United Hospital Fund staff will develop a “change package” based largely on Next Step in Care materials, evaluation metrics, and other tools for the full-scale collaborative, whose results will be disseminated widely through the Next Step in Care Web site.

### Conclusion

High on policymakers’ agendas are measures to reduce costly rehospitalizations, create medical homes for the sickest and most vulnerable patients, improve care coordination, and delay or avoid nursing home placement. Improved transitional care, which is critical in these efforts, depends on family caregivers’ involvement, training, and support. Yet explicit attention to family caregivers is largely absent.

Four main areas urgently need the attention of policymakers, especially during discussions of health care reform.

**INFORMATION** We need more comprehensive information about family caregivers. Hospital patient satisfaction surveys, such as the CMS Hospital Patients’ Perspectives of Care Survey and commercial surveys, do not capture family caregivers’ experiences. Direct surveys of family caregivers largely focus on such issues as activities of daily living and psychosocial concerns; they do not explore their interactions with the health care system or their training and support for medical tasks.

The family caregiver module of the Centers for Disease Control and Prevention’s Behavioral Risk Factor Surveillance System is optional for states, and results are seldom widely disseminated. These existing mechanisms should be adapted to acquire a fuller, more nuanced, and policy-relevant understanding of the roles family caregivers play and their unmet needs. New surveys and report cards dealing with chronic care issues should directly engage family caregivers, not just patients.

**TRAINING** The ability to develop strong relationships with family caregivers and provide necessary training and support throughout the continuum of care should be defined as a core competency for all health care professionals and built into professional training and continuing education. Experienced clinicians have developed methods for teaching family caregivers

**High on policymakers’ agendas are measures to reduce costly rehospitalizations, create medical homes for the most vulnerable patients, improve care coordination, and delay or avoid nursing home placement.**

the skills they need to provide high-quality care, and these methods should be integrated into professional training and practice.<sup>43</sup> Responsibility should not fall to any single discipline. Rather, physicians, nurses, and other professionals must be trained to work in teams, and, as we have argued, these teams should proactively engage family caregivers as partners in care.

**PROGRAM DEVELOPMENT** Policymakers should ensure that attention to family caregivers’ needs is explicitly included in proposals for transitional care and medical home programs, with appropriate funding and staff training.

**FINANCING** Various approaches to pay-for-performance and “bundling” payments should incorporate well-defined protocols and outcome measures that gauge the organization’s capacity to identify and address the needs and roles of family caregivers.

As the IOM report asserted, family caregivers are an essential part of the health care workforce. But they are often unaware that the services they provide out of love, duty, or necessity are essential to the health care system as well as to their family members or friends. Isolated and unorganized, they cannot on their own be expected to change entrenched systems.

Policymakers are often moved by family caregivers’ powerful stories. But these stories, supported by relevant evidence and practitioners’ commitment, must be translated into specific policy actions that address the needs of family caregivers as well as the people they care for. If

health care providers and policymakers join forces with family caregivers, their combined efforts can become a positive force for better coordination and integration of all of the elements of long-term care. ■

## NOTES

- 1 Coleman B, Pandya S. Family caregiving and long-term care fact sheet [Internet]. Washington (DC): AARP; 2002 Nov 1; cited 2009 Dec 6]. Available from: <http://www.aarp.org/research/ppi/lte/Other/articles/aresearch-import-779-FS91.html>
- 2 Houser A, Gibson MJ. Valuing the invaluable: the economic value of family caregiving, 2008 update. Washington (DC): AARP Public Policy Institute; 2008 [cited 2009 Aug 24]. Available from: [http://www.aarp.org/research/ppi/health-care/health-costs/articles/i13\\_caregiving.html](http://www.aarp.org/research/ppi/health-care/health-costs/articles/i13_caregiving.html)
- 3 Institute of Medicine. Retooling for an aging America: building the health care workforce. Report Brief. Washington (DC): National Academies Press; 2008 Apr. p. 257.
- 4 AARP Public Policy Institute. Chronic care: a call to action for health reform. Washington (DC): AARP; 2009. p. 5.
- 5 Coleman EA, Min S, Chomiak A, Kramer AM. Posthospital care transitions: patterns, complications, and risk identification. *Health Serv Res.* 39(5):1449–65.
- 6 Arras J, editor. Bringing the hospital home: ethical and social implications of high-tech home care. Baltimore (MD): Johns Hopkins University Press; 1995.
- 7 Pantilat S. What is a hospitalist? [Internet]. *Hospitalist.* 2006 Feb; cited 2009 Nov 17]. Available from: [http://www.the-hospitalist.org/details/article/255837/What\\_Is\\_a\\_Hospitalist.html](http://www.the-hospitalist.org/details/article/255837/What_Is_a_Hospitalist.html)
- 8 Sharma G, Fletcher KE, Zhang D, Yong-Fang KI, Freeman JL, Goodwin JS. Continuity of outpatient and inpatient care by primary care physicians for hospitalized older adults. *JAMA.* 2009;301(16):1671–80.
- 9 Arora V, Gangireddy S, Mehrotra A, Ginde R, Tormey M, Meltzer D. Ability of hospitalized patients to identify their in-hospital physicians. *Arch Intern Med.* 2009;169(2):199–201.
- 10 Shaywitz DA. Overattentive families may be underrated. *New York Times.* 2006 Sep 19.
- 11 Agency for Healthcare Research and Quality. 20 tips to help prevent medical errors: patient fact sheet [Internet]. Rockville (MD): AHRQ; [cited 2009 Aug 24]. Available from: <http://www.ahrq.gov/consumer/20tips.htm>
- 12 Spath PL. Empowering families in emergencies [Internet]. *Health and Hospitals Network Magazine.* 2007 Feb 20 [cited 2009 Nov 16]. Available from: [http://www.hhnmag.com/hhnmag\\_app/jsp/articledisplay.jsp?derpath=HHNMAG/Article/data/02FEB2007/0702HHN\\_Online\\_Spath=HHNMAG](http://www.hhnmag.com/hhnmag_app/jsp/articledisplay.jsp?derpath=HHNMAG/Article/data/02FEB2007/0702HHN_Online_Spath=HHNMAG)
- 13 Decker FH. Nursing homes, 1977–99: what has changed, what has not? Hyattsville (MD): National Center for Health Statistics; 2005.
- 14 Dennison TH. Changes in nursing home care, 1996–2005: New York State. New York (NY): United Hospital Fund; 2008 Feb.
- 15 Hall V. Applying holism in the home care environment for clients with advanced ALS: a toolkit for practice. *Topics in Advanced Nursing eJournal.* 2003 May 7 [cited 2009 Aug 24]. Available from: <http://www.medscape.com/viewarticle/452535>
- 16 Levine C, Albert SM, Hokenstad A, Halper DE, Hart AY, Gould DA. This case is closed: family caregivers and the termination of home health care services for stroke patients. *Milbank Q.* 2006;84(2):305–31.
- 17 Institute of Medicine. Retooling for an aging America: building the health care workforce. Report Brief. Washington (DC): National Academies Press; 2008 Apr. p. 257.
- 18 Vladeck BC. You can't get there from here: dimensions of caregiving and dementias of policymaking. In: Levine C, editor. Family caregivers on the job: moving beyond ADLs and IADLs. New York (NY): United Hospital Fund; 2004. p. 124.
- 19 National Center for Health Statistics. The National Nursing Home Survey: 2004 overview. *Vital and Health Statistics.* 2009 Jun; Series 13, no. 167.
- 20 Weimer DL, Sager MA. Early identification and treatment of Alzheimer's disease: social and fiscal outcomes. *Alzheimers & Dementia.* 2009;5:215–26.
- 21 527 U.S. 581.
- 22 Miller EA, Allen SM, Mor V. Commentary: navigating the labyrinth of long-term care: shoring up informal caregiving in a home- and community-based world. *Journal of Aging and Social Policy.* 2009;21:1–16.
- 23 Wisconsin Department of Health Services. Family care: options for long-term care [Internet]. Madison (WI): DHS; [cited 2009 Aug 24]. Available from <http://dhs.wisconsin.gov/lcicare>
- 24 U.S. Administration on Aging. National Family Caregiver Support Program (OAA Title IIIIE). Washington (DC): AoA; [cited 2009 Nov 16]. Available from: [http://www.aoa.gov/AoARoot/AoA\\_Programs/HCLTC/Caregiver/index.aspx](http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/Caregiver/index.aspx)
- 25 ARCH National Respite Coalition [Internet]. Annandale (VA): ARCH; c2009. Press release, Lifespan respite to receive \$2.5 million for this fiscal year; [cited 2009 Nov 16]. Available from: <http://ktop.org/ARCH/ARCH-National-Respite-Coalition.html>.
- 26 Ferris S. In-home care program thrust into budget debate. *Sacramento Bee.* 2009 Feb 10.
- 27 Reinhard S. The work of caregiving: what do ADLs and IADLs tell us? In: Levine C, editor. Family caregivers on the job: moving beyond ADLs and IADLs. New York (NY): United Hospital Fund, 2004. p. 37
- 28 Albert SM. Beyond ADL-IADL: Recognizing the full scope of family caregiving. In: Levine C, editor. Family caregivers on the job: moving beyond ADLs and IADLs. New York (NY): United Hospital Fund, 2004. p. 99–122
- 29 Zuckerman C. End of life care decisions and hospital legal counsel: current involvement and opportunities for the future. New York (NY): Milbank Memorial Fund; 1998.
- 30 Berwick D. Escape fire: designs for the future of health care. New York (NY): Jossey-Bass; 2003.
- 31 Kane RL, West JC. It doesn't have to be this way: the failure of long-term care. Nashville (TN): Vanderbilt University Press; 2005.
- 32 Berger JT. Patients' concerns for family burden: a nonconforming preference in standards for surrogate decision making. *J Clin Ethics.* 2009;20(2):1–4.
- 33 Jencks SF, Williams MV, Coleman EA. Rehospitalization among patients in the Medicare fee-for-service program. *N Engl J Med.* 2009;360(14):1457–9.
- 34 Bodenheimer T. Coordinating care—a perilous journey through the health care system. *N Engl J Med.* 2008;358(10): 1064–71.
- 35 Peikes D, Chen A, Schore J, Brown R. Effects of care coordination on hospitalization, quality of care, and health care expenditures among Medicare beneficiaries: 15 randomized trials. *JAMA.* 2009;301(6):668–70.
- 36 Society for Hospital Medicine. The Project BOOST mentoring program [Internet]. Philadelphia (PA): SHM; [cited 2009 Aug 24]. Available from: [http://www.hospitalmedicine.org/ResourceRoomRedesign/RR\\_CareTransitions/html\\_CC/](http://www.hospitalmedicine.org/ResourceRoomRedesign/RR_CareTransitions/html_CC/)

- project\_boost\_background.cfm
- 37 Centers for Medicare and Medicaid Services. Care Transitions QIOSC [Internet]. Baltimore (MD): CMS; [cited 2009 Aug 24]. Available from: <http://www.cfmc.org/caretransitions/>
- 38 Greenwald JL, Jack BW. Preventing the preventable: reducing rehospitalizations through coordinated, patient-centered discharge process. *Prof Case Manag.* 2009;14(3):135-40.
- 39 Levine C. Rough crossings: family caregivers' odysseys through the health care system. New York (NY): United Hospital Fund; 2000.
- 40 Donelan K, Hill CA, Hoffman C, Scoles K, Feldman PH, Levine C, et al. Challenged to care: informal caregivers in a changing health system. *Health Aff (Millwood).* 2002;21(4):222-31.
- 41 Balas EA, Boren A. Managing clinical knowledge for health care improvement. *Yearbook of Medical Informatics 2000.* Bethesda (MD): American Medical Informatics Association; 2000. pp. 65-70.
- 42 Institute for Healthcare Improvement. Testing changes [Internet]. Cambridge (MA): IHI; [cited 2009 Aug 24]. Available from: <http://www.ihp.org/IHI/Topics/Improvement/ImprovementMethods/HowToImprove/testingchanges.htm>
- 43 Kelly K, Reinhard SC, Brooks-Danso A. Executive summary: Professional partners supporting family caregivers. *American Journal of Nursing.* 2008;108(9 Suppl): 6-12.

## ABOUT THE AUTHOR



### Carol Levine

Carol Levine directs the Family and Caregivers Health Project for the United Hospital Fund, a nonprofit health services research and

philanthropic organization focused on improving health care in New York. A bioethicist who formerly edited the *Hastings Report*, she directed the Citizens Commission on AIDS in New York City from 1987 to 1991; she then went on to found the Orphan Project, which advocates for assistance to families and children affected by HIV. In 1993 she won a MacArthur Foundation Fellowship in recognition of her work in AIDS policy and ethics.

That medical ethics and policy background suddenly melded with the personal in 1990, when Levine and her

husband, Howard Levine, were in a serious car accident. She survived, but he suffered a traumatic brain injury and was left a quadriplegic. For much of the next seventeen years, until he died in 2007, she worked by day and was her homebound husband's caregiver by night—as well as his lead care coordinator on a 24/7 basis.

Having learned firsthand about the unrelenting stresses imposed on caregivers, Levine soon became their advocate in her current position at United Hospital Fund. Just last year she launched a new project,

Next Step in Care, to support patients and family caregivers as they make the transition from hospital settings to home and family-based care. She has written extensively on the personal and community obligations of caring for the seriously disabled, including a collection of essays by family caregivers, *Always on Call: When Illness Turns Families into Caregivers* (2d ed., Vanderbilt University Press, 2004), and, with Thomas H. Murray, *The Cultures of Caregiving: Conflict and Common Ground among Families, Health*

*Professionals, and Policy Makers* (Johns Hopkins University Press, 2004).

A frequent *Health Affairs* author, Levine wrote in 1999 (with Peter S. Arno and Margaret M. Memmott) about the market value of care provided by unpaid friends and family members of the disabled. And in a Narrative Matters essay in 2002, she wrote eloquently about why relatives of those injured by medical errors bring lawsuits against providers—drawing on an experience that cost her husband his right arm following his devastating accident.