

**SYNOPSIS** » Family caregiving and paid caregiving are typically treated as two separate worlds. In reality, these two caregiving realms often interface, with paid caregivers substituting for or supplementing family caregiving. Featuring two real-life caregiving stories that illustrate how family and paid caregiving work together, this issue brief focuses on the intersection of family and paid care – what it looks like now and how it could be shaped in the future in order to promote high quality long-term care. It describes the demographic and economic trends affecting the demand for, and supply of, both family and paid caregiving, and offers ideas about moving towards a new caregiving paradigm, which integrates and supports both informal and formal caregiving.

## Family Care and Paid Care: Separate Worlds or Common Ground?

### INTRODUCTION

Daily care from family members and relatives sustains millions of frail elders as well as adults and children with disabilities, chronic illnesses and functional impairments. While many of these individuals provide care without the assistance of paid direct-care workers, significant numbers of “informal” caregivers function side-by-side with “formal” paid caregivers who have been trained to provide hands-on help with daily living activities. Paid caregiving may either substitute for or supplement family caregiving, but it is rare for these two caregiving systems not to interface in some way.

Nonetheless, in the worlds of advocacy and policy making these caregiving systems are almost never considered as two parts of a complex whole. Each has its own lobbyists and

allies, and each is addressed as if it functioned independently of the other.

In an attempt to break down this false dichotomy, this issue brief focuses on the intersection of family and paid care. What does this intersection look like and to what extent are these two types of care similar or dissimilar but nonetheless interconnected? Moreover, as American society inexorably moves into an era where caregiving issues are front and center, how do we want to shape this intersection, and, in particular, what kinds of partnerships between family and paid care should be cultivated?

This brief explores these issues first by drawing out some of the key themes conveyed by actual caregiving stories such as the two featured vignettes. Next, we look at the information available on the degree of inter-

The term caregiver loosely refers to anyone who provides assistance to someone else who is to some degree incapacitated and needs help. “Informal” is often associated with unpaid care provided by family members -- spouses, children, or siblings. For this reason, informal caregivers are commonly referred to as family caregivers, but the two are not always synonymous; informal care may be provided by friends or neighbors.

Formal caregivers, by contrast, are paid care providers, who may either work for an agency or be independently employed by the person needing care. For simplicity’s sake, this issue brief will use the terms “informal care” and “family care” interchangeably, while “formal care” is used interchangeably with “paid care.”

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## TWO CAREGIVING VIGNETTES

**The Weinbergers\***

Dan Weinberger, 82, lives in Florida with his wife Mary. Four years ago, he was diagnosed with Shy-Drager syndrome, a progressive disorder of the nervous system that makes him prone to drastic drops in his blood pressure and a steady weakening of his muscles. “He went from playing tennis to a wheelchair in a couple of months,” recalls his son Mark.

The rest of the family rallied around Dan and Mary after the diagnosis. Mark, who lives in Massachusetts, started visiting for a few days every couple of months to help with the finances and take his father swimming. Other relatives also helped out, but Mary needed daily assistance to lift and transfer her much larger husband. She also needed someone to sit by his bed at night, since he often woke up disoriented and could pass out or fall if he tried to get up.

At first, Mary tried using a home health care agency, but she and Dan didn’t like having a constant stream of new people coming in and out of their home. Worse yet, few of the aides seemed able or willing to do what was needed. “The people they were sending either weren’t motivated or didn’t have the proper skills,” Mark recalls.

They did like one certified nursing assistant, Yvonne. Yvonne now works exclusively for the Weinbergers, putting in 80-hour weeks by staying overnight on weekdays and for most of the weekend. She also helped Mary find Eva, the certified nursing assistant who stays with Dan during the day.

Yvonne and Eva help Dan shower, dress and use his bedpan. They shave him, help him brush his teeth, cut his hair, give him his medications and take his blood pressure. They also do some laundry and ironing, prepare meals and help Dan do what little physical exercise he can still do. In the course of performing these intimate tasks, they have become part of the family.

The Weinbergers are particularly close to Yvonne. “We wouldn’t classify her as an employee, that’s for sure,” says Mark. “She seems more like a sister to us, and a daughter to my mother and father. My father brightens up when he sees her and she and my mother have a terrific relationship. My mom talks to her about everything. She knows all the family stories now.”

Yvonne is a great help to Mark, too. Knowing she’s there, he says, “frees me a lot, because otherwise I’d probably have a lot more guilt and anxiety. I certainly worry about my father, but I don’t worry about him like I would.”

Mark is grateful that he and his siblings haven’t had to provide direct care for their father, which he thinks would have created an enormous strain within the family. “I took care of my grandfather one summer when I was a young man,” he recalls. “He ended up not being nice to me, and it totally changed our relationship. And if my sister were the caregiver instead of Yvonne, it wouldn’t have worked.”

As for Mary, she relies on Yvonne to provide the care she cannot. “I don’t have the strength or the knowledge that she has,” she says. “She has made my life bearable, frankly.”

\* All names have been changed at the request of the family

mixing of family and paid caregiving and finally, we consider the future trends most likely to shape the demand for both family and paid caregiving. Recognizing that sheer demographic imperatives will work to limit and constrain

the future supply of both informal and formal caregiving, we conclude by considering the implications for shaping a new caregiving paradigm that intentionally integrates and supports both informal and formal caregiving.



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## The Dusseaults

About two years ago, Terry Dusseault's Alzheimer's disease began to erode the independence she had always prized. Now 76 and unable to drive, she needs help with the housework and errands that she used to take care of. She also wants constant companionship.

The Dusseaults' three sons and daughters-in-law and Terry's sister all live nearby their parents' New Hampshire home and help out. But Terry relies mainly on her husband, Paul – to the point, says their son Paul Jr., that she "doesn't want him out of her sight."

Becoming his wife's caregiver has been difficult in some ways for Paul. Keeping up with the housework is hard, but giving up his independence is harder. "There's no break for him," says Paul Jr. "He used to be able to go to the garage and putter or take off and see a friend or whatever, and now he can't."

To give Paul a break, the family hired Karen Supry, a home companion from a local home care agency, who comes to the house every Wednesday for three hours. When Karen is there, says Paul Jr., "my dad can get out, run a few errands and just have a little quiet time on his own. She also does some of the housework so my dad doesn't have to."

His mother was initially angry at having a stranger in her house, says Paul Jr., and she still resists her help with the housework. At first, she wouldn't even talk to Karen. But Karen found shared interests. For instance, he says, "Karen found out that my mom likes animals, especially cats, so she's brought over pictures of her cats to get some kind of relationship going."

It's a relationship, like one between the ardent suitor and his brain-damaged love in *50 First Dates*. It has to be recreated every time the two get together. "I can't picture coming into that situation cold, not knowing the person and having to win them over, in a sense, week to week," says Paul Jr. "I think Karen does a great job. She has a good way – I guess from her training – of knowing how to deal with the situation. If my mother says she doesn't want her to do the housework, Karen she says okay and distracts her into something else. Karen knows how to build a relationship one interaction at a time."

Thanks to Karen's weekly visit, Paul Jr. says, his father is "just generally a little more relaxed. When he gets stressed out, he retreats to a room alone, and then mom gets concerned because she doesn't know where he is, so it's a little bit of a cycle there. So when he's not retreating, it's better for both of them."



## CONNECTING THE WORLDS OF FAMILY AND PAID CAREGIVING

While the stories of the Weinberger and Dusseault families depict just two situations where formal and informal caregiving interface, they nonetheless touch on important themes that illustrate the similarities, differences and interconnections between the worlds of unpaid and paid care.

- **The two systems sometimes complement and sometimes substitute for one another**

Real-life mixes of formal and informal care span a wide continuum of possible arrange-

ments. Exclusive family care is the predominant form of assistance to elders and people with disabilities, but there are also those who rely entirely on paid caregivers. Between these two extremes lie many possible arrangements that blend family and formal care, including those where family caregiving is primary and is supplemented by formal care, and others in which formal care is primary and is complemented by family care.

The two caregiving examples suggest some of the forms that this "mixing" can take. Dan Weinberger's home health aides, Yvonne and Eva, meet most of his needs for



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assistance with basic activities of daily living. His wife and children have more complementary companionship roles, care management and housekeeping functions. In the case of Mrs. Dusseault, her family meets most of her needs but her husband needs respite from his wife's care at least once a week. Karen, their home health aide, can provide that support and relief.

- **Formal care arrangements affect both care recipients and their family caregivers**

The two stories show the impact that formal care has on both parties in a caregiving relationship. The recipient's condition and overall quality of life is obviously affected by the paid services he or she may receive. But high-quality paid services also can improve the quality of family caregiving. Paid services can reduce the stress experienced by family members and help them maintain their own physical and mental health. It underscores the need to treat the care recipient and his or her family caregivers as a team.

- **Care arrangements change over time**

Care arrangements are, by their very nature, dynamic—they evolve and change as the recipient and their family's needs change. At one point, only family members cared for both Dan Weinberger and Terry Dusseault. Both then transitioned to care arrangements involving a combination of paid and family care.

The types and intensity of tasks that caregivers perform, and the tenure of family members as caregivers, can vary dramatically depending on caregivers' gender, age, and availability and their role in the family, e.g., spouse versus adult children (AOA, 2001). Notably, spouses are less likely to think of themselves as caregivers and therefore less likely to use formal support. Adult children experience a more dramatic role change and associate the strain they experience with their caregiving role. But as adult children become elderly themselves—and 70 year-old "children" care for 90 year-old parents—care arrangements may require change because of the caregivers themselves are elderly.

- **Roles and obligations become blurred for both family and paid caregivers**

There can be important differences in family and formal "cultures of care" which may affect the roles, obligations and expectations of formal and informal caregivers. The Weinberger and Dusseault stories make it clear that there is no single, generic caregiver role. For family caregivers, caregiving grows out of prior family relationships such as husband, wife, daughter or son (Montgomery and Kosloski, 2001) and is supported by values such as familial and moral obligation, emotional rewards and shared history (Levine and Murray, 2004).

Though paid caregiving is governed by the rules of the marketplace and government policies, the nature of the work makes the transaction more complex. Direct-care workers such as Yvonne and Eva have become more than "health care professionals" to the Weinbergers. For example, Yvonne appears to be more "family" than a part of the formal care system. Yet Yvonne's job is defined and her actions are governed by her paraprofessional training and licensing.

- **Quality of care can be at its best when family and formal care work together**

The two caregiving stories depict two situations where paid and family care appear to be working very well. While neither necessarily depicts the "norm" in a community-based setting, they do show how high-quality interactions between formal and informal care providers can improve the health of both caregiver and care recipient.

However, this doesn't mean that the two types of care always function seamlessly or without problems. Differences in caregiving cultures and orientation can result in tension over roles and responsibilities. And increasing diversity in the caregiving workforce also increases the potential for conflicts and communication problems arising from differences in cultural background and preferences among care recipients and paid workers. Family caregivers sometimes report negative experiences with direct-care workers in both home care and nursing home settings.

The Weinbergers, for example, were very dissatisfied with their first experience with paid home care. Direct-care workers, on the other hand, may experience family members as impeding their ability to provide quality care. In a study of family-staff relationships in nursing homes entitled “Wary Partners,” Shield (2003) reports that, while many CNAs felt that family members were supportive and actively contributed to the resident’s well-being, others reported experiencing lack of respect, harsh treatment and racism from family members.

### HOW MANY CAREGIVERS ARE THERE AND HOW INTERMIXED ARE FAMILY AND FORMAL CAREGIVING?

Estimates of the number of family caregivers nationwide vary enormously, from 7 million up to 54 million, or from 3 percent of individuals to 27 percent (AOA, 2001). This wide range reflects the fact that there is as yet little consensus on how caregiving is defined and measured or which care-recipient populations are to be included.

Some of the confusion is due to definitional issues. Informal caregivers include friends and neighbors who provide substantial unpaid assistance to disabled people. But some estimates exclude non-family members. Surveys also differ due to definitions of assistance. Official federal surveys on caregiving define the term to mean help provided to those who have functional limitations and need help to perform at least one activity of daily living (ADL), such as bathing, eating, dressing, walking across a room and toileting, or instrumental activities of daily living (IADLs), such as help with shopping, housekeeping, using a telephone and preparing meals. Taking someone to the doctor’s office or running an errand does not qualify. But it can sometimes be hard to draw the line.

On the paid caregiver side, experts agree that official workforce counts of paraprofessionals significantly understate their real numbers (National Clearinghouse on the Direct Care Workforce, 2004; Health Resources Services Administration, 2004)

In 2003, the Bureau of Labor Statistics (BLS) counted approximately 2.4 million workers in the three direct-care categories it tracks: nursing aides, home health aides and personal assistant workers/aides. Personal care workers

who are directly hired and supervised by consumers are left out of this count because of their status as independent contractors.

One national study found that 29 percent of workers providing assistance to the Medicare population in the home were self-employed (Leon and Franco, 1998). Based on data from the 2003 American Community Survey from 2003, the Center for Personal Assistance Services at the University of California, San Francisco, estimates the total number of personal assistance workers in the country at 1,076,470. Substituting this number for the BLS estimate for personal and home care aides yields an estimate of about 3 million direct-care workers.

The challenge of counting caregivers could get even more difficult as increasing numbers of family members qualify to become paid caregivers under state consumer-directed home care programs, such as “Cash and Counseling.” A new category might have to be added to long-term care surveys to capture whether individuals are receiving help from a paid provider who is also a family member, neighbor or friend (i.e., an informal caregiver who is receiving payment for their services).

What do formal surveys say about how the degree of mixing of paid and informal caregiving? In general, the family caregiving literature emphasizes the preponderant role that family as opposed to paid caregiving plays in the lives of persons with functional limitations. An oft-quoted statistic is that roughly 75 percent of people receiving long-term care in the community rely exclusively on care from their family members, relatives and/or friends, with only a quarter of arrangements involving both family and paid care.<sup>1</sup>

However, results from the National Long-Term Care Survey (NLTC) indicate that, in 1999, up to a third of caregiving arrangements for people aged 65 and older may have involved both paid and unpaid care.<sup>2</sup> The 1994 NLTC showed an even greater role for “mixed”

<sup>1</sup> This statistic first came from a survey that is now about a decade old, the 1994/95 National Health Interview Surveys on Disability.

<sup>2</sup> Federal Interagency Forum on Aging-Related Statistics (2004), Table 37a. While there are no reliable estimates of how much unpaid, family care is provided to people living in nursing homes, the categories “Informal and formal care” and “Formal only” have been added together to reflect the upper bound of “mixed caregiving”, since “Formal only” refers to care received in nursing homes where many family members continue to play important caregiving roles.





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caregiving arrangements ranging as high as 43 percent, which led analysts at that time to predict a trend toward increased use of paid care side-by-side with family care (Spillman and Pezzin, 2000; Liu, Mantoon, and Aragon, 2000). By the time of the next survey in 1999, these mixed arrangements appear to have declined, probably in large part due to reductions in Medicare funding for home care services.

In sum, there is need for more reliable data on long-term caregiving. One can find survey results that bolster the primacy of family caregiving or, alternatively, the growing importance of paid care and its sensitivity to changes in Medicare and Medicaid financing. What is lacking is agreement about what should be measured and how to measure it. But, in terms of improving policy development for both paid and unpaid caregivers, perhaps more important than “getting the numbers right” is identifying the main trends going forward that are likely to affect the future demand for both paid and unpaid caregivers, a subject we turn to next.

### TRENDS AFFECTING SUPPLY AND DEMAND FOR PAID AND FAMILY CAREGIVING

Understanding the trends affecting future demand for, and supply of, paid and family caregiving is essential to designing a holistic caregiving system that can meet the needs of care recipients, their family members and direct-care workers. Several key trends – many of which impact both demand and supply – are summarized below.

**Care recipients:** America is aging, and, with that fundamental shift in demographics, long-term caregiving is becoming not only more widespread but more complex. Those over 85 years old are most likely to need long-term care assistance and their numbers are expected to grow from 4.2 million in 2000 to nearly 21 million by 2050. While overall rates of disability among the elderly have declined since the mid-1980s, most of the decline was among people reporting limitations in instrumental activities of daily living rather than in activities of daily living (Freedman, 2002).

In addition, long-term caregiving must accommodate increasing numbers of individuals who are living longer with cancer, AIDS, cardiovascular disease, diabetes, dementia, obesity and a variety of intellectual and developmental

disabilities. Their care often requires complex medication schedules and treatment, substantial clinical skills, as well as the use of sophisticated technology. In general, people prefer to continue to live in their own homes. When you add this preference to the expected increase in the real income of elders and in private long-term care insurance (Bishop, 2004), the demand for support services provided in the home increases dramatically.

**Family caregivers:** As Feinberg and Newman (2004) underscore, “[f]amily caregiving is at the core of what sustains frail elders and adults with disabilities and is a major part of the American family experience.” At the same time, marked changes have occurred in the family over the last 50 years. In particular, families have fewer children and childbearing has been delayed, shrinking the pool of available family caregivers.

Families are now more geographically dispersed. Daughters and wives, the traditional caregivers, are more often employed. Overall female labor force participation rates increased from 52.6 percent in 1982 to 59.6 percent in 2002, and by 2012 they are projected to reach 61.6 percent (Toossi, 2004).

For most families today, reliance on a stay-at-home spouse to handle family responsibilities is not an option. Compared to previous generations, divorce is more prevalent among those approaching retirement. Divorce has been shown to weaken late-life economic ties (such as intergenerational co-residence) and to reduce informal caregiving (Schone and Pezzin, 1999). Each of these developments affects the “supply” of family members to provide care, and in turn their potential demand for paid care.

With this decrease in the overall number of family caregivers, the stress on those who take on these obligations may be increasing. Evidence suggests that the demands and stresses of caregiving negatively affect the health and well-being of caregivers, create financial strain and risk, exacerbate workplace difficulties and subject entire family systems to chronic strain (Stone, R., 2000; Schulz and Beach, 1999).

**Direct-care workforce:** Problems attracting a sufficient number of direct-care workers have received considerable attention around the country. In local labor markets, long-term care providers report relatively high rates of vacancy

and turnover, indicating difficulty in finding and keeping qualified workers. This set of labor market problems is directly tied to the poor quality of direct-care jobs: their low wages, lack of benefits, minimal training and in the case of home care, erratic, part-time work.

At a deeper layer, sheer demographic forces are lining up to severely constrain the traditional sources of new entrants into direct-care work (Dawson and Surpin, 2001). The pool of entry-level workers who have traditionally made up the core of the direct-care workforce—namely, women 25 to 44—is projected to decline by 1.5 percent over the period 2002 to 2012. At the same time, the demand for direct-care workers is projected to increase by 34 percent (Toossi, 2004).

Beyond just numbers, the perceived quality of the direct-care workforce may affect demand for paid care. To the extent that the skills and reliability of paid workers are regarded as poor, then demand may be weakened. But if the skills and reputation of direct-care workers are enhanced, for example, through better training and career ladders that develop more skilled workers, demand may rise.

#### **Growth of private long-term care insurance:**

While covering just a small proportion — about 4 percent — of long-term care spending for older adults, private long-term care insurance policies are growing steadily. At the end of 2001, over 8 million long-term care insurance policies had been purchased, up from 5 million in 1996. About 70 percent of these policies are still in effect. A study of caregiving patterns among elders with private long-term care insurance indicates that this group is six times more likely to rely exclusively on formal care than non-privately insured disabled elders living in non-institutional settings (Cohen, et al., 2001). Private long-term care insurance claimants are typically older, higher-income, widowed and less likely to have children living nearby than elders in the general population. These patterns suggest that the continued growth of private long-term care insurance sales is likely to increase the demand for paid care.

#### **State and federal long-term care financing and regulations:**

In 2004, roughly 60 percent of long-term care expenditures for older people were paid for by Medicare and Medicaid (CBO, 2004). But federal and state policies on reimbursement for these programs change,

which can affect the numbers of people whose care is paid by a third party. For example, when the Balanced Budget Act of 1997 required changes in home health care Medicare payment policies, home health care visits plummeted, declining from 8,227 visits per 1,000 enrollees in 1997 to 2,295 in 2001—a decrease of 72 percent (Federal Interagency Forum on Aging Related Statistics, 2004).

Medicaid cost containment strategies now being considered by the federal and state governments could have similar impacts. The Bush administration has proposed a number of changes to the Medicaid program to contain cost growth. How these developments will play out is unknown but they could affect the ability of recipients to access paid long-term care at home and in institutions. As long as the entitlement to Medicaid long-term care services for low-income seniors is not reduced significantly, however, more elderly will apply for coverage to meet their long-term care needs.

The public sector is also looking to shift the balance of the long-term care delivery system to emphasize community-based options and lower-cost alternatives such as consumer-directed home care and non-medical residential facilities. All but six states now have programs in place to pay family members for caregiving services (Feinberg et al., 2004).

The likely net impact of these “program effects” on the demand for informal and formal care is difficult to untangle. Increased demand for consumer-directed home care will increase the demand for paid care but some of the demand will be met by paying family caregivers, leading to a blurring of the lines between formal and informal care in these programs. Greater numbers of non-medical residential facilities on their own will require greater numbers of direct-care workers, but it is not clear whether that will add to or take away from the demand for these workers in home care or nursing homes.

**Assistive technology:** The Federal Interagency Forum on Aging-Related Statistics (2004) reported an intriguing trend – the use of assistive devices may be increasing.<sup>3</sup> From the mid-1980s until the end of the 1990s, the percentage of older Americans with a disability that

<sup>3</sup>Assistive devices refer to any item or piece of equipment, or product system, whether acquired commercially, modified or customized, that is used to increase, maintain or improve functional capabilities of individuals with disabilities.





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received personal care from a paid or unpaid source declined from 15 percent in 1984 to 11 percent in 1999. At the same time, assistive device use increased from 13 percent to 26 percent. This suggests that in some cases assistive devices are substituting for personal care, a kind of labor-saving technological change. More technological changes – such as using sensors to monitor a care recipient’s daily routine and vital signs – may have an important affect on the use of personal care, whether formal or informal.

Much is unknown about how the above trends will play out and interact. But, even with the growth in the use of assistive technologies and changes in public financing, the demand for caregiving will increase steadily as America ages. At the same time, basic demographic forces will work to limit the supply of both potential informal and formal caregivers. In other words, the pool of available family caregivers will shrink while the working-age population is expected to grow only very slowly at best, with most of the modest increase due to net immigration. The need for developing public policies to retain and support both paid and non-paid caregivers is clear.

### SHAPING THE INTERSECTION OF FAMILY AND PAID CAREGIVING

American society has entered an era where caregiving issues in later life and for people with disabilities are becoming much more dominant parts of our lives. We enter this era at a time when the family caregiving system is under great stress and there are growing shortages of direct-care workers. It makes little sense from a policy and advocacy perspective to treat family and formal caregiving as two separate worlds. But separate treatment is in fact the status quo and this has led to largely independent policy agendas that potentially compete for the same attention and resources.

A new lens on caregiving is in order—one that recognizes that formal and family caregiving are not independent phenomena but rather are highly interconnected and interdependent. As Surpin and Hanley (2004) put it, “[Family care] should be interwoven with the formal care system—not treated as a separate system that must be essentially depleted before formal services are called upon.” Surpin and Hanley go further and argue for moving towards “a new model for long-term care

based on collaboration between and among family caregivers and formal caregivers.” “[E]xperiments with the most potential for long-term impact,” they believe, “are programs seeking to coordinate services for long-term clients across the various care settings, to integrate medical and social needs and to blend formal caregiving with family and volunteer caregiving.”

As new models of long-term caregiving are explored, advocates and policy makers have the opportunity to make headway in developing an integrated agenda that speaks to the needs of both paid and unpaid caregivers and care recipients. Before identifying possible elements of such an agenda, it is important to clarify the commonalities and shared values and goals that could serve as the foundation of an integrated agenda:

- Recognition that paid and family caregiving are not independent but rather are highly interconnected and interdependent. To put it simply, family and paid caregivers are on the same team.
- Recognition that, while there are differences in culture, roles and training, family and paid caregivers share a common reality – society’s undervaluing of caregiving labor, stemming in large part from caregiving’s long history as a female-dominated sphere. For paid workers, this results in low pay, poor working conditions and lack of respect. For family members, the view that this work is unexceptional yet obligatory “domestic labor,” has resulted in a dearth of public policies designed to help families balance caregiving and workplace responsibilities and has left caregivers isolated in their private, domestic worlds.
- Shared desire to attain the highest quality of care for the care recipient through healthy partnerships between care recipients, families and formal caregivers.
- Willingness to tackle the difficult problems in caregiving, such as the trustworthiness of the formal care workforce and the competency of family caregivers (Gould, 2004), as well as the exploitation or abuse of caregivers by family members.

Given agreement on basic principles, concerns and values, there may be considerable self-interest on the part of care recipients and

their family caregivers, and direct-care workers and their employers, in working together. Their common agenda would allow families to support the highest possible quality of life for their relatives by interweaving their care with that of formal care providers. As a beginning, three broad agenda items are presented: training, support and the development of holistic caregiving approaches which integrate family and paid care.

### **Training for Paid Direct-Care Workers and Family Caregivers**

While family caregivers are not technically part of the formal system, their need for training and support should be formally recognized and addressed. As Mezey (2004) writes, “[F]amilies are being called on to provide ever more complex care to ill relatives. Family caregivers provide care unassisted in situations requiring more clinical skill than should be expected of lay people, especially those new to the caregiving role.”

In addition to training in clinical skills, family caregivers need information and resources to support problem-solving and care decisions. The care decisions that family members confront can be wide ranging, complex and frequent. They need to know whom and when to call for health care or social services assistance, how to manage multiple medications and how to assess changing care needs based on improvements or worsening of conditions. And very often, they need information and support on how to manage and work with paid caregivers.

Direct-care workers, with appropriate training and time, could provide much of this training and support to family members. In a more integrated system, these workers would be trained in assessing not only the needs of the care recipient but also the whole family. They could identify the clinical skills that family members need to learn and refer family members to supportive resources available in the community.

To improve the quality of interactions between formal and informal care providers, workers also need greater skills development in communication techniques, expressive support, problem-solving and assessment. According to Piercy and Dunkley (2004), “It was often the emotional support through friendships with home care workers, and their

affirmation of caregiver efforts, that were so highly valued by family caregivers.” These enhanced skills are especially needed in consumer-directed situations, where workers must balance the client’s lifestyle decisions against concerns about safety and overall health (Surpin and Hanley, 2004). But even in nursing homes and assisted living facilities, there is greater awareness of the need to train direct-care workers to communicate effectively with family members involved in caregiving.

### **Supporting and Sustaining Family Caregivers and Direct-Care Workers**

If a key goal is to attract and retain as many caregivers as possible to meet the rising demand for long-term care services, then providing adequate supports to both paid and unpaid caregivers should be a critical priority for policy. Better-supported caregivers are a win-win all around because they raise the quality of care received by consumers, increase retention among caregivers and attract new caregivers.

Advocates for family caregivers and direct-care workers have each put forward agendas for raising the quality of caregiver roles and jobs. For paid workers, this agenda includes:

- An increase in the quality of direct-care jobs through higher wages and benefits,
- Improved work environments and supervision,
- Better training programs and credentialing systems, and
- The creation of meaningful career ladders

Family caregivers have stressed the following reforms:<sup>4</sup>

- Access to a well-functioning system of paid direct care that provides affordable, readily available, high-quality care,
- Family-friendly workplace policies that accommodate and support employee caregiving responsibilities,
- Assistance with the financial strain of caregiving that can come from lost earnings from missed or reduced work, and

<sup>4</sup>See Statement developed by a collaborative group of family caregiver advocates on December 1, 2003, “Family Caregiving and Public Policy: Principles for Change.” [www.caregiving.org/principles04.pdf](http://www.caregiving.org/principles04.pdf)





Programs that blend formal and informal care ... will require changes in Medicaid and Medicare ... [they] currently pay for “the time needed to perform specific tasks” and not the time needed to “build caring relationships.”

- Training on how to assist with activities of daily living, use of medical equipment, administration of medications and proper lifting and transferring.

While the merits of these separate agendas are undeniable, better integration of these support strategies could come from creating community-based caregiver access points that would provide services to care recipients, family caregivers and direct-care workers. Such integration particularly makes sense as family caregivers become paid caregivers through such programs as Cash and Counseling and other consumer-directed programs.

Caregiver access points could link consumers and families with direct-care workers or other family caregivers in order to receive information, training and respite care. Direct-care workers could find training programs and information about different kinds of paraprofessional employment. Specially trained direct-care workers and family-caregiver mentors could more easily reach those family caregivers who have the most difficulty engaging or accessing service networks. Community-based one-stop access points could be an antidote to the tremendous fragmentation of long-term care services and a location for creating opportunities for blending voluntary and paid care, and for better supporting both paid and family caregivers.

### **Building a Holistic, Integrated Approach to Caregiving**

Moving towards a paradigm that treats paid and unpaid caregiving and caregivers as central, interconnected components of the long-term care system has important implications for how caregiving programs should be structured and managed. It will lead us toward creating programs that offer a comprehensive, interdisciplinary care management framework, designed to address the needs of the care recipient as well as his or her family caregivers. A number of innovative programs that take a holistic approach to care management are already underway. These programs stress the coordination of services, the integration of medical and social needs and the blending of formal caregiving with family and volunteer caregiving.

A 2004 report by the Family Caregiver Alliance (Toseland, 2004) showcased five family

caregiver education and support programs that proved to be effective through empirical-based evidence. One program from the Rosalynn Carter Institute for Caregiving, “Caring for You, Caring for Me: Education and Support for Family & Professional Caregivers,” brings family and professional caregivers together to learn about caregiving issues and resources and to share ways to cope with caregiving stress. In the process, they come to better appreciate each other’s perspectives and find ways of working together to reduce frustrations. More programs like this are needed, both to build an effective caregiving team and to optimize limited training resources.

Programs that blend formal and informal care and offer a holistic approach to care management will require changes in Medicaid and Medicare reimbursement and program structures. In an environment of strict cost control, Medicare and Medicaid reimbursement structures currently pay professionals and paraprofessionals for “the time needed to perform specific tasks” and not the time needed to “build caring relationships” (Surpin and Hanley, 2004). Surpin and Hanley (2004) make the case that these reimbursement structures and the programs they support need to be changed to create incentives for:

- Assessing the caregiving needs of the whole family,
- Allowing time to observe the caregiving skills of family members,
- Teaching skills required to perform such tasks as ambulation, dressing, bowel management, comfort care and pain management, and
- Including communication and conflict resolution skills in training for paid caregivers.

The financial implications of such an integrated caregiving agenda are unknown at this point. In the current federal and state fiscal climates, there is pressure to cut support for caregivers and postpone spending that would enhance the job quality of direct-care workers. But while a holistic, integrated agenda will require up-front investment, it may well reduce overall costs to the long-term care system over the long-run by improving the quality and efficiency of care that people receive and reducing the physical, psychological and emotional stress on millions of family caregivers.

Independent scholar and social commentator Deborah Stone argues that American society has entered an era where “right to care” issues are front and center: “We have the Bill of Rights and we have civil rights. Now, we need a Right to Care and it’s going to take a movement to get it.” The right to care, Stone says, means, first, that families are permitted and helped to care for their members, second, that paid caregivers are supported to give human, high-quality care without compromising their own well-being, and, third, that people who are dependent can receive the care they need (Stone, D., 2000).

From a policy and advocacy perspective, treating family and formal caregiving as two separate worlds makes little sense. But joining forces to create an integrated caregiving agenda will require a fundamental shift toward more explicit partnerships and alliances between family caregivers, paid direct-care workers, their employers and the millions of individuals needing long-term care assistance.

Robyn Stone, a long-term care leader and advocate who has studied family and paid caregiver issues for over 20 years, agrees that a critical piece is missing in the long-term care arena: “There are too few efforts to join forces in the political advocacy arena. Family and paid caregiver groups need to come together to urge support for public policy and private financing changes that support their common needs.”

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FAMILY CAREGIVING RESOURCES	PAID CAREGIVING RESOURCES
National Alliance for Caregiving <a href="http://www.caregiving.org">www.caregiving.org</a>	Better Jobs Better Care <a href="http://www.bjbc.org">www.bjbc.org</a>
National Center on Caregiving Family Caregiver Alliance <a href="http://www.caregiver.org">www.caregiver.org</a>	Paraprofessional Healthcare Institute <a href="http://www.paraprofessional.org">www.paraprofessional.org</a>
National Family Caregivers Association <a href="http://www.thefamilycaregiver.org">www.thefamilycaregiver.org</a>	National Clearinghouse on the Direct Care Workforce <a href="http://www.directcareclearinghouse.org">www.directcareclearinghouse.org</a>
National Family Caregiver Support Program Resource Room Administration on Aging U.S. Dept of Health & Human Services <a href="http://www.aoa.gov/prof/aoaprogram/caregiver/caregiver.asp">www.aoa.gov/prof/aoaprogram/caregiver/caregiver.asp</a>	National Alliance for Direct Support Professionals <a href="http://www.nadsp.org">www.nadsp.org</a>  Service Employees International Union <a href="http://www.seiu.org/health">www.seiu.org/health</a>
United Hospital Fund Families and Healthcare Project <a href="http://www.uhfny.org">www.uhfny.org</a>	American Federation of State, County, and Municipal Employees <a href="http://www.afscme.org">www.afscme.org</a>

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