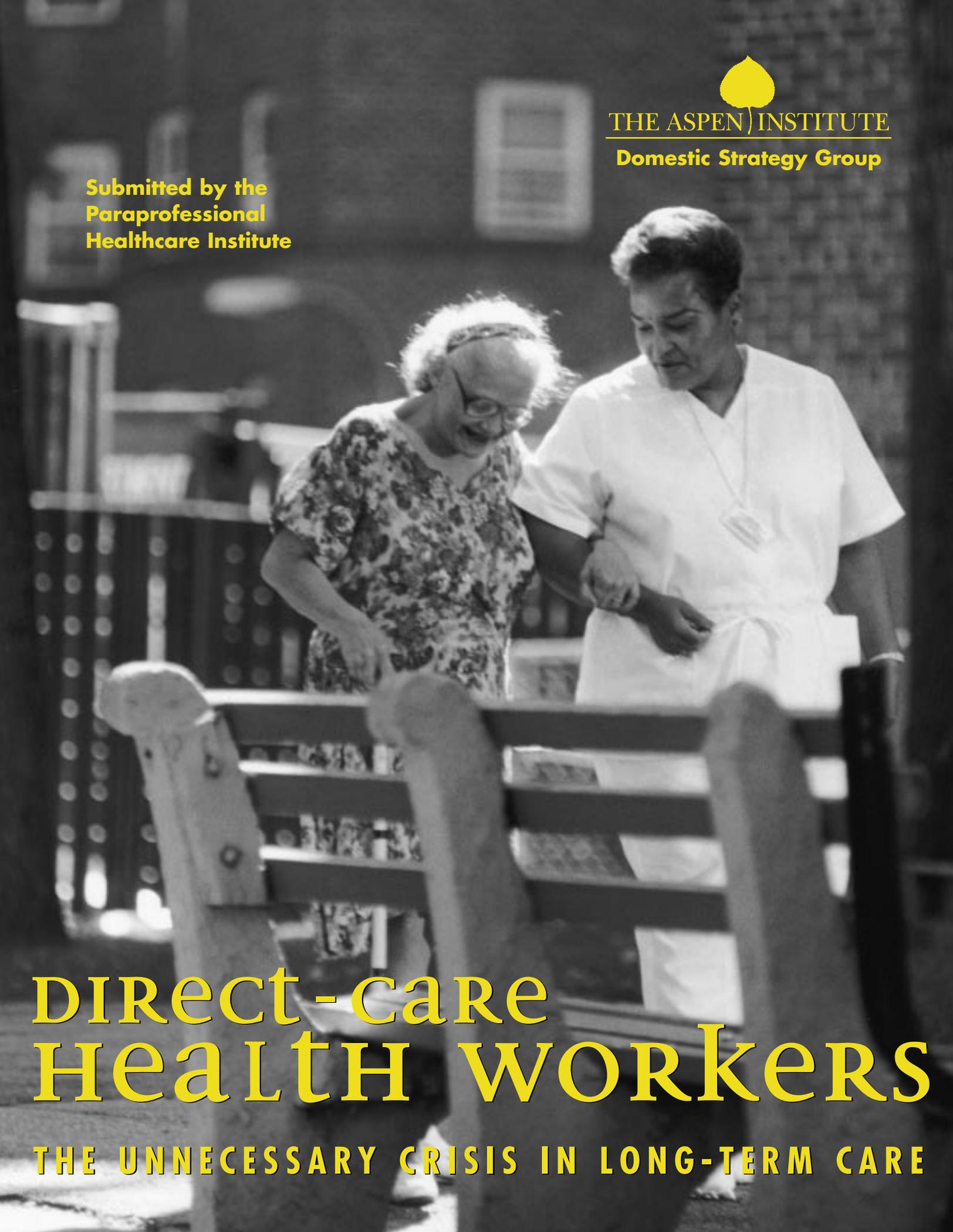




THE ASPEN INSTITUTE

Domestic Strategy Group

Submitted by the
Paraprofessional
Healthcare Institute



DIRECT-CARE HEALTH WORKERS

THE UNNECESSARY CRISIS IN LONG-TERM CARE

the ASPEN INSTITUTE

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The Domestic Strategy Group (DSG) is a policy program of the Aspen Institute. The DSG has 30 members including corporate CEOs, labor leaders, public officials, journalists, leading academics, and non-profit executives. Since 1997, it has focused on “Work and Future Society,” engaging in dialogues on the changing workplace and workforce, the income and wage gap, work and family life, education and skill development, and the creation of job ladders and mobility. As a part of this dialogue series the DSG commissioned a study, to be done by the Paraprofessional Healthcare Institute, of the long-term care industry and its workforce.

JANUARY 2001

DIRECT-CARE HEALTH WORKERS

THE UNNECESSARY CRISIS IN LONG-TERM CARE

SUBMITTED TO THE:

Domestic Strategy Group
of the Aspen Institute

BY THE:

Paraprofessional
Healthcare Institute

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PARAPROFESSIONAL HEALTHCARE INSTITUTE

The Paraprofessional Healthcare Institute (PHI) is a national nonprofit health care employment and advocacy organization, based in the South Bronx, New York. The mission of PHI is two-fold:

- To create decent jobs for low-income individuals, with an emphasis on women who are unemployed or transitioning from welfare-to-work, and
- To provide high-quality health care to clients who are elderly, chronically ill or living with disabilities.

PHI has linked this twofold mission through a “Quality Jobs / Quality Care” school of thought: Creating quality jobs for low-income individuals—who comprise the majority of paraprofessional healthcare workers—is not only consistent with, but necessary to, the provision of high-quality, cost-effective care.

At the practice level, PHI has helped organize the Cooperative Healthcare Network, a federation of worker-owned, paraprofessional health care providers and training programs in the states of New York, Pennsylvania, New Hampshire, Michigan and Arkansas. PHI is also a prime sponsor of Independence Care System (ICS), a nonprofit managed long-term care program for people living with physical disabilities in New York City.

At the policy level, PHI staffs the national Direct Care Alliance, an advocacy voice representing consumers, workers and concerned providers to create both quality jobs and quality care within the long-term care sector. In addition, PHI recently launched the National Clearinghouse on the Direct Care Workforce, to act as a national information center on the staffing crisis in long-term care.

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A black and white photograph showing a female doctor on the right, smiling warmly at an elderly female patient on the left. The doctor is wearing a white lab coat and has a stethoscope around her neck. She is holding the patient's hand with both hands. In the background, a large medical chart or X-ray is visible, held by another person whose face is partially obscured. The overall scene conveys a sense of care and connection in a clinical setting.

...the result is a spiral of instability: a growing exodus of direct-care staff that leaves behind a workplace that is ever less attractive to potential new staff.

executive summary **DIRECT-CARE HEALTH WORKERS:** **THE UNNECESSARY CRISIS IN LONG-TERM CARE**^a

PART I: THE ENDANGERED HEALTH CARE WORKER

Eight out of every ten hours of paid care received by a long-term care client is provided by a “direct-care” paraprofessional—a home health aide, personal care attendant, or certified nurse’s aide. These direct-care staff members are the primary delivery system for long-term care, yet more than 40 states now report critical shortages of paraprofessionals. Turnover rates range between 40 and 100 percent annually. Vacancies and turnover are dangerously high for three reasons:

- 1) The quality of direct-care jobs tends to be extremely poor.
- 2) The full-employment economy offers better job alternatives.
- 3) Post-Baby Boom demographics in the United States have created a “care gap” that will worsen over the next 30 years.

The long-term care industry has long structured itself on the presumption of a seemingly endless supply of low-income workers. Now that this decades-old presumption is no longer valid, unprecedented pressure is placed not only on the “formal,” paid health care delivery system, but also on family caregivers.

PART II: IMPACT OF THE “CARE GAP”

High rates of staff vacancies and turnover harm all three “key stakeholders” within long-term care:

Impact on Consumers (and their families): The emerging “care gap” is causing 1) care without continuity, 2) inadequate and unsafe care, and, 3) in some cases, denial of care.

Impact on Providers: Staff vacancies and high turnover create 1) high recruitment and orientation costs, 2) high retention costs, 3) high separation costs, 4) high temporary replacement costs, and 5) foregone sales revenues.

Impact on Workers: “Working short” means 1) higher rates of injuries, 2) higher levels of stress and frustration, and 3) less training and supervisory support. The result is a spiral of instability: a growing exodus of direct-care staff that leaves behind a workplace that is ever less attractive to potential new staff.

PART III: “HIGH-INVESTMENT, HIGH RETURN”

In response, policymakers can begin to pursue “win-win-win” high-investment/high-return employment strategies that provide workers with higher wages and better working conditions—benefiting all three stakeholders:

**“JUST DON’T GET SICK...
AND DON’T GROW OLD EITHER.”**
—advice of a home health aide

Workers would earn a livable wage, provide health insurance for their families, and become a more respected member of the care team. Provider agencies would direct their management and financial resources away from recruitment and disciplinary actions, and toward training, support, and retention. Consumers would receive consistent assistance from more highly trained, paid caregivers who could focus their attention solely on care for their clients.

PART IV: THE LONG-TERM CARE SYSTEM

Section A: Three Key Stakeholders. The three stakeholders are those whose lives are touched each day within long-term care settings:

Paraprofessional Workers: Nationwide, paraprofessionals total more than 2.1 million workers; 86 percent are women, 30 percent are women of color, and most are between the ages of 25 and 54—more than 28 percent return from work to a family living in poverty. Since direct-care positions cannot be replaced by technology, nor moved offshore, over the next eight years they are projected to be the nation’s seventh fastest-growing occupation.

Long-Term Care Consumers: The U.S. long-term care population currently numbers about 12 million. Although diverse, all of these people require assistance with personal activities of daily living, hygiene, and household maintenance. The elderly make up approximately half of the long-term care population at 6.4 million; 5.3 million non-elderly adults and 400,000 children also require long-term care.

The need for direct-care services is expected to grow geometrically during the next 30 years: 1) the population of those requiring paraprofessional care is increasing; 2) the acuity of illness and disability of those in need is increasing; and 3) the preference for living in home- and community-based settings

^a We define “long-term care” to include both medical and social services provided to the elderly, chronically ill, and disabled in home-, community- and facility-based settings.

(where more assistance is required than in institutional-based care)—is increasing.

Provider Agencies: Nearly 120,000 long-term care agencies—ranging from small nonprofits to massive, for-profit chains—offer care in a range of institutional, home-based, and community-based settings. The financial viability of the entire industry is currently endangered, in part by passage of the Balanced Budget Act of 1997. In the last two years, more than 20 percent of all Medicare-funded home care agencies have closed and five of the ten largest for-profit nursing home chains have entered Chapter 11 bankruptcy.

Section B: Primary Financiers. In 2000, long-term care expenditures for the elderly alone are expected to total \$123 billion—60 percent from public sources (primarily Medicaid and Medicare), 4 percent by private insurance, and 36 percent by out-of-pocket and other sources. By 2020, Medicare and Medicaid funding will likely increase over 70 percent to \$126 billion in constant year 2000 dollars, yet still remain 60 percent of the elderly long-term care finance system.

Medicaid: Funded jointly at the federal and state levels, Medicaid provides health coverage primarily for low-income citizens. The program is intentionally designed to provide certain long-term care benefits, with approximately 35 percent of all Medicaid funding flowing to long-term care needs.

Medicare: Funded solely by the federal government, Medicare is designed to provide coverage for acute care (assistance for relatively short-term, intensive medical care) to those 65 years and older and for people living with disabilities. Thus Congress has intentionally restrained Medicare's participation in long-term care for chronic conditions.

Section C: A Disaggregated System. The resulting structure has become a rickety system of disparate program “silos,” where function follows form. These vertical structures fail to recognize that clients move laterally through the long-term care system and that many paraprofessionals also work across settings.

PART V: HEALTH, LABOR, AND WELFARE POLICIES

The low-income, direct-care worker stands at the intersection of three public policy worlds—health care policies, labor policies, and welfare policies—yet coordination between these three policy worlds is absent.

Health Care Policies: Governmental procedures play the dominant role in the structuring and implementation of our long-term care system. Yet health care delivery policy has been designed without recognition of its labor impact: When the

Health Care Financing Administration (HCFA, the manager of Medicare and Medicaid) issues proposed regulatory changes, it assesses the likely affect on clients, states, and providers, but not workers.

Labor Policies: The federal government invests more than \$8 billion to prepare Americans for new and better jobs, yet public training programs often preclude the long-term health care industry by requiring participants graduating from those programs to secure wages higher than direct-care workers typically earn. In 1999, Congress passed the new Workforce Investment Act (WIA), which may allow new flexibility at state and local levels for experimentation.

Welfare Policies: Since direct-care staff are typically low-income women, they are often supported by, and entangled in, public assistance agencies. For years the interweaving of welfare and health care employment provided a hidden employment subsidy to the health care system. In 1996, Congress passed the Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA) that curtailed welfare as an entitlement. Although welfare rolls have been reduced by 50 percent, many low-income health care workers are still entangled in public programs such as food stamps, support for child care, and transportation.

The Gulf Between the Three: Although health, labor, and welfare policies all intersect the lives of direct-care workers, none are designed with the worker in mind. Furthermore, these three centers of policy do not communicate with one another on paraprofessional workforce matters—even though the creation of a stable, well-trained workforce would serve the interests of all three.

PART VI: DYNAMICS OF THE DIRECT-CARE LABOR MARKET

If the health care labor market were functioning perfectly, direct-care vacancies would not continue for long. The supply of workers would expand to meet demand as employers improved their “price” (wages, benefits, and working conditions) to attract and retain more workers. Yet several factors prevent our health care system from achieving rapid labor-market “equilibrium,” including 1) continually expanding pressures on the demand for health care services, 2) limitations on the supply of additional workers, and 3) restrictions on the ability and/or willingness of employers to increase their labor “price.”

Factors of Demand: The health care labor market is driven by massive demographic and technological forces that push to accelerate aggregate demand for services. Simultaneously, powerful third-party payers (both public and private) attempt

to brake that demand through regulatory constraints and cost containment. The result is likely to be continued expansion of effective demand, but an expansion that will remain irregular and balky depending largely on political and financial—not simply care-related factors.

Factors of Labor Supply: The pool of likely entry-level workers—women in the civilian workforce within the age range of 25 to 44—is projected to decline by 1.4 percent during the next six years. This new decline follows three decades of significant expansion of the equivalent labor pool—nearly tripling from 1968 through 1998. We thus face a labor supply that is profoundly different from what our long-term care system has presumed over the past 30 years.

“Price” Inflexibility: To address the labor vacancies, one realistic path remains open to long-term care providers: competing successfully against other employers for workers. While successful competition requires improving the “price” of labor—examining ways to increase wages, benefits, and working conditions—this path also requires aggressive action by third-party payers and employers, both of whom have been slow to react to the emerging direct-care labor crisis.

PART VII: ESSENTIAL ELEMENTS OF THE DIRECT-CARE WORKFORCE

The five essential elements necessary to frame a quality health-care job are:

- a “family wage,” health insurance, and other benefits;
- balanced and safe workloads;
- higher training standards;
- opportunities for advancement and professional development; and
- employee supports provided by both the community and the employer.

To fully implement these five elements will require a different vision of our long-term care system, as well as a wide range of experimentation.

PART VIII: A VISION FOR THE FUTURE

The emerging direct-care crisis creates an opportunity to redesign the care system around the core relationship of the client and her paid/family caregivers. Attributes that a new model should encourage include:

For Consumers: A seamless blending of social and health needs, seamless blending of family care and paid caregiving, rapid response to a client’s changing needs, continuity of care, and a mechanism for accountability to consumers.

For Direct-Care Workers: The “essential elements” of a stable paraprofessional job; parity of pay for workers across care settings; opportunities for career advancement, specialized assistance for child care, transportation, and other needs unique to direct-care employment; and a mechanism of accountability to workers.

For Providers: A stable and more rational funding environment, an adequate base of skilled, direct-care staff, and a positive business logic for a high-investment/high-return strategy toward direct-care staff.

Letting Form Follow Function: A redesign of an entirely new care system must accept two realities: the role of government and the role of the marketplace. Balancing these two roles effectively will prove inconceivable without eventually reconstructing the long-term care system as a single, integrated sector. To accomplish such a sectorwide integration will in turn require horizontal mechanisms, both within government and within the marketplace:

Federal and State Governments: Allowing form to follow function, one core element of redesign would likely require:

- A single, public long-term care entity that acknowledges the dual responsibility for long-term care at both the federal and state levels. This single entity would administer and coordinate all long-term care funding streams and regulations and work to blend social and medical services to ensure continuity laterally across the varied settings.

Conceptualization of long-term care as a single system—and experimentation to coordinate governmental funding streams laterally at the federal and state levels—should be encouraged. This in turn will help facilitate the market-based changes in management and service provision described below.

The Marketplace: The presence of horizontal intermediaries will likely be required to balance the needs of third-party payers (both private and public) with the needs of consumers, providers, and workers. One approach might include:

- Several competing long-term care intermediary organizations, within any one particular geographic region, coordinate services for long-term care clients across the various care settings, integrating social with medical needs and blending formal caregiving with family and volunteer caregiving.

The governance structure of these intermediaries is critical. To gain the greatest support of consumers, providers, and labor, these regionally competing intermediaries could be structured as nonprofit organizations to ensure accountability to all three stakeholders.

With more unified funding streams and coordinating mechanisms that integrate care horizontally, providers would enjoy a more rational, stable environment within which to compete for contracts and to be rewarded for combining high-quality care with cost-effectiveness. This might result in:

- Regional/local providers offering a broad range of long-term care services that would deliver care directly to clients but would be coordinated through the regional intermediaries. Paraprofessional services could be either embedded within the regional provider agencies or within paraprofessional-only agencies focused specifically on direct-care services.

PART IX: EXPERIMENTS IN DIRECT-CARE RESTRUCTURING

Both government entities and the long-term care industry are experimenting to improve the quality of paraprofessional jobs:

Government actions include: 1) wage and benefit “pass-through” legislation at the state level, 2) state health insurance programs for home care workers, 3) minimum staffing regulation initiatives at the federal and state levels, and 4) new training and welfare resources at the state level.

Industry practices include: 1) job redesign programs and 2) new recruitment, training, and career pathways consortia among regional employers.

Part X: RECOMMENDATIONS

In response to the emerging direct-care crisis, we propose the following initial steps:

1) Create a National Long-Term Care Workforce Commission.

This sectoral commission could be sponsored by one or more nationally respected foundations, modeled after the Kaiser Commission on Medicaid and the Uninsured. The commission’s charge would be to propose how the nation’s long-term care system can be assured of an adequate, well-trained, and stable direct-care workforce. Initial activities of the commission might include recommendations to:

- Structure a cross-departmental dialogue at the federal administrative level, particularly between the Departments of Health and Human Services (HHS), Labor (DOL), and Education (DOE).

- Research paraprofessional demographics and document para-professional job quality.

- Design a system of workforce data, reported by each publicly funded direct-care employer.

- Encourage further “effective practice” experimentation at the federal and state levels.

- Encourage further “effective practice” experimentation among employers, consumers, and organized labor.

2) Identify a few key states in which to create an administrative, cross-departmental Long-Term Care Council.

Each state council would explore ways to remove inefficiencies, identify opportunities to rebuild that state’s direct-care workforce, and encourage further experimentation among demonstration programs.

3) Consider promoting a single initiative across several states – e.g., “health care for health care workers.”

This initiative could build on the success of child-care workers in Rhode Island, as well as on the research and legislative initiatives undertaken by the Service Employees International Union on behalf of home care workers in California and New York State.

4) Support cooperation and organization among the three key stakeholders.

Nationally, representatives of these three key actors within the long-term care system have formed the Direct Care Alliance (DCA). Assistance could be provided to the DCA to encourage information interchange among providers, workers, and consumers.

Our system that provides long-term care to our most vulnerable citizens is truly in danger. While the demographics are inexorable, the resulting crisis is not.

We built a system of care when labor was plentiful, and thus we could “afford” to offer poor-quality jobs. Now that labor is a scarce resource, our presumptions, and prescriptions, must change.

In this period of high competition for labor, we must create jobs that will attract workers. To do so will void the crisis. To do otherwise will be to witness the wealthiest health care system on Earth perpetuate poverty-level jobs—offering to its most vulnerable citizens care that is hurried, care that is delayed, and increasingly, care that is foregone.



part I paraprofessionals: the endangered health care worker

When your loved one falls ill or becomes too frail to manage alone, who will provide her care and companionship when you cannot be with her?

Whether your loved one is cared for in her home, an assisted living facility, or nursing home, a “direct-care” aide provides eight out of every ten hours of paid care your loved one receives¹—not a doctor, not a nurse, but a paraprofessional, a home health aide, personal care attendant, or certified nurse’s aide who typically has received one month or less of formal health training.

Paraprofessionals are the hands, face, and voice of health care for millions of America’s long-term care clients. They bathe, toilet, feed, and transfer from bed to chair the frail elderly, the chronically ill, and those who are physically or developmentally disabled. Some aides monitor medications, assist in physical rehabilitation, or change the dressings on wounds. All provide comfort and companionship to individuals who may be isolated, depressed, or disoriented—offering a lifeline to the outside world.

Yet today, for reasons this paper explores fully, your loved one will be fortunate to find any direct-care staff at all. Rates of vacancies and staff turnover are now so high that, in some parts of the country, state associations representing nursing homes and home care agencies report that their member agencies are increasingly unable to provide care to clients due to an absence of nursing^b and direct-care staff.

If your loved one does obtain service, her direct-care aide may well be overworked and dangerously rushed. In the past year, 44 states have responded to, or formed special task forces to study, the long-term care workforce crisis.²

Causes of Vacancies and High Turnover

By providing the vast majority of face-to-face contact for long-term care clients, paraprofessional workers constitute the

primary delivery system of the long-term care industry. Yet an industry that fails to maintain its delivery system is an industry that, by definition, can run neither effectively nor efficiently.

Why are vacancies and turnover now so high among direct-care positions? Three reasons are key:

- 1) The quality of direct-care jobs tends to be extremely poor. Wages are low and benefits few; ironically, most direct-care staff do not receive employer-paid health insurance³. Home care work typically offers only part-time hours and thus part-time pay, and aides in many nursing homes are now forced to serve far too many “beds,” which creates unsafe conditions for both client and worker.

Furthermore, focus group interviews among paraprofessionals document that supportive supervision at nursing homes is rare and supervision in home care is nearly nonexistent⁴. Therefore, with her knowledge and daily insight of the client’s condition typically ignored, the aide is often treated by the rest of the health care system as invisible. In short, she is rarely considered as a true part of the health care team.

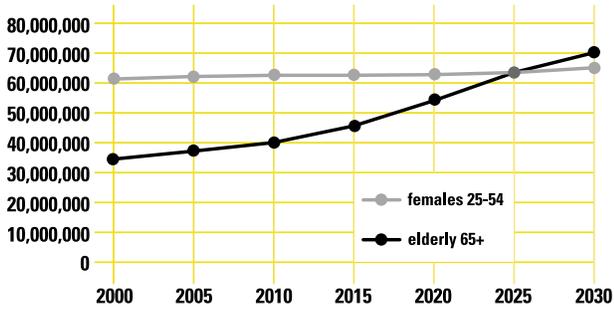
- 2) The full-employment economy offers better job alternatives. With the lowest U.S. unemployment rate in 30 years, vacancies now stretch throughout the service industry: “Help Wanted” signs are posted in nearly every convenience store, food court, and service center in the country. Pointedly, these clerical and food-counter positions offer jobs that are safer and less demanding than direct-care health positions, and yet pay as well or better. Offered the alternative of stable and safe service-sector employment, compared to the increasingly stressful demands of long-term care, even people who love to assist others are choosing to leave the health field.

In the past year, 44 states have responded to, or formed special task forces to study, the long-term care workforce crisis.

b Although many of the issues we will review here also affect professional nursing staff within the long-term care system, this paper focuses exclusively on the paraprofessional workforce.

fig. 1) The Care Gap: Women of Care-Giving Age in U.S., 2000-2030

(females aged 25-54; individual aged 65 and older)



Source: U.S. Census Bureau, National Population Projections, Summary Files, "Total Population by Age, Sex, Race, and Hispanic Origin," <http://www.census.gov/population/www/projections/natsum-T3.html>

3) Post-Baby Boom demographics in the U.S. have created a "care gap" that will worsen over the next 30 years. Were staff vacancies and turnover the result only of our full-employment economy, the health care system could simply wait and hope for the next economic downturn. However, the number of people requiring paraprofessional care is growing, while those who traditionally provide that care—primarily women between the ages of 25 and 54—cannot keep pace.

This ever-expanding demand for greater health and personal care services derives from several factors, including medical advances that allow people with chronic illnesses and disabilities to live longer, technology that permits high-need individuals to live in home-and other community-based settings, and, most of all, a growing elderly population. At the same time, a smaller population cohort following the Baby Boom is now passing through the U.S. workforce, yielding relatively fewer workers available for caregiving tasks.

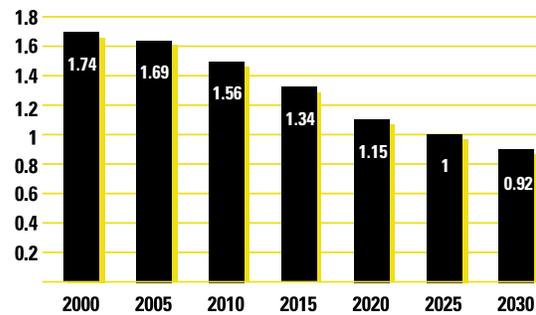
For one dramatization of this growing mismatch between the supply and demand for direct-care services, note above that the U.S. elderly population is projected to double over the next 30 years, while the "traditional" female caregiving population is projected to grow by only 7 percent (see fig 1).

In short, the demographic mismatch between the demand for and supply of direct-care workers is a long-term structural problem that will persist, even if higher unemployment rates return^c.

Viewed from a slightly different perspective, we can use this same data to calculate an "elderly support ratio" that compares the relative availability of caregivers over time. As the chart below shows, the U.S. population currently includes 1.74 females aged 25 to 54 per elderly person, at a time when we are already experiencing significant direct-care vacancies. Yet this ratio will decline steadily over the next 30 years and, by 2030, reach a point where there will be fewer than one woman of caregiving age per elderly individual (see fig 2).

Unfortunately, this shrinking ratio of support will place pressure not only on the formal, paid health care delivery system but also on family caregivers. Since women provide the majority of both paid direct-care services and family care, this "care gap" in the U.S. will increasingly become a double-bind: When families who cannot care for loved ones by themselves turn to the formal system for assistance, they will find relatively fewer paid staff available.

fig. 2) Elderly Support Ratio, 2000-2030
(females aged 25-54 per individual aged 65 and older)



Source: calculated from U.S. Census Bureau, National Population Projections, Summary Files, "Total Population by Age, Sex, Race, and Hispanic Origin," <http://www.census.gov/population/www/projections/natsum-T3.html>

Reframing the Debate

The long-term care industry long ago structured itself on the presumption of a seemingly endless supply of low-income individuals (usually women, and disproportionately women of color). The industry presumed that these women would always be willing to provide care and companionship for our loved ones—despite jobs that kept them working, but poor.

Given the very low quality of these jobs, it could reasonably be argued that our long-term care system—paid primarily by public tax dollars—has an obligation to create jobs that provide

^c Given the very low population and labor force growth projected over the next several decades, a "normal" business cycle recession will likely result in only a modest increase in the number of unemployed. Dr. Richard Judy, director of the Hudson Center for Workforce Development, suggests that the United States over the next 20 years can expect unemployment rates to vary only within the narrow range of 3.5 to 6.5 percent. See testimony of Richard W. Judy to the Subcommittee on Oversight and Investigation, Committee on Education and the Workforce, U.S. House of Representatives, February 17, 2000. Hudson Institute, Indianapolis, Indiana. <http://www.hudson.org>

a livable wage; that our publicly funded health system has a responsibility, at the very least, to provide its own workers with health insurance. Yet to date, moral persuasion alone has failed to effect significant improvements in the quality of direct-care jobs.

Clearly, the decades-old presumption of an endless supply of low-income women is no longer valid. In order to maintain a stable, competent direct-care workforce, both providers and consumers now find it in their essential self-interest to improve the quality of paraprofessional jobs.

In short, our nation—with growing numbers of those in need of assistance and so relatively few young people available to provide that assistance—must fundamentally reframe the delivery of long-term care for our loved ones.

PART II impact of the “care gap”: LINKING QUALITY JOBS AND QUALITY CARE

High rates of staff vacancies and turnover harm all three key stakeholders within the long-term care system: consumers (and their families), providers, and workers. Although these three stakeholders have often competed with each other for long-term care resources, all are publicly stating their common concern that vacancies and turnover are now causing our direct-care delivery system—the very point where long-term care touches the client⁵—to disintegrate.

Impact on Consumers

Health care researchers have long noted the connection between the quality of direct-care jobs and the quality of care received by clients.⁶ As Sallie Tisdale wrote in *Harvest Moon: Portrait of a Nursing Home* (Henry Holt, 1987):

Ordinary, even familial things happen here, though often unwittingly. Wounds are healed, muscles strengthened, faces washed, and hands held. Each small movement is tiny in its fruition, huge in its absence.

High rates of direct-care vacancies and turnover deeply affect consumers in three ways:

- 1) **Inadequate, unsafe care.** High turnover results when staff are relatively inexperienced and fewer senior staff are available as mentors. Remaining staff are often forced to serve relatively more clients in a rushed or unsafe manner—unsafe to both client and worker—cleaning only “face, hands, and butts” (in the vernacular of direct-care staff), or transferring a client from bed to wheelchair alone (when two or more staff are required).
- 2) **Care without continuity.** Constant replacement of staff disrupts the care setting and precludes the development of relationships that are centrally important to both the client and the caregiver. In addition, each long-term care client is an individual with particular needs and preferences, yet new staff members rushing from bed to bed are understandably slow to learn those particulars. This churning of staff creates needless opportunities for mistakes and remove

from the client a sense of dignity and control over herself and her environment.

- 3) **Denial of care.** Many clients are simply turned away. For those clients who are admitted, overworked staff may fail to provide essential bathing, toileting, feeding, and hydration.

High rates of staff vacancies and turnover harm all three “key stakeholders” within long-term care—consumers, providers and workers.

Most important, formal paid caregiving does not function in isolation. It must be placed in context within the far larger reality of family and volunteer care. Caregiving by friends and family was valued at \$196 billion in 1997, far greater than the \$105 billion spent that same year nationally on nursing home and home care by the formal care system.⁷

Therefore, for an easily disoriented or frightened loved one, continuity of care also requires a smooth interface between the formal system of paid staff and family caregivers—an interlacing of schedules and information that changes from day to day. This continuity is impossible to achieve if the formal system is constantly disrupted by staff vacancies and turnover.^d

National organizations representing consumers are so troubled by the link between poor staffing and poor-quality care that they have identified staffing shortages as a critical issue. For example, 13 state chapters of the national Alzheimer’s Association have selected staffing issues as their top priority in the year 2000. In addition, a recent report published by The Commonwealth Fund found that inadequate staffing, a lack of individualized care, and high nurse-aide turnover are key causes of malnutrition and dehydration, affecting an estimated one-third of our nation’s nursing home residents.⁸

Finally, the National Citizens’ Coalition for Nursing Home Reform (NCCNHR) selected staffing issues as the key focus of its September 1998 annual meeting and NCCNHR continues to cite inadequate staffing levels as a primary advocacy issue: “Short staffing affects the welfare of every resident in nursing homes, and in some cases even endangers the lives of residents.”⁹

d For a compelling statement on the importance of all forms of caregiving, see Deborah Stone, “Why We Need a Care Movement,” *The Nation*, March 13, 2000.

Impact on Providers

Staff vacancies and high turnover have become a primary concern for providers—this within a long-term care industry that is already beset by a host of challenges ranging from mounting regulatory paperwork to shrinking reimbursement rates. The impact of direct-care staffing problems on health-care employers includes:

- 1) **High recruitment and learning/training costs.** High turnover and heated competition for workers force providers to divert financial and managerial resources toward additional advertising, hiring incentives, and orientation activities. Until they achieve full job mastery, new employees tend to lower overall productivity as they absorb both formal and on-the-job training.
- 2) **High retention costs.** Since providers are offering relatively unattractive jobs within the current competitive environment, they are more likely to be selecting from a pool of candidates with greater barriers to employment within the health care field—low education, poor work histories, poor health, drug or alcohol abuse, inadequate child care or transportation—than was true just two or three years ago. This means, in turn, that additional financial and managerial resources must be diverted toward oversight and disciplinary actions.
- 3) **High separation costs.** As employee turnover reaches high levels, separation activities—exit interviews, administrative functions related to terminations, separation pay, unemployment taxes, and loss of efficiency prior to termination—become costly.
- 4) **High temporary replacement costs.** Many facility-based providers are forced to hire replacement staff from temporary-employment agencies at hourly costs of up to 100 percent more than that of regular employees, simply to ensure that a “warm body” is present. This is particularly true of nursing home facilities during second shift (3pm to 11pm) and weekends.
- 5) **Foregone income.** A shortage of workers exists, by definition, when an agency has more demand for its services than its workforce can meet. Providers are therefore losing income across the country due to sales volume constricted by a lack of labor.

National trade associations representing long-term care providers have put labor vacancies among their top concerns. For example, the National Association for Home Care states: “In all geographic regions of this country, there is an ongoing inability to hire staff to provide the most fundamental care needed. The crisis for home care used to be lack of adequate

business opportunities. Now agencies have to turn away requests for service for lack of competent, appropriately trained staff.”¹⁰

The Spiraling Impact on Workers

Direct-care jobs have always been of such poor quality that many paraprofessional workers have long endured poverty-level wages, part-time hours, and no benefits—relegated to the bottom rung of respect within the health care workforce hierarchy.

Now, however, shortages and high turnover are forcing a downward cycle of deteriorating job quality. Those who do show up are forced to work “short,” able to offer only “drive-by home care” as they rush from one apartment across town to another—or forced to care for twice the number of nursing home residents during an isolated night-shift because a co-worker called in sick. The impact of these conditions on direct-care workers includes:

- 1) **Higher rates of injuries.** Nationally, nursing home aides experience 18.2 injuries per 100 workers—more than 200,000 injuries per year—far greater than such other high-risk occupations as coal mining (6.2 per 100), construction (10.6), and warehousing/trucking (13.8).¹¹
- 2) **Higher levels of stress and frustration.** Pressured by administrators to speed up, direct-care workers are less able to provide the level of care they know their clients require and deserve, which makes the job increasingly stressful and less personally satisfying. Home care workers are forced to spend less time with clients and more time traveling between clients (often unpaid); nursing home workers are often required to work overtime and double shifts.
- 3) **Less training and support.** High turnover and vacancies leave new workers with fewer mentors for on-the-job learning, less time for training, and less support from supervisors who are themselves over-stretched.

The result is a truly alarming spiral of instability: a growing exodus of experienced direct-care staff who leave behind a workplace that is increasingly less attractive to potential new staff.

The Service Employees International Union (SEIU), the largest health care union in the country that represents more than 700,000 health care workers, has stated: “There is a staffing crisis in nursing homes and it is getting worse. Short staffing lowers the quality of care for residents, creates a hazardous environment for workers, and leads to nurse aide turnover rates greater than 100 percent.”¹²

part III HIGH INVESTMENT, HIGH RETURN=WIN³

With all three stakeholders now in agreement that the erosion of the direct-care workforce poses a profound threat to the entire long-term care system, a rare opportunity presents itself: to articulate a redesigned delivery system based on the reality that direct-care workers are now—and will be for the foreseeable future—a scarce resource.

Recognizing direct-care workers as scarce, policymakers and industry leaders can restructure the long-term care system toward “high-investment/high-return” employment strategies to create a system that respects, rather than ignores, the needs of the direct-care employee. If designed pragmatically, a high-road strategy can stabilize and then rebuild the paraprofessional labor market to forge a “win – win” benefit for all three stakeholders:

- **Workers** would earn a livable wage, be able to provide health insurance for their families, and become respected members of the care team. Currently, many of them are still dependent on public assistance or must piece together several jobs.

Policymakers can pursue high investment/high return employment strategies that will benefit each of the three key stakeholders.

- **Providers** would direct their managerial and financial resources away from the headaches of recruitment, disciplinary actions, and termination and toward training, support, and retention—fewer help-wanted ads, greater rewards for job tenure.

- **Consumers** would receive consistent, more highly trained assistance from paid caregivers who could focus their attention solely on caring for their clients, rather than worrying about how to pay the rent or how to cover their own child’s medical bills.

Part IV depicts in greater detail the key stakeholders and financiers within the long-term care system, and then describes in depth the instability that now marks our nation’s direct-care services.

part IV the LONG-term care system

SECTION A: THREE KEY STAKEHOLDERS

The three key stakeholders—workers, consumers, and providers—are those whose lives are touched each day within nursing homes, assisted living and residential-care facilities, and home care settings across the country. They are:

Paraprofessional Workers

Nationwide, paraprofessionals in all formal health care sectors total more than 2.1 million; 86 percent of whom are women, 30 percent are women of color. More than 28 percent return from work to a family living in poverty.¹³ In addition, beneath the formal sector lies a gray-market workforce of paid caregivers who are hired directly by consumers, but whose income is not reported. The size of this unreported workforce is significant but unquantifiable.

Nationwide, paraprofessionals total more than 2.1 million workers; 86 percent are women, 30 percent are women of color.

In fact, the U.S. Bureau of Labor Statistics predicts that personal care and home health aides will be among the top ten fastest-growing occupations in the nation during the next eight years.

The typical direct-care worker is a low-income woman, between the ages of 25 and 54, who is a single mother. Many were, or still are, dependent on some form of public assistance—a type of hidden subsidy of the health care labor market paid for by public tax dollars.

Median hourly wages vary from state to state but fall typically within a range of \$7.17 to \$7.99,¹⁴ with entry-level wages starting below \$6.50 in many states. A majority are not offered health insurance programs by their employers.¹⁵ While those working in home care may receive a somewhat higher hourly wage than facility-based workers, home care tends to be only part-time work, and thus weekly wages for home care workers typically average far below that of nursing home workers.

Although the rate of unionization among direct-care staff is low (less than 10 percent nationwide) several international unions, including SEIU and the American Federation of State, County and Municipal Employees (AFSCME), have targeted direct-care staff for organizing drives. In 1999, SEIU successfully organized 74,000 direct-care staff in Los Angeles County, California, in the largest single union vote in 60 years.

Direct-care staff duties are defined in part by federal Medicare and Medicaid regulations but may be further specified by state policy. In general, paraprofessional health care positions range from personal care attendants (the least skilled, requiring no hands-on health care assistance) to home health aide and certified nursing assistant (CNA) positions. Yet the resulting differentiation of tasks and responsibilities among paraprofessionals is relatively narrow, particularly when compared to the responsibilities of the next rung up the long-term care ladder, the licensed practical nurse.^e

fig. 3) National Employment in Direct-Care Occupations, 1998 and 2008 (projected)

Occupation	1998	2008	% Change
Nursing aides, orderlies, and attendants	1,367,000	1,692,000	23.8
Home health and personal care aides	746,000	1,179,000	58.1
Totals	2,113,000	2,871,000	35.9

Source: U.S. Bureau of Labor Statistics (November 1999) "Occupational employment projections to 2008," Monthly Labor Review, Table 2, pp. 56 -71

The paraprofessional role is here to stay: Paraprofessional services can neither be replaced by technology nor moved offshore. In fact—assuming individuals can be convinced to take these jobs—the paraprofessional workforce is expected to grow in number dramatically over the ten-year period from 1998 to 2008, increasing by over one-third (see fig 3).

e Some consider facility-based positions a slight step above a home-health aide, but that is due not to task differentiation but primarily to the connotation of working at a facility compared to working in someone's home, and to the fact that home care is typically part-time compared to full-time in a nursing home. The duties of each, however, are essentially parallel, and some states require CNA certification for both home care and nursing home work. Similarly, the personal care attendant is considered a step below the home health aide, yet within the isolated privacy of in-home care, the tasks that personal care attendants are asked to perform easily blur with those of home health aides.

Finally, entry into direct-care positions requires little formal education. Although some provider agencies require a high school degree or equivalent as a matter of hiring policy, governmental regulations usually only require competency in minimal language and math functions—typically eighth-grade English and fifth-grade math.

Similarly, little or no formal training is required of direct-care staff. For example, the federal Medicare minimum requirement (and thus the norm) for home health aide and nursing home workers is the equivalent of two weeks of training. For personal care attendants who have no “hands-on health care” duties, the federal Medicaid program requires no formal training at all.^f At most, some states require up to four weeks of training for CNAs.

Long-Term Care Consumers

The long-term care population in the U.S. currently numbers about 12 million.¹⁶ Constituting a diverse population with a wide age spectrum and variety of service needs, these individuals require assistance with personal activities of daily living, hygiene, and household maintenance. Most long-term care is delivered in home-or community-based settings, such as adult day care facilities. About 12 percent of the long-term care population receives care in nursing homes or other institutional residential facilities.¹⁷

The elderly make up approximately half of the long-term care population and use a disproportionately greater share of long-term care services. These elderly have varying levels of impairment, ranging from various physical disabilities to Alzheimer’s and related diseases.⁸ Approximately 5.1 million elderly receive long-term care in their communities while another 1.3 million live in nursing homes.

A significant number of non-elderly adults also need long-term care (approximately 5.3 million), along with an estimated 400,000 children.¹⁸ These individuals include persons with mental retardation and serious mental illness as well as adults living with AIDS and children with developmental disabilities due to congenital HIV infection or maternal substance abuse.

Long-term care is needed by individuals of all ages who have a variety of physical disabilities due to conditions such as heart disease, multiple sclerosis, cerebral palsy, spinal cord injury, and stroke. In general, improved trauma care and medical technologies are extending the lives of those with life-threatening or debilitating illnesses or conditions, thus expanding and

changing the composition of the long-term care population. The need for direct-care services is expected to grow geometrically during the next 30 years. Two factors will interact to cause this unprecedented growth:

- 1) **The population of those requiring paraprofessional care is increasing, as is the acuity levels of those in need.** The Baby Boom generation is now aging, and technology is extending the lives of that generation. Similarly, technology is extending the lives of clients who have high care needs, such as those with developmental disabilities.
- 2) **The preference for, and ability to live in, home-and community-based settings is increasing.** Home-and community-based care settings require proportionately more paraprofessional-level staff than do facilities.

These factors will multiply upon each other as the decades unfold to forge a magnitude of increased need unimagined by the current long-term care system.

fig. 4) Providers of Long-Term Care in the U.S., 1998

Type of Provider	Number
Nursing facilities	17,458
Intermediate care facilities for the mentally retarded	6,553
Residential facilities for adults/aged	51,227
Residential facilities for non-aged	13,277
Adult day care centers	3,590
Home health care agencies (certified or licensed)	23,263
Hospice organizations (certified or licensed)	4,336
TOTAL	119,704

Source: Charlene Harrington, et al, 1998 State Data Book on Long Term Care Program and Market Characteristics. San Francisco, CA: Department of Social & Behavioral Sciences, University of California, November 1999 <http://www.hcfa.gov/medicaid/ltchomep.htm>

Provider Agencies

Agencies providing long-term care services range from small, community-based nonprofit agencies to massive, for-profit chains. As shown below, they provide care in a range of institutional, home- and community-based settings (see fig 4).

^f A small number of states do require a limited number of hours of training for personal care attendants.

^g Alzheimer’s and related diseases affect approximately 11 percent of individuals 65 and older and nearly 48 percent of those over 85 years of age.

Recently, the percentage of for-profit providers throughout the long-term care industry has increased significantly. For example, in home care, for-profit ownership increased from 6 percent in 1980 to 43 percent in 1995.¹⁹ Growth in for-profits has been greatest in the southern and western states.

Within the past three years, the long-term care industry has experienced the most chaotic public reimbursement environment of the past 30 years, threatening the financial viability of the entire industry.^h In 1997, the U.S. Congress passed the Balanced Budget Act, which both restructured and significantly reduced reimbursements to home care agencies and nursing home facilities across the country. The result disrupted the long-term care sector: it closed more than 25 percent of all Medicare-funded home care agencies over the past three years and five of the ten largest for-profit nursing home chains are undergoing Chapter 11 bankruptcy proceedings.

Overall, industry observers expect continued consolidation of provider agencies while nonetheless still predicting a growth in total services to meet increased long-term care demand. For example, in many states, the disruption in federal Medicare funding is causing Medicaid programs for home care services to expand.

SECTION B: PRIMARY FINANCIERS

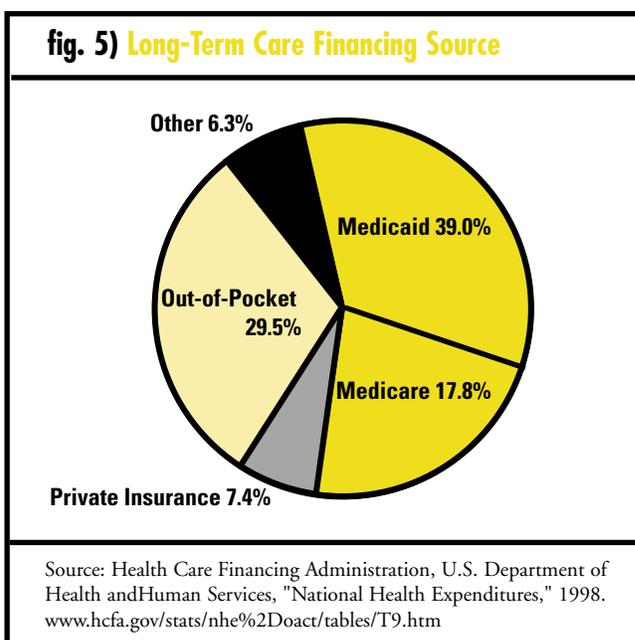
As shown in figure 5, the nation's long-term care system is mainly financed by three types of sources: public payers (primarily Medicaid and Medicare), private insurance, and individual "out-of-pocket" payments. In 1998, expenditures for long-term care services totaled \$117.1 billion (see fig 5).

In 2000, long-term care expenditures for the elderly are expected to rise to \$123 billion, according to the Congressional Budget Office. Sales of long-term care private insurance have increased somewhat in recent years and are projected to expand to about 18 percent of the total of all long-term care spending for the elderly by the year 2020. This expansion of private insurance will likely reduce the percentage of out-of-pocket expenditures, while government sources—Medicare and Medicaid—are expected to continue funding approximately 60 percent of the elderly long-term care system in 2020.²⁰

Medicaid

Medicaid provides health coverage primarily for low-income citizens. The program is intentionally designed to provide certain long-term care benefits, with approximately 35 percent of all Medicaid funding flowing to long-term care needs.²¹

In the past three years, as Medicare policy restricted its assistance to home care clients, responsibility for those services has increasingly shifted to Medicaid. Although Medicaid is also an entitlement, certain programs—such as in-home personal care services—are optional at a state's discretion.ⁱ Medicaid is paid for in part by federal funds and matched by states on a sliding scale based on statewide average per-capita income.



Medicaid now spends approximately \$44 billion on long-term care for the elderly. Since Medicaid is funded at both the federal and state levels, regulatory policies are established at certain minimum thresholds federally but then vary significantly from state to state. Therefore, attempts to change Medicaid's impact on direct-care workers could be undertaken either at the state or federal level.

h The HealthCare Market Groups of Houston reported that share prices of long-term care and assisted-living providers dropped by more than 69 percent during 1999 (compared to the Dow Jones average increase of 25 percent). In January 2000, the Phoenix Lending Survey of Philadelphia revealed that 85 percent of commercial lenders surveyed would not invest in the health-care industry. This was the highest negative rating any industry has received since the survey was initiated in 1995.

i Thirty-one states offer the Medicaid-funded personal care option. In order to have greater flexibility and independence from federal Medicaid regulations, some states offer a similar option that is paid for entirely with state funds. Other states offer both the Medicaid waiver program and additional personal care programs funded solely by the state.

Recently, the U.S. Supreme Court decision in *Olmstead v. L.C.* determined that individuals with physical or mental disabilities who are eligible for nursing-homes have the right to receive care in the least restrictive setting. This ruling will likely force states to accelerate recent experimentation with Medicaid-managed long-term care and care coordination services—most likely in home-and community-based settings—for low-income and disabled patients.

Medicare

Medicare was designed to provide coverage for acute care needs—that is, assistance for relatively short-term, intensive medical care—to people 65 years and older and people with disabilities. Therefore, Congress has intentionally restrained Medicare’s participation in long-term care financing for chronic conditions. Medicare has waived a limited number of “social health maintenance organizations” by blending social and health care services, but these focus primarily on acute health needs.

Medicare is paid solely by federal funds (augmented by individual co-payments) and is structured as an entitlement that is not “means-tested”. All citizens 65 years and older and those who are disabled can receive Medicare benefits without regard to assets or income. Since Medicare is a federal-only program, the federal government sets its regulatory and reimbursement structure. Therefore, any attempt to change Medicare’s impact on direct-care workers would require action by either Congress or the Executive branch.

Total Medicare spending on home-and long-term care was predicted last year to reach nearly \$30 billion for 2000. However, as noted, the Balanced Budget Act (BBA) of 1997 severely reduced Medicare funding for long-term care services, in large part by significantly restructuring reimbursement formulas. As a result, the \$30 billion projection is now likely overstated.

By the year 2020, combined Medicare and Medicaid funding for the elderly is projected to increase by over 70 percent, to \$126 billion in constant, year 2000, dollars.²² However, as public expenditures increase in response to greater demand, federal and state programs tend to institute restraints by limiting either reimbursement rates, amount of service per client, or both. These limits further exacerbate worker vacancies and turnover.

SECTION C: A DISAGGREGATED SYSTEM OF PROGRAM SILOS

The U.S. long-term care system has become a rickety structure of disparate programs, each with its own segregated funding “silo.” In this vertical design, nursing home services are funded separately from home care services, which in turn are funded separately from assisted-living and special residential-care settings.

In this siloed structure, function inevitably follows form. The segregation of long-term care programs encourages waste and inefficiency by creating competing “sub-industries,” each with its own trade association, lobbyists, and advertisers fighting one another not only over public resources, but over clients as well. In addition, siloed financing streams spur “cost shifting” between funders, encouraging federal and state programs to compete with each other to avoid paying for services. For example, the U.S. Congress recently rewrote regulations for Medicare (funded only at the federal level) to discourage extended home care visits, knowing Medicaid (funded in part by states) would pick up at least some of the shifted costs.

Most important, our current disaggregated system of vertical structures fails to recognize that long-term care clients typically move laterally back and forth through the system, shifting from one funding silo to another: A home care client might contract pneumonia, be placed in a skilled nursing facility for a few weeks, and then return home. Years or merely months later, she may become so frail that she must leave her home for residence in a long-term care facility.

Similarly, many workers move across long-term care settings—when not blocked by incompatible training or credentialing requirements—since job responsibilities are similar within the settings. Unfortunately, they move not to follow their clients but rather to leave one job for another or to patch together several part-time jobs.

Clearly, our long-term care system is serving none of its key stakeholders well—neither clients nor providers, and (judging from the current vacancies and high rates of turnover) certainly not its workforce. Not even public or private financiers are receiving cost-effective services for their investments.

Part V explores public policy’s impact on the quality of direct-care employment for low-income workers, and then Part VI describes the resulting dynamics of the direct-care labor market.

part v the gulf between health, labor, and welfare policies

The low-income, direct-care worker stands at the intersection of three public policy worlds: health care policies designed to deliver long-term care services; labor policies designed to improve employment prospects for all U.S. citizens; and welfare policies designed both to help families living in poverty and people transitioning from welfare to work.

Health Care Policies

As we have noted, government is the largest payer of long-term care services in the U.S.; it provides more than 56 cents of every dollar expended. Hence, government regulations and reimbursement procedures play a dominant role in the structuring and operation of our long-term care system.

Unfortunately, health care delivery policy has been designed without recognition of its labor impact, particularly on low-income workers. For example, even though direct labor constitutes the majority of expenses for long-term care, reimbursement rates typically reflect historic, not current, labor market conditions. When labor competition in the economy is low, this structure allows the health care system to “bargain” for workers at the lowest price possible with little regard for the resulting quality of job. Yet when budget constraints collide with heightened labor competition, as is now the case, the health care system is unable to offer competitively attractive employment.

In addition, the very structure of direct-care work itself has been designed around the needs of financiers, providers, and clients without regard to whether the resulting job offers a livable wage or decent working conditions. For example, home care has been structured primarily around morning care, based on the desire of clients and the financial savings derived from employing only a contingent, per-diem workforce. Yet the result is an entire industry built of part-time workers—sustainable perhaps in a high-unemployment economy, but now revealing itself to be unworkable during a period of intense labor competition.

Similarly, recent reports of a high incidence of malnutrition and dehydration among residents in nursing homes have spurred federal Medicaid officials to consider the creation of a new class of workers, called “single task workers,” such as people to be hired on an hourly basis during mealtimes only.

Yet these “feeders” would have little time to develop relationships with residents and, thus, will likely garner little knowledge of the particular eating, drinking, and swallowing needs of each individual. Clearly, for the worker, the resulting job would produce neither a livable wage, decent benefits, nor acceptable working conditions.

The Health Care Financing Administration (HCFA), in the federal Department of Health and Human Services, is the agency responsible for managing both Medicare and Medicaid. HCFA itself has stated that the paraprofessional jobs that it funds are “ridden with high turnover rates.”²³ Yet when it issues proposed regulatory changes, HCFA assesses the likely impact on clients, on states, on providers, and on physicians—but not on direct-care workers.

The low-income, direct-care worker stands at the intersection of three public policy worlds—health care, labor, and welfare—each formed in isolation from the other.

Labor Policies

The federal government invests more than \$8 billion annually to prepare Americans for new and better jobs. These funds are further augmented by state and local funding. Although many government training and employment services are available to all citizens, the majority of them are targeted toward low-income and unemployed individuals.

Except in occasional demonstration projects, federal and state employment and training agencies rarely target a particular industry for a “sectoral” workforce development strategy. In the case of the health care sector, the opposite is often true. State and federal employment agencies often preclude the long-term care health industry from participating in training support programs because they require participants graduating from those programs to secure wages that are higher than what direct-care workers typically earn.^j

While the public-policy basis for high wage standards is clear (federal and state employment and training agencies do not want to support poverty-level jobs) the irony remains that these low-paying paraprofessional jobs are paid for primarily by federal and state health agencies.

State agencies responsible for employment programs typically reside within the particular state’s department of labor. At the federal level, the U.S. Department of Labor’s Employment

j For example, in 1999, the New York City Department of Employment required participants in its training programs (funded in part with federal training dollars) to earn a minimum of \$11 per hour, which effectively excluded entry-level long-term care positions.

and Training Administration (ETA) primarily manages these programs. Although the federal government currently manages more than 90 distinct training-related programs, the primary training and employment delivery system is the Workforce Investment Act (WIA) established by Congress in 1999.

The new WIA legislation is currently being implemented across the country in coordination with state agencies. Final state plans were to be completed by October 2000. WIA allows increased flexibility at the state and local levels and may offer opportunities for experimenting with sectoral initiatives focused on employment within the health care industry.

Welfare Policies

Since direct-care staff members typically are low-income women, they often find themselves both supported by, and entangled in, public-agency systems designed to improve their living conditions and increase their employment prospects.

For years, low-income women have straddled the two worlds of welfare benefits and health care employment. Some have moved back and forth between the two, leaving welfare for work but then cycling back to public assistance as soon as the next family crisis hit. Many other low-income women have continued to receive cash, food stamps, and other forms of public assistance—even while employed as direct-care workers—because their part-time, direct-care jobs have offered only poverty-level income.

This interweaving of welfare and health care employment has long provided a hidden subsidy to the health care system. Agencies could offer artificially low wages and no benefits, forcing their workers to rely, at least in part, on public assistance programs for the necessities of food, housing, and health insurance.

In 1996, Congress passed the Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA). This law substantially curtailed welfare as an entitlement, and for most welfare recipients, placed maximum life-time limits on the number of months they could receive public assistance. In concert with a full-employment economy, PRWORA and state-level initiatives have resulted in a 50 percent reduction of welfare rolls nationwide over the past five years. Thus, in part due to welfare “reform,” our long-term care system is now relatively less able to rely upon the welfare system to subsidize its direct-care workforce.

Although the welfare rolls have been slashed, many low-income health care workers still are affected by the public assistance system. Programs such as food stamps and support for child care, transportation, and housing vary enormously from state to state. The presence or absence of these programs—and the quality of their implementation—can ease or frustrate the lives of those who work as our caregivers.

Finally, the intent of PRWORA was to increase “work opportunities” for welfare recipients. However, embedded within the law is a presumption, often referred to as “work first,” that heavily discourages entry-level, skilled-based training. This philosophy instead recommends “immediate attachment” of welfare recipients to a job—that is, securing any job as quickly as possible and without taking the time to invest in training.

Therefore, at the same time that the federal government requires skill-based training to become a home-health aide or certified nurse aide, it also supports policies that deter low-income women from gaining access to training as a pathway to work. Fortunately, in recent months, the ideological support for “work first” has begun to soften, and newly issued regulations may provide limited encouragement of skill-based training.

The state agencies that manage the various welfare benefits and welfare-to-work programs typically reside in the particular state’s department of health and human services. At the federal level, the U.S. Department of Health and Human Services (HHS) implements the Transitional Assistance to Needy Families (TANF) program, which in turn manages the federal funding of welfare benefits. In addition, HHS manages most welfare-to-work training programs (although, during the past two years, the Clinton Administration’s \$3-billion, welfare-to-work Challenge Grant program has been administered by the U.S. Department of Labor).

The Disconnect

Although health, labor, and welfare policies all intersect the lives of direct-care workers, none are designed with the health care worker in mind. Furthermore, these three policy centers fail to communicate with one another on matters that might either support or harm the direct-care worker—even though the creation of a decently paid, well-trained workforce would serve the interest of all three.

More troubling yet, coordinated planning and communication fails to occur even *within* the U.S. Department of Health and Human Services, which is responsible for designing and implementing both health policy and welfare policy.

This absence of coordination might have been acceptable years ago, before direct-care staff vacancies within health care began to emerge as a true crisis. Now, however, as the needs of low-income workers and consumers merge, an opportunity exists to blend resources from these three policy worlds into a cohesive sectoral strategy—where training, public assistance, and health care delivery dollars would be integrated into a comprehensive health care workforce development system.

The result would be a far more cost-effective system, one that develops decently paid, trained, and well-supported direct-care workers who will be more fully prepared for their roles as caregivers for our burgeoning elderly, chronically ill, and disabled populations.

part VI dynamics of the direct-care labor market²⁴

As is true for every sector of the economy, health care employers compete for workers within a dynamic labor market. However, if the health care labor market were functioning perfectly, direct-care vacancies would not continue for long. That is, the supply of workers would expand to meet demand as employers adjusted their “price” (wages, benefits, and working conditions) upward to attract and retain more workers.

Unfortunately, several factors prevent our health care system from achieving rapid labor-market “equilibrium” to fill all available positions. These factors include:

- continually expanding pressures on the demand for health care services;
- limitations on the supply of additional workers who might enter the formal health care labor market; and
- restrictions on the ability and/or willingness of employers to increase their labor “price” sufficiently to attract an adequate supply of workers.

To understand the particular dynamics of labor demand, supply, and price for the long-term care industry, it is helpful to sketch the key attributes of this imperfectly functioning labor market.

Factors of Labor Demand

Demand for health care workers is pushed by such factors as the aggregate number of consumers living with higher levels of acuity and consumers’ strong preference to receive services within their homes. As noted earlier, these demand factors are now multiplying upon themselves and are creating geometric pressure for increased direct-care services.

However, while these multiple factors push the “need” for more labor, other attributes of the health care labor market suppress, or at least distort, the “effective demand” for labor, as determined by the level of services that payers are able or

willing to fund. In particular, since health care is funded largely by public and private third-party payers who have strong financial incentives to limit costs, “effective demand” (as determined by third-party payers) will typically be less than the “need” perceived by either consumers or health service providers.

Federal and state third-party payers must apportion tax dollars to an array of public services, health care being only one among many. Similarly, private insurers—accountable to shareholders and corporate purchasers—have created capitation

arrangements, utilization reviews, and rigorous definitions of what constitutes “medically necessary” services in order to control costs. Completely independent of increased requests for health services, third-party payers may therefore choose to constrict, or perhaps even

reduce, “effective demand” for long-term care services, which in turn suppresses effective demand for labor.

Therefore, the health care labor market can best be understood as driven by massive demographic and technological forces accelerating aggregate demand for services. Simultaneously, powerful third-party payers (both public and private) attempt to brake that demand through regulatory constraints and cost containment measures. This reality makes official predictions of the resulting labor demand difficult to rely upon. For example, despite an absolute decline in home health aides nationwide during 1999 (due to major cuts in Medicare funding), the Bureau of Labor Statistics still predicts that home health aides and personal aides will increase 58 percent nationwide between 1998 and 2008, claiming that together these positions still constitute the seventh fastest-growing occupation in the nation.

In all, we can reasonably expect a continued expansion of effective demand for health care-related labor but an expansion that is likely to remain irregular and balky, depending largely on political and financial—not simply care-related—factors.

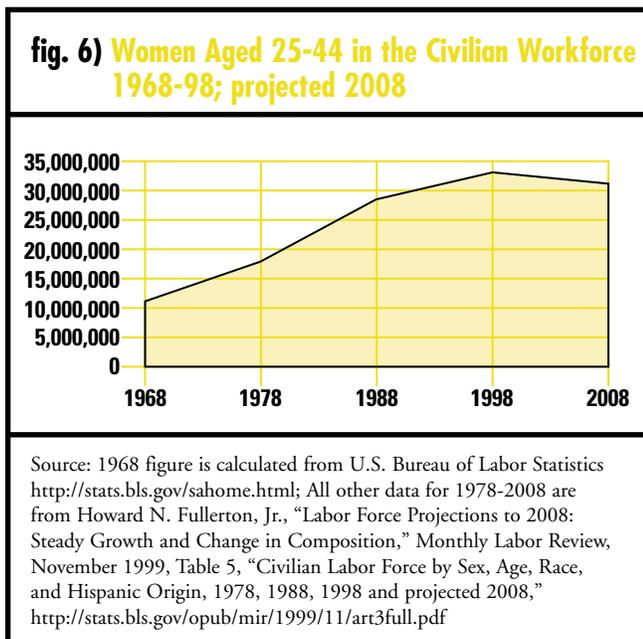
Our long-term care system was designed during three decades of unparalleled expansion in the labor market—expansion that abruptly ceased in the past few years.

Factors of Labor Supply

As noted earlier, the pool of traditional caregivers—women between the ages of 25 and 54—is predicted to increase by only 7 percent during the next 30 years. Even more stark: the pool of likely entry-level workers—women in the civilian workforce aged 25 to 44—is projected to decline by 1.4 percent during the next eight years.

This somewhat narrower age range is particularly crucial, since this is the cohort of individuals that provides the “fresh recruits” for whom health care employers must compete. The current decline of these younger women in the civilian workforce follows three decades of significant expansion—*nearly tripling from 1968 through 1998*. Note that our current long-term care system was designed during these three decades.

Two interacting factors caused the expansion of this female cohort during the past three decades: the increasing number of women from the Baby Boom generation coming of adult age and the increasing percentage of those women participating in the workforce (45.0 percent in 1968, rising to 76.7 percent in 1998)(see fig 6).



Now, however, the Baby Boom workforce has passed through this age range, leaving a smaller workforce to follow. Moreover, the rate of increased participation of women in the workforce is slowing considerably (from 76.7 percent in 1998 to only 79.5 percent projected for 2008).

In addition to these demographic realities, projections of a smaller pool of potential direct-care workers take into account welfare reform, which has already squeezed millions of low-income women out from the welfare rolls and into the workforce.^k Furthermore, these projections assume relatively high net international annual migration levels ranging between 780,000 and 950,000 through the year 2030.^l Immigration policy is set solely by Congress, and only a small portion of immigration visas (less than 13 percent over the past five years) are employment-related. Of these employment-related immigrants, more than half are professionals or other high-skilled workers.

Therefore, only a substantial change in immigration policy would significantly expand the pool of potential direct-care staff. Yet unless these health care positions are also linked to livable wages and benefits, any major targeting of immigrants for paraprofessional jobs would have to address the political and economic realities of importing low-wage workers, individuals whose essential needs for food, housing, child care, and transportation would have to be subsidized, at least in part, by taxpayer dollars.

Clearly, the supply of individuals from which employers can draw new direct-care workers is quite limited. In the coming decade and beyond we face a supply of labor for all social-service sectors that is profoundly different from what we have come to take for granted over the past 30 years. Therefore, public policies and employment strategies must change accordingly.

“Price” Inflexibility

Given that options for expanding the general labor pool are likely to remain very limited—and that the number of “traditional” entry-level caregivers is actually shrinking—one final path remains open for long-term care providers: competing successfully against other employers for workers. Put bluntly,

^k Note also that those who remain on public assistance after welfare reform are now more likely to have multiple barriers to employment—e.g., substance abuse, physical or mental disabilities, or others such as limited transportation resources. While these individuals will remain part of the potential direct-care labor pool, the more barriers potential employees face, the more costly it will be for the public, and employers, to move those individuals into stable employment.

^l The U.S. Census Bureau assumes that immigration will decrease slightly between 1999 and 2010, from 1.236 million to 1.036 million, while emigration will increase slightly, from 282,000 to 322,000, over the same period. The overall change is modest—from a net migration of 954,000 in 1999 to 713,000 in 2010—although important since a significant proportion of net population growth over the projected period will be attributable to international migration. See Frederick W. Hollmann, Tammy J. Mulder, and Jeffrey E. Kallan, *Methodology and Assumptions for the Population Projections of the United States: 1999 to 2100*. Population Division Working Paper No. 38, Washington, DC: Population Division, Bureau of the Census, U.S. Dept. of Commerce, January 2000.

only by improving the relative quality of direct-care positions can health care employers hope to recruit workers from other parts of the labor market and then realistically expect to retain those workers once they are employed.

This strategy requires improving remuneration (the “price”) of health care jobs: wages, benefits, and working conditions. To do so, however, two core factors inherent in the health care labor market must be addressed: third-party payers and provider employment practices.

Third-party Payers

As noted, a “perfect,” or at least traditionally functioning, labor market would respond to the system’s current mismatch between supply and demand by improving wages, benefits, and working conditions. However, not only do third-party payers play a primary role in determining “effective demand,” they also indirectly (and sometimes directly) influence the price of labor by determining the amount of money public agencies and private insurers are willing to pay per client, per illness/episode, or per visit. In addition, public regulators affect direct-care “productivity” by the amount of nonservice activities (i.e., paperwork) they require of providers.

While provider agencies have some flexibility in setting wages and benefits (see below), they are limited by this third-party payer constraint. In periods of high labor competition, if reimbursement fails to keep up with the true cost of providing services, agencies have correspondingly less flexibility to meet the market. This third-party payer dynamic has played a significant role in suppressing wages and benefits artificially below the levels necessary to attract and retain quality staff.^m

Provider Practices

Although third-party payers constrain provider flexibility, agencies nonetheless retain a degree of discretion over the allocation of total reimbursements among the full range of agency costs and profitability. After all, direct-care wages and benefits do vary even among employers within the same segments of the industry.

Furthermore, although wages and benefits are an essential part of labor pricing, working conditions are equally important. Working conditions include a broad array of factors, from the tangible (part-time employment or unsafe workloads) to the intangible (feeling “respected”) and much in between (good training or opportunities to advance).

In recent focus groups in New England, direct-care workers reported multiple examples of insulting supervisory practices and sometimes dangerous working conditions; they also reported that working conditions were equally as important as wages and benefits in their decisions to remain employed within health care.²⁵

Providers retain a large degree of control over working conditions within their agencies and facilities, and improvements in the quality of supervision and the workforce culture can often be implemented at relatively limited expense. In addition, costs associated with improving the price of labor should at least be offset partially by savings from reduced turnover. Several studies suggest that staff turnover and vacancy costs within health service industries—including recruitment and training costs, increased management expenses, and lost productivity—range from \$1400 to \$4300 per direct-care worker.²⁶

Summary: Labor as a Scarce Resource

Staff vacancies and turnover in direct care currently exist within a highly competitive labor market. Some efforts to increase the supply of potential labor—for example, by facilitating movement of people on public assistance into health care jobs—are worthy of careful examination. Yet the primary response remaining within the health care system’s control is to help health employers compete more successfully for labor against other employers.

Successful competition essentially requires improving the price of labor—that is, increasing wages, benefits, and working conditions in order to attract and retain a higher percentage of the existing labor supply. Given the key attributes of the direct-care labor market reviewed above, effectively improving the price will require recognition that:

- due to the predominance of government funding, direct-care workers are essentially “public employees once removed.” Therefore, increasing the competitiveness of direct-care employment will require fundamental political choices;
- direct-care workers are entangled in three disparate policy worlds—health, labor, and welfare—and thus an effective response will require a “sectoral” strategy that improves communication, planning, and coordination between departments of labor and health and human services at both the federal and state levels;

m Compare the third-party payer dynamic to the more perfectly functioning “gray-market,” in which higher-income consumers can pay privately for in-home services provided by agencies that target the private-pay market or by caregivers who work directly for in-home consumers (often within unreported under-the-table arrangements in which payroll taxes are not withheld). During the current period of high labor competition, these private-pay arrangements can adjust prices more easily to meet the demands of the labor market and drain workers away from the less flexible, publicly-funded portion of the health-care system.

- although funded primarily by government, direct care is nonetheless implemented through private providers who retain a significant responsibility for, and control over, the quality of direct-care jobs; and
- the current direct-care delivery system was designed during a period of a relative labor surplus, which allowed the long-term care system to build its workforce cheaply, with little regard to job quality. Conversely, the new reality of labor scarcity will require a rethinking of long-term care designed around both consumers and direct-care workers.

Although this analysis might appear daunting, a profound change has occurred recently among the three key stakeholders. All agree that current labor vacancies are unacceptable. Thus the opportunity at hand is to leverage this shared perspective and bridge the divide that has separated these common stakeholders and traditionally prevented the design of new strategies. In addition, many improvements in wages, benefits, working conditions, and other public supports can be achieved through a more thoughtful restructuring of public policy and private practice that will produce cost-efficiencies and more effective use of existing public dollars.

Finally, for those elements requiring additional public expenditures, note that budgetary constraints are easing at both the federal and state levels. In the past two years, for example, legislatures in 16 states modestly increased wages or benefits for direct-care workers.

To begin the discussion of how to address the emerging crisis in long-term care, Part VII briefly describes the essential elements of a good direct-care job when it is “priced” in a way that would become competitively attractive within our labor-short economy.

part VII essential elements: stabilizing the direct-care workforce

The essential elements that frame a quality health care job are neither difficult to imagine nor particularly presumptuous in scope. They are likely to be what any individual—particularly one with the benefit of several employment options—would ask of an employer. The five essential elements are:

- **A “family wage,” health insurance and other benefits:** A reasonable hourly starting wage for a person entrusted with the care of an ill or frail human being should be at least 200 percent of the minimum wage (currently \$10.30 per hourⁿ total), which is still less than the median hourly wage in the U.S. of a carpet installer (\$12.73/hour), auto mechanic (\$13.16/hour), or embalmer (\$13.55/hour).²⁷ Additional compensation should be offered for weekend and off-hour shifts, which are essential to providing adequate and safe care to long-term care clients.

In addition, the health care industry should provide health insurance to its own workers and their families, as well as vacation pay, sick pay, paid holidays, retirement benefits, and family medical leave.

- **Balanced and safe workloads that offer full-time employment but do not overwork employees:** Much of the home care industry is structured on the presumption of part-time work. For those seeking full-time employment, home care jobs should offer a minimum of 35 hours per week without overuse of off-hour shifts. Scheduling full-time home care work requires greater provider and client flexibility as well as the geographic “clustering” of cases to ensure a minimum of time lost to transportation.

In facility-based care, “working short” frequently requires either overtime, or rushed and unsafe care, or both. Overtime should never be mandatory, and staffing levels should be increased to 4.13 hours of staff time per resident, per day, the minimum required to meet consumers’ medical and psychosocial needs.²⁸

- **Higher training standards:** Providing care to vulnerable clients requires more formal training than the federally mandated 75 hours. Paraprofessional entry-level training should be updated and expanded to reflect current care needs, clinical realities, and adult life-long learning techniques— particularly to cultivate problem-solving, interpersonal, and communication skills and specific skills related to caring for clients with Alzheimer’s disease, physical disabilities, and depression.
- **Opportunities for advancement and professional development:** To both attract and retain good, dedicated staff within the long-term care health system, potential workers must have access to career pathways to develop themselves and, over time, receive higher levels of compensation for higher levels of experience, skills, and responsibilities.

The essential elements of a quality health care job are what any individual would ask of an employer.

However, creating a career lattice that extends above the entry-level position must not be an excuse for keeping lower-rung positions at low wages. Many individuals prefer to remain as direct-care workers and should be rewarded for doing so. Otherwise, “forcing” staff up a career ladder—because it is the only way to escape poverty—will merely exacerbate rapid turnover of direct-care staff.

- **Employee support:** The nature of direct-care jobs requires two types of support. External to the employer, paraprofessional work often entails off-hour and multi-site employment. Therefore, community services such as special-hour child care and transportation must be arranged, most likely through community-based services outside the provider agency.

Internal to the employer, paraprofessionals require a job design that recognizes their skills as well as their special knowledge of the client. One approach is to ensure that paraprofessionals are made a central member of the care team. This in turn requires higher levels of effective supervision^o—including

n The Massachusetts Family Economic Self-Sufficiency (MassFESS) Project, sponsored by the Women’s Educational and Industrial Union, found that a single adult in Boston with a preschooler needs a self-sufficiency wage of \$15.28 per hour to cover the basic costs of housing, child care, food, transportation, health care, miscellaneous expenses, and taxes. Self-Sufficiency Standard for Massachusetts (1998).

o Nurses are trained in clinical procedures but are rarely schooled in effective supervision practice.

job-coaching and other approaches that emphasize problem-solving over disciplinary actions—and training in the cultural differences that often divide professionals from paraprofessionals and staff from clients.

Effectively combining these internal and external supports will likely require an individual-by-individual system of employee management and support that recognizes both the multiple challenges of low-income workers' lives and the difficulties of their everyday, on-the-job tasks.

In short, stabilization of our direct-care workforce depends on our ability to devote serious attention and greater resources to five essential elements: compensation, reasonable workloads, training, advancement opportunities, and employee supports. While fully implementing these five elements will be difficult within today's ill-structured system of long-term care, many worker-centered initiatives are now being encouraged in a variety of experimental settings, a few of which are described later in this paper.^p

However, full reform of direct-care employment will require a fundamental rethinking of long-term care services. As an initial attempt to consider alternative frames, Part VIII offers one possible redesign of long-term care to meet the needs of consumers, providers, and workers.

^p Dr. Susan C. Eaton, Assistant Professor of Public Policy at the John F. Kennedy School of Government, Harvard University, makes this case for nursing home workers and consumers in *Pennsylvania's Nursing Homes: Promoting Quality Care and Quality Jobs*. Keystone Research Center High Road Industry Series, No. 1. Harrisburg, Pennsylvania: Keystone Research Center, April 1997.

part VIII a VISION FOR THE FUTURE²⁹

As it deepens throughout this decade and beyond, the direct-care staffing crisis will likely become so severe that it will eventually present a rare opportunity: to redesign fundamentally our entire care system around the core relationship of the client and her paid and family caregivers.

Such a redesign may require decades (and perhaps a profoundly different political environment) to emerge. However, articulating one vision of a re-configured system, conceived upon wholly different assumptions, may prove helpful to our understanding of the emerging direct-care crisis.

Desired Attributes

Conceiving a new model of long-term care provides an opportunity to create a system in which function would properly dictate form. Therefore, we will first describe the attributes we believe a new system should encourage, followed by broad outlines of one structure designed to facilitate those outcomes.

A new model of long-term care should encourage the following attributes:

For Consumers

- **A seamless blending of social and health needs.** Long-term care clients require not just medical care but a range of nonmedical assistance (including feeding, bathing, and simple human companionship), and thus it is wasteful and inefficient to separate completely those needs into two distinct systems, one health care and the other social service.
- **A seamless blending of family care and paid caregiving.** Family/voluntary care is the predominant form of assistance to long-term care clients, and therefore family/voluntary care should be interwoven thoughtfully with the formal care system—not treated as a separate system or simply presumed.
- **Rapid response to a client's changing needs.** Even though a long-term care client has a “chronic condition,” that condition might change instantly (a broken hip, heart failure, the death of a spouse) and her system of care must adapt just as quickly.

Without conceiving of long-term care as a single system, the direct-care staffing problems we face today will become increasingly aggravated as labor demand further exceeds supply.

- **Continuity of care.** Allow a direct-care client's paid caregiver to remain with her over time and to move with her across care settings whenever possible (e.g., from home care to an adult day-care facility).
- **A mechanism for accountability to consumers by the long-term care system.** This will ensure that consumers receive services in a comprehensive and flexible manner.

For Direct-Care Workers

- **The “essential elements” of a stable paraprofessional job.** This includes full-time employment, a livable wage, family health benefits, adequate training, and supportive working conditions.
- **Parity of pay for workers across care settings.** This ensures equal pay for equal work based on duties and responsibilities, not on historical practices.
- **Opportunities for career advancement.** Provide job ladders and career pathways, employer-based training programs, and credentials that are as “portable” as possible across different care settings throughout the long-term care system.
- **Specialized assistance for child care, transportation, and other needs unique to direct-care employment.** Long-term care is not a 9am to 5pm job, and the discontinuous and geographically dispersed nature of direct-care jobs requires flexibility for workers who must travel between clients; work afternoons, nights, or weekends; and may have young children (and frail parents) of their own.
- **A mechanism for accountability to workers by the long-term care system.** Ensure that workers are neither presumed nor exploited as caregivers.

For Provider Agencies

- **A stable and more rational funding environment.** Well-managed agencies offering cost-effective, high-quality services are assured continuity of support, with service provision organized around client need and service delivery, not around arbitrary funding distinctions.

- **An adequate base of skilled, direct-care staff.** With such a base, a single aide can provide a more diverse range of services, across a variety of settings, and participate as an effective member of an interdisciplinary care team.
- **A positive business logic for a “high-investment/high-return” strategy toward direct-care staff.** With a stabilized workforce, providers would enjoy lower recruitment expenses, higher retention rates, fewer disciplinary problems, and, most important, higher quality care.

Allowing Function to Determine Form

Pragmatically, even a redesign of an entirely new care system to encourage these functions must still accept two realities of U.S. health care: the role of government and the role of the marketplace. At the same time, effectively balancing these two roles across the various long-term care settings is inconceivable without eventually re-constructing the entire long-term care system as a single, integrated sector.

Designing long-term care as a true, integrated system will require building new, horizontal mechanisms that synthesize funding and program silos across the sector, blending medical with social needs, and formal with family care-giving needs. Accomplishing such sectorwide integration will require two key sets of lateral mechanisms, one within government and the second within the marketplace:

- Within federal and state governments, an integrated funding, planning, and regulatory mechanism.
- Within the marketplace, horizontal mechanisms for both care management and the provision of services.

By treating long-term care as a true system, we can create an arena in which those paying for care can more fully recognize the common needs—and more openly negotiate the competing needs—of consumers, providers, and workers.

Federal and State Governments

As the primary funders of long-term care, governments have the central task of creating chronic-care funding streams that are stable, relatively rational for providers to access, and, most important, smoothly integrated. Government is also responsible for ensuring that the sector provides quality services at a

reasonable cost. Therefore, in order to allow form to follow function, one core element of redesign would likely require:

- **A single public long-term care entity.** Emerging out of a broader definition of our current Medicaid program, which acknowledges the dual responsibility at both the federal and state levels for long-term care, this single entity would administer and coordinate all long-term care funding streams and regulations and work to blend all social and medical services, ensuring continuity laterally across the varied settings.^q

Building a single arena for long-term care funding and regulations would, among many other benefits to quality of care, allow a fundamental and consistent emphasis on effective service delivery. It would make the needs of the direct-care workforce more highly visible and, thereby, help ensure a stable supply of high-quality, paraprofessional staff across the country.

Frankly, such a restructuring of long-term care funding may be so fundamental—requiring the rethinking of both Medicare and Medicaid—that it may be politically impossible. However, without conceiving of, and working toward reformulating, long-term care as a single system, the direct-care staffing problems we face today will become increasingly aggravated as demand for long-term care further exceeds the supply of willing caregivers.

Therefore, conceptualization of long-term care as a single system and attempts to coordinate government funding streams at the federal and state levels should be encouraged. Such efforts in turn will help facilitate the market-based changes in management and service provision described below.

The Marketplace

With a more streamlined, coordinated system of funding and regulation at the federal and state levels, the long-term care marketplace can function far more effectively and cost-efficiently. However, given the predominance of third-party payers within that marketplace—no matter how streamlined and coordinated they might eventually become—a system of local/regional intermediary organizations will be required to mediate the needs of those third-party payers (both private and public) with the needs of consumers, providers, and workers.^r

q Such a structure would still result in two health-funding silos: long-term care and acute care. Coordination of and distinctions between these two systems would therefore still require adjudication by HHS. Although fully integrating the long-term care system with the acute-care system might be theoretically ideal, the profound differences between the two will likely always require distinct management systems. However, if each system were more rationally organized, coordination between the two could be more fully achieved.

r The ideas for this section are derived primarily from the five years of design and implementation activities undertaken by Independence Care System (ICS) sponsored by the Paraprofessional Healthcare Institute, one of the nation’s first Medicaid-funded managed-care demonstration programs for adults who are physically disabled.

Allowing form to follow function might create several options within the marketplace. One such option could include:

- **Several long-term care intermediary organizations within each geographic region.** These intermediaries would purchase and coordinate services for long-term care clients across the various care settings, integrate social with medical needs, and blend formal caregiving with family and volunteer caregiving.^s Ideally, these long-term care intermediaries would also integrate 1) acute-care funding sources for a chronic-care patient's short-term medical needs and 2) funding sources for alternative housing when a client's living arrangement becomes inappropriate due to changes in health.

Funding structure: To ensure the benefits of the marketplace, these intermediary organizations would be free-standing and allowed to compete against one another for their client base. Each intermediary would receive funding directly from the public-payer system, blended with third-party insurance sources, based proportionally on the organization's ability to attract consumers. New organizations working primarily with consumers eligible for public support could receive special public start-up funding for core administrative costs.

Each consumer seeking long-term care services would choose one of the competing intermediaries in his or her region, essentially becoming a "member" of that intermediary. The member would enjoy specific rights and responsibilities, including the ability to end his or her membership.

Although many financing mechanisms are possible, one likely structure is a blend of capitation and fee-for-service payment.^t Using this model, the intermediary organization would receive a budgeted amount of money for most of the costs of each enrolled member based on that member's functional status. This capitated part of the mechanism would allow the intermediary the freedom to plan for health care and social supports as needed. However, to purchase member services that are particularly expensive or episodic, the intermediary would also be reimbursed on a fee-for-service basis.

A combination of capitation and fee-for-service provides a balance. By setting budgeted rates that are adjusted to reflect

differences in functional health status and needs, public and private third-party payers would ensure that intermediary organizations are paid fairly for their enrolled members—not for the average aggregate population—while at the same time exercising their role of ensuring cost accountability. However, capitation also creates financial incentives to withhold services even when those services are appropriate. Therefore, allowing additional reimbursements, on a fee-for-service basis, for unusual or very expensive services is designed to redress those incentives.

Governance structure: The intermediary described above is similar to, but distinct from, the managed-care organizations currently operating within the U.S. health care marketplace. Long-term care advocates, organized labor, and providers have often criticized managed care as solely a cost-containment mechanism unconcerned with either quality of care or quality of job. Greater flexibility, to allow for more seamless service provision, is an intended virtue of the managed-care model. However, that flexibility can be directed in a variety of ways—toward or away from quality care and quality jobs—depending on the values of those who control the intermediary as well as the structures they create to implement those values.

Therefore, while a flexible financial structure would be a defining element of the intermediaries proposed here, their governance structure—that is, who formally controls the intermediary—is also a critical element of design. To gain the greatest support of consumers, providers, and labor, these regionally competing intermediaries could be structured as nonprofit organizations to ensure accountability to all three stakeholders. Representatives of each would be placed on the intermediary's governing board of directors.^u If some were structured as for-profit intermediaries, then consumer and labor representation on the corporate board of directors could be required by public funders as one way to "open the board room" to full financial and informational disclosure and accountability.

Service delivery structure: To coordinate service provision, the intermediary organization would use a care-management system in which each client, or member, is supported by an interdisciplinary team—blending health care and social service expertise—that would integrate services and advocate for the client across all care settings.

s The PACE/On Lok programs are an early forerunner of this design for the frail elderly, based on an adult day program as the center of service delivery. New models are also emerging using a broader community setting, such as VNS Choice, a managed long-term care program for the elderly sponsored by the Visiting Nurse Service of New York, the Wisconsin Partnership Program, and PHI's Independence Care System

t See Joseph Newhouse, "Risk Adjustment: Where Are We Now?" *Inquiry*, 1998, Summer 35: 122-31, and Gail Wilensky and Joseph Newhouse, "Medicare: What's Right? What's Wrong? What's Next?" *Health Affairs*, 18:1, 92 – 106.

u These long-term care intermediary organizations will likely emerge as hybrids of what are now provider, insurance, and consumer advocacy entities.

In addition, the intermediary would contract for both long-term care and acute-care services from providers competing at the regional level (see next bullet). Such a range of provider options will enhance consumer choice.

Using these mechanisms, the intermediary could create employment standards for direct-care staff through contractual arrangements with providers and ensure that providers across the long-term care setting were creating stable jobs with parity across the care settings. Finally, the intermediary could help integrate training and workforce resources from outside the health care funding stream to ensure the maintenance of a well-trained and well-supported direct-care workforce.

With more unified funding streams and coordination mechanisms, structured to integrate care horizontally across settings, provider agencies would enjoy a more rational, stable environment as they competed for contracts. They would also be rewarded for combining high-quality care with cost-effectiveness. Beneath the regional intermediaries, provider agencies could be restructured to maximize the benefits of that stabilized environment in the following manner:

- **Regional provider agencies offering long-term care services.**

These regional providers would deliver care directly to long-term care clients but be coordinated through the regional intermediaries described above. This coordination could be further enhanced if providers were encouraged to offer a variety of long-term care programs—not just isolated, siloed services. This would produce efficiencies of scale and allow those agencies to grow large and varied enough to build and support a stable workforce.

Again, to encourage the benefits of the marketplace, these provider agencies would be free-standing and compete against one another for contracts with the regional intermediaries. They would also be free to offer services directly on a private-pay basis. However, policies should be designed to encourage scale within a geographic region, as distinct from

scale at the national level, and emphasize cooperative and nonprofit ownership structures to enhance further governance control by consumers and labor.^v

Within this model of regional long-term care providers, paraprofessional services could be embedded within either regional provider agencies or paraprofessional-only agencies that could focus specifically on the training and support of direct-care workers and the delivery of quality paraprofessional services.

Within these regional structures, paraprofessionals could assume a wider range of responsibilities and offer clients a more sophisticated level of services. These broader responsibilities could then be structured into additional steps within a career pathway or lattice—creating intermediate rungs of responsibility and authority for direct-care staff short of a full nurse’s license. The result would be a stable, clearly demarcated employment structure that a paraprofessional could traverse over time, with increased training rewarded with increased responsibilities and pay.^w

One primary intent of a more lateral system of care and workforce management is to make more cost-efficient use of the resources now deployed throughout our current system of fragmented, vertically organized structures. Therefore, while additional levels of long-term care funding will inevitably be required—simply to address the burgeoning growth in demand for those services—at least part of that rising cost can be borne by a more effective redeployment of existing resources.

No doubt the direct-care labor crisis must deepen—and reports of deteriorating care quality increase—before the nation will be ready to consider such a fundamental, horizontal restructuring of our long-term care system. Yet using the constructs developed above, we can identify in Part IX emerging experiments across the country—experiments that, if encouraged, will help prepare us to respond with increasing sophistication as the shortages and vacancies worsen in the coming years.

^v While for-profits should of course be allowed to participate as providers, it is worthy to note that the Henry J. Kaiser Family Foundation determined, in 1994, that for-profit home care agencies provided Medicare services, on average, costing \$1064 higher per patient than nonprofit providers—a 25 percent difference that added \$1 billion to overall Medicare expenditures that could not be explained by any other factor except ownership structure.

^w The nursing profession has often resisted granting higher levels of responsibilities to paraprofessional staff. However, the same demographics that are shrinking the pool of paraprofessional workers are limiting the future pool of nurses as well. Nationwide, health-care providers report high vacancy rates for professional staff, and nursing schools report a 15 percent drop in enrollments over the past five years. Such high vacancies underscore that the jobs of nursing professionals should not be threatened by encouraging higher levels of responsibilities for paraprofessionals. However, great care must still be taken to respect the nurse’s legal liability, since paraprofessionals in health-care settings work under the direction of a nurse and, therefore, the nurse’s license is at risk if a paraprofessional harms a patient.

part IX experiments in direct-care RESTRUCTURING^x

Even within our current, disaggregated system—and even given the current political and industry framework—experiments are taking place across the country to improve the quality of paraprofessional jobs. These experiments can most easily be described within two categories: those within government and those inside the long-term care industry.

Government Actions

- **Wages and benefits:** In response to reported vacancies and turnover, 16 states in the past two years have modestly increased direct-care wages and benefits, many using a “pass-through” mechanism that requires provider agencies to direct all or a stated portion of reimbursements to direct-care wages and/or benefits.

Rhode Island and New Jersey included in their wage enhancements additional funding for in-home services provided at night and on weekends and holidays. The State of Washington now requires providers to pay in-home staff as they travel between case assignments.

Most recently, Massachusetts passed a \$42-million Nursing Home Quality Initiative that includes a \$32-million wage pass-through for CNAs, as well as a \$5-million demonstration program to create career-ladder programs within nursing home facilities to encourage higher retention of direct-care staff.

- **Health insurance:** In 1998, the State of Rhode Island guaranteed health insurance for all in-home child care providers by expanding its Medicaid insurance program—an initiative that could be replicated for health care workers. In 2000, New York State passed the Health Care Reform Act, vigorously supported by both providers and organized labor, that in part increased access to health care benefits for home care employees.
- **Minimum staffing ratios:** The National Citizens’ Coalition for Nursing Home Reform (NCCNHR) has proposed mini-

Massachusetts passed a \$42-million Nursing Home Quality Initiative that includes a wage pass-through, as well as a \$5 million career ladder demonstration program.

mum staffing ratios in nursing facilities^x to ensure adequate and safe care for residents and safe working conditions for employees. While NCCNHR’s proposals are national in scope, several states are now considering their enactment.

- **Training resources:** Virginia has increased the minimum requirement for nurse aide training from 80 to 120 hours. The federal Departments of Labor and Health and Human Services (and their counterparts at the state level) could target or reserve resources specifically for innovative, employer-based, health care training programs that support higher requirements. These programs

should take advantage of advances in training promoted by such nonprofit organizations as the Career Nurse Assistant Programs of Ohio, the Piton Foundation of Colorado, and the Paraprofessional Healthcare Institute of New York.

- **Welfare-to-work resources:** The final regulations issued for the federal Transitional Assistance to Needy Families (TANF) program allow states to use their TANF resources on training, child care, and transportation programs—not only for welfare recipients but also for other low-income families at risk of becoming dependent on public assistance. At the state level, this increased flexibility could be exploited to create and sustain programs that train and support entry-level and incumbent direct-care staff.

Industry Practice

- **Job redesign:** Experiments in restructuring direct-care jobs are taking place within both facility- and home-based settings despite current public policy.³¹ Some of these experiments, such as that promoted by nursing homes affiliated with the Pioneer Network, have been designed to change the entire culture of the agency in order to ensure quality care—with improved direct-care jobs an effective means to that end. Other experiments, such as those by affiliates within

^x These proposed standards set a maximum number of clients per worker, which varies depending on time of day and acuity of residents.

the Cooperative Healthcare Network,^y have been designed more directly around the paraprofessional employee.

- **Recruitment, training, and career pathways consortia:**

Independent employers within local recruitment areas are meeting—in Colorado, New Hampshire, Massachusetts, and elsewhere—to explore the possibilities of jointly sponsoring a “direct-care consortium.” Such consortia would pool financial and management resources to create regional systems of recruitment, training, and even career pathways across separate employers.

This consortium design may require “competing” employers to build a high level of trust among each other in order to be willing to share not only resources, but access to direct-care workers.

These experiments constitute an important base of knowledge and operational expertise essential to articulating possible answers to the emerging direct-care crisis. However, this base is still limited by current public reimbursement and regulatory structures and constrained by stakeholders’ past perceptions. This report’s final section suggests initial steps that should significantly encourage more rapid and widespread experimentation and, at the same time, may stimulate a fundamental rethinking of how to restructure direct-care within our long-term care system.

^y This network includes five enterprise and training programs across the country affiliated with the Paraprofessional Healthcare Institute.

part X Recommendations

Across the country each morning, long-term care providers, consumers, and workers wake to a thicket of logistics and emotions. How to arrange for so many who need care when there are so few caregivers? As this report has documented, these problems will not disappear; in fact, they will likely become far worse and remain with us for decades unless both policymakers and industry leaders consider unprecedented action.

Although we have described a long-range vision of a fully integrated system of care, such a massive restructuring first requires initial, realistic steps. We therefore propose the following:

1) Create a national Long-Term Care Workforce

Commission. This sectoral commission could be sponsored by one or more nationally respected foundations and modeled after the Kaiser Commission on Medicaid and the Uninsured. The commission would be charged to propose how the nation's long-term care system can be assured of an adequate, well-trained, and stable direct-care workforce.

The commission's advisory board would include representative from the three primary stakeholders—providers, consumer organizations, and organized labor—and senior administrative, congressional, and state government representatives from the three critical funding streams affecting direct-care employment: health care, workforce development, and welfare.

The Workforce Commission's long-range goals would be to ensure that direct-care staff earned a livable wage, including health benefits, and to create parity of labor rates across care settings. The commission would review and assess, on behalf of direct-care workers, all public workforce and welfare-to-work resources, including specialized child-care and transportation services.

To determine how best to foster the market intermediaries described above, the commission could contract for policy analysis. To encourage additional workforce experimentation,

the commission could raise public and foundation monies for both planning and implementation grants.

Finally, the commission would recommend a standing mechanism to monitor and assess the health care labor impact of any proposed changes in health care, labor, or welfare policy. This would ensure that the direct-care workforce was strengthened, or at least not harmed, by any future government actions.

Initial activities of the commission might include:

- **Structuring a cross-departmental dialogue.** This would take place at the federal administrative level, particularly between the Department of Health and Human Services (HHS) and the Department of Labor (DOL)—and even between HHS's welfare and health care functions. The Department of Education (DOE) might also cooperate based on its funding of employment-oriented education programs. This dialogue should identify departments within DOL, HHS, and DOE that affect direct-care service delivery, inform relevant key staff persons of the emerging direct-care crisis, and involve those staff in addressing the interrelated problems. Parallel efforts should occur within all states.
- **Profiling paraprofessional demographics and documenting para-professional job quality.** Commissioned jointly with HHS, this research should serve to provide common definitions, identify areas where data are missing or inadequate, and recommend an annual or biennial system of future data collection and publication.
- **Designing a system of workforce data, reported by each publicly funded direct-care employer.** This data would track activities in which quality of staffing intersects with the quality of consumer care—e.g., rates of annual turnover, ratios of staff to clients, vacancy rates, employer contributions to health insurance, and percentage of reimbursements directed

In a period of high competition for labor, the long-term care industry must create jobs that will attract workers.

to wages and benefits. This data would then be published as part of a “score card” to assist consumers and workers in their choice of care providers.

- **Encouraging further “effective practice” experimentation at the federal and state levels.** These funding and program design efforts could include targeting dollars from TANF, WIA, and H1-B (immigration fee) programs toward paraprofessional training initiatives, increasing and rationalizing the number of minimum hours required for similar paraprofessional positions across care settings, and targeting worker supports—such as child care and transportation—specifically toward the direct-care workforce.

- **Encouraging further “effective practice” experimentation at the regional level and among employers, consumers, and organized labor.** These “sectoral” demonstration programs, modeled after the emerging regional experiments to change workplace culture, should focus on forging practical alliances among providers, consumers, and workers to reduce the misunderstanding and distrust that often separate key stakeholders within the long-term care system.

2) **Identify several key states that would choose to create an administrative, cross-departmental Long-Term Care Council.** Such a statewide council would be assisted by the national dialogue, documentation, data collection, and experimentation referenced above. These initial councils would explore ways to remove inefficiencies and identify opportunities to rebuild their state’s direct-care workforce. They would encourage further experimentation among demonstration programs and share lessons learned—within their state, with other states, and with the federal government.

If these structures proved useful, then they could be extended to other states, with an analog eventually created at the federal level.

3) **Consider promoting a single initiative across several states—e.g., “health care for health care workers.”** Workers within the health care sector should be guaranteed health insurance for themselves and their families. This initiative could build on the experience of child-care workers in Rhode Island as well as the research and legislative initiatives undertaken by SEIU on behalf of home care workers in California and New York State.

Should these initiatives prove successful, consideration could be given to a national health insurance program, through an expansion of the Medicaid program, for all direct-care workers. This program could be funded all or in part with federal dollars.

4) **Support cooperation and organization among the three key stakeholders.** Nationally, representatives of these three key actors within the long-term care system have formed the Direct Care Alliance (DCA). Its purpose is to encourage information interchange among providers, workers, and consumers and promote public awareness of the emerging direct-care worker crisis. Parallel efforts are forming in several states, supported in part by foundations and community-based organizations.

“Crisis” is an overused word, particularly when describing a dilemma within the health care industry. Unfortunately, the reality of this nation’s demographics—in which our elderly and ill require ever-increasing care and our traditional source of entry-level caregivers is shrinking—in this instance justifies the term.

As Dr. Karl Pillemer, director of the Applied Gerontology Research Institute at Cornell has stated: “As a social scientist, I don’t use the word ‘crisis’ lightly, but I do think that over the next ten years we face a true crisis regarding frontline workers in long-term care.”³²

Clearly, our system that provides long-term care to our most vulnerable citizens is truly in danger. While the demographics are inexorable, the resulting crisis is not. We built a system of care when labor was plentiful, and thus we could “afford” to offer poor-quality jobs. This approach kept the health care system functioning at relatively low cost, yet from the worker’s perspective it typically ignored quality jobs, and from the consumer’s perspective it often resulted in poor-quality care.

Now that labor is a scarce resource, however, our presumption must change. Simply stated: In a period of high competition for labor, the long-term care industry must create jobs that will attract workers. To do so will void the crisis. Otherwise, the wealthiest health care system on earth will continue to perpetuate poverty-level jobs, offering to its most vulnerable citizens care that is hurried, care that is delayed, and increasingly, care that is foregone.

endNotes

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