

# The Launch of the Direct Care Alliance

June 14 – June 16, 2000 ♦ Hotel Washington ♦ Washington, DC



A Report on the Conference Proceedings

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**Our Mission:** To improve the quality of care for consumers through the creation of higher quality jobs and working conditions for “direct-care” paraprofessional workers. The DCA promotes recognition that direct-care paraprofessionals are the foundation of good care, particularly for long-term care clients.

**Our Purpose:** Consumers, workers, and concerned providers — who have often held divergent viewpoints — have joined together to ensure a stable, valued, and well-trained workforce to meet the urgent demand for high-quality paraprofessional caregiver services. Our coalition believes that every American is a stakeholder in ensuring that older adults and people with disabilities have access to high-quality paraprofessional care.

Through advocacy, education, and public awareness, the DCA works to achieve fundamental change in direct-care industry practice as well as in both legislative and regulatory policy.

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## PART I: Introduction

**F**rom June 14 through June 16, 2000, the Direct Care Alliance (DCA) — a coalition of consumers, workers, and concerned providers dedicated to ensuring a stable, valued, and well-trained direct-care workforce in long-term care — came together to identify goals and strategies to pursue over the next two years. The invitation-only conference, called by an initial steering committee<sup>1</sup> that had been meeting for eighteen months, marked the emergence of a unified voice calling for higher quality jobs for direct-care workers — home health aides, nursing assistants, personal care attendants — who provide 80 percent of hands-on care for consumers who are elderly, chronically ill, or living with disabilities. The DCA firmly believes that the quality of long-term care is directly linked to the quality of direct-care jobs. Conference attendees brought their concerns to the Capitol on Friday, June 16, during a Congressional briefing hosted by Senators James M. Jeffords and Edward M. Kennedy, Chair and Ranking Member respectively, of the Senate Committee on Health, Education, Labor, and Pensions.

### DCA Principles and Goals

Prior to the conference, the DCA steering committee defined the following set of organizational principles and goals as well as key issues around which to focus the organization's agenda.

- ◆ DCA brings awareness of the value and contribution of direct-care workers to the quality of long-term care and bestows fundamental dignity and respect on those who dedicate their work lives to the humane act of caring, for the greater good of the community.
- ◆ DCA's strength is its tripartite structure. It is an organization comprised of consumers, workers, and concerned providers. DCA is unique in having a strong constituency base of local, grassroots organizations and individuals as well as organizations at the state and national levels.
- ◆ The core belief of the DCA is that the quality of care delivered to long-term care consumers across settings is directly related to the quality of the direct-care worker's job.
- ◆ Therefore, DCA is dedicated to achieving a stable and competent frontline long-term care workforce.
- ◆ DCA believes that the essential components of a high-quality job include: adequate pay, access to affordable and full health insurance, safe workloads, adequate training and support, and opportunities for advancement.

In order to achieve its overall goal of a stable and competent workforce, the DCA identified the following priority issues:

- ◆ Recognition of the value and dignity of caregiving work
- ◆ Higher wages and improved benefits
- ◆ More comprehensive training and job support
- ◆ Workloads that enable workers to deliver high-quality care while working sufficient hours to earn adequate salaries

The DCA pursues its goals through education and advocacy. Although the coalition does not support specific pieces of legislation, it tracks state and federal bills and keeps constituents informed about their content and status.

<sup>1</sup> Members of the Steering Committee included Kevin Bail and Charlene Boyd, Providence Mount St. Vincent Nursing Home; Katherine Cox, American Federation of State, County, and Municipal Employees; Steven Dawson and Mary Ann Wilner, Paraprofessional Healthcare Institute; Genevieve Gipson, National Network of Career Nursing Assistants; Elma Holder, National Citizens' Coalition for Nursing Home Reform; Karen Love, Consumer Consortium on Assisted Living; Ingrid MacDonald, Service Employees International Union; Lorrene Maynard, Virginia Association of Professional Nursing Assistants; JoAnn Poue, Cooperative Home Care Associates; Dawn Savatone, Maricopa County (Arizona) Area Agency on Aging; and Tom Zwicker, Lakewood Health and Rehabilitation Center (Milwaukee, WI). Julie Trocchio from the Catholic Health Association, and William Painter, a long-term care consultant, participated as individuals. Other organizations that assisted in the formation of the DCA included the Iowa CareGivers Association, New York State Certified Caregivers Association, Older Women's League, Pathways to Care, and the Pioneer Network.

## The Conference Participants, Goals, Agenda

To broaden its membership and develop strategies for moving its agenda forward, the DCA steering committee invited about 100 people to participate in a two-day meeting in Washington, DC. Conference participants included a wide range of consumers and consumer organizations, including disability rights organizations, family caregivers, nursing home reform activists, area agencies on aging, and local ombudsmen offices, among others; direct-care workers, labor unions, and professional associations; nursing home and home care providers; and a sprinkling of state policymakers, researchers, and other interested parties. The steering committee put a great deal of effort into ensuring equal participation of all stakeholder groups.

The DCA steering committee identified four initial goals for the conference:

- ◆ Identify strategies — with concrete policy or practice objectives — to pursue over the next two years.
- ◆ Define an organizational structure that will effectively marshal members' expertise and resources to help move the DCA agenda forward.
- ◆ Begin to build among the meeting's participants an exchange network of ideas and materials for improving wages and benefits, training, and career paths for direct-care workers.
- ◆ Hold a briefing to educate Congressional staff about the critical issues facing our nation's direct-care workforce and the clients they serve.



*Conference coordinators (left to right): Mary Ann Wilner, Diane Ferring, and Gregory Smith confer at the registration table.*

To spur dialogue and begin to develop some key strategies, the conference planners divided the agenda into three parts: a plenary session on Wednesday afternoon, June 14, and two working sessions, Thursday, June 15, in which conference participants divided into small groups and reported their recommendations to the larger group. These sessions were followed by the Congressional Briefing on Friday morning, June 16. Summarized here, the conference sessions and Congressional Briefing are described in more detail below.

### **Improving Job Quality for Direct-Care Workers: Showcase of Activities from around the Country**

A panel of presenters discussed their efforts to improve the quality of direct-care jobs. This panel was followed by a panel of direct-care workers, who addressed the challenges they face as caregivers who often work “short,” are paid poverty wages, receive inadequate training, and have little, if any, control over their working conditions.

### **Building the Direct Care Alliance**

In cross-stakeholder groups of about a dozen people that included providers, consumers, and workers, conference participants discussed how to build local coalitions of providers, workers, and consumers in their areas. Each group identified factors that could promote effective coalitions, barriers to coalition building, and strategies to overcome those barriers.

### **DCA Products, Activities, and Services**

Single stakeholder groups (e.g., consumers and consumer advocates) met to identify how their constituency could benefit from DCA activities. Participants recommended a wide range of coalitional activities, products, and services that would support their efforts to improve the quality of direct-care jobs — and, thus, the quality of long-term care — in their states.

### **Congressional Briefing**

Panels of consumers, workers, and providers addressed an audience of about 100 congressional staffers; Washington policy analysts and advocates; members of the press; and DCA conference participants. Speakers repeatedly emphasized the growing labor crisis in long-term care, the policies and practices that have led to the crisis, and the impact on both workers and consumers.

In addition, time was allotted for informal gatherings, so that participants could share information about activities in their organizations, regions, or states. A keynote address by Deborah Stone, “Summertime... and the Carin’ Ain’t Easy,” provided an overview of some of the many challenges ahead for a coalition focused on bringing dramatic change to long-term care.

## PART II: **Plenary** Improving Job Quality for Direct-Care Workers

### Showcase of Activities

#### *Panel moderator:*

Elma Holder, Founding Director, National Citizens' Coalition for Nursing Home Reform

#### *Panel presenters:*

Deborah Thomson, Director of Public Policy, Alzheimer's Association of Eastern Massachusetts

Barbara Frank, Director of State Health Policy, Paraprofessional Healthcare Institute

Diana Findley, Director, Iowa CareGivers Association

Chuck Hawley, Vice President, Providence Health System in Washington State

Catherine Sullivan, Home Care Analyst, SEIU

Simi Litvak, Senior Researcher & Policy Analyst, World Institute on Disability

Hale Zukas, Policy Analyst, World Institute on Disability

William Painter, Long-Term Care Consultant and DCA Steering Committee member

#### A. **Massachusetts CORE Makes Significant Strides**

**Deb Thomson**, from the Alzheimer's Association, discussed successful coalition efforts in Massachusetts, which are bringing attention to the staffing crisis in long-term care and deepening understanding of why that crisis has become so critical today. The Coalition of Organizations to Reform Eldercare (CORE) has brought together consumer groups such as the Alzheimer's Association, AARP, and Greater Boston Legal Services; organized labor (SEIU Locals 285 and 767); providers (Massachusetts Extended Care Federation and Mass Aging); and PHI and the Massachusetts chapter of the National Association of Social Workers to improve staffing in nursing homes. CORE successfully advocated for the Nursing Home Quality Initiative, which, at the time of the conference, was before the Massachusetts legislature.<sup>2</sup> The initiative has a number of provisions, including a \$35 million wage pass-through, constituting a 10 percent raise for CNAs; a \$5 million career-ladder demonstration program; a \$1 million scholarship fund for nurse aide training; and \$1 million for educational and job support for current and former welfare recipients who choose direct-care work.

**Barbara Frank**, from PHI, described additional efforts to raise wages for home health workers with a wage pass-through in the Medicaid home health rate and a legislative salary reserve that would provide a wage increase for home care workers funded through elder services. In addition, Frank has been working with a coalition of long-term care associations, CORE, and the Boston Workforce Development Coalition to help employers attract and retain direct-care workers by improving working conditions and strengthening the caregiving culture. Through this coalition, the long-term care community has been learning about the resources and expertise available through the workforce development community, and the workforce development community has made a commitment to prioritizing the long-term care sector in its career ladders work. The group has undertaken a sectoral initiative on Quality Management and Supervision and is working with an alliance of long-term care providers who are serving as a demonstration site for new workforce practices.

The next phase of the Massachusetts effort will be a fully unified sectoral approach that will encompass direct-care workers across long-term care settings. The Direct Care Workers' Initiative will seek higher wages and benefits, better training and supervision, and safe workloads in nursing homes and home care.

<sup>2</sup> The \$42.5 million bill passed the Massachusetts legislature in July 2000.

Agreement on two points — (1) everyone benefits from strengthening the caregiving connection between consumers and caregivers and (2) it is essential to improve the quality of jobs for direct-care workers in order to strengthen that connection — has provided a strong base for Massachusetts to build effective coalitions.

## **B. Iowa CareGivers Association Provides a Voice for Direct-Care Workers**

**Diana Findley** founded the Iowa CareGivers Association in 1992 as a professional association for CNAs, home care aides, and other direct-care workers to enhance the quality of care through dedication to the direct-care workers. The association, Findley explained, provides advocacy, continuing education opportunities, and support groups for direct-care workers. In addition, the association conducts statewide public awareness campaigns to bring attention to the important work done by direct-care workers.

Although there have been numerous barriers to organizing a professional group — including industry politics, fear on the part of employers that the association might be a union in disguise, and lack of resources — the Iowa CareGivers Association has been successful in bringing attention to challenges that face long-term care and direct-care workers. To improve recruitment and retention in Iowa, the association received funds to assess and address the needs of direct-care workers. With these funds, in 1998, Iowa CareGivers conducted a statewide survey of direct-care workers, who identified four major concerns: (1) short staffing, (2) wages and benefits, (3) lack of opportunities for continuing education, and (4) lack of respect for direct-care workers and the work that they do. Respondents also noted that a key determinant of job satisfaction was their relationship with their direct supervisor. In 1999, the association did a follow-up survey with licensed nurses — the supervisors of direct-care workers — who identified the same four issues.

The survey, Findley noted, didn't uncover any surprises. It has been a tool for bringing attention to the issues, providing hard data that can be used in advocacy work.

Finally, Findley asserted that though demand is growing for direct-care services, Iowa doesn't face a shortage of certified workers; the problem is job dissatisfaction. People are leaving the profession at the same (or possibly faster) rate than new CNAs are being certified. *The key issue is not recruitment, but retention* — how to keep people in the field once they have been trained and certified.

## **C. Washington State Yields Lessons in Shaping Public Policy**

Sharing his experiences in the state of Washington trying to bring about some of the changes advocated by the DCA, **Chuck Hawley** of Providence Health System emphasized the importance of influencing public policy. As he noted, the bulk of reimbursement throughout the long-term care system comes from public tax dollars. In order to make change happen, it is essential to be involved in determining how those public tax dollars are spent. With facilities in four West Coast states, Providence is well aware of the disparities in reimbursement that affect the quality of jobs and, thus, the quality of care for their residents. A service reimbursed at \$80 in Los Angeles County, California, is reimbursed at \$275 in Anchorage, Alaska. This is a public policy choice that impacts what can be paid to staff.

In Washington, Hawley noted, Providence has been involved in several successful coalitions focused on improving wages and benefits for direct-care workers. A “wage parity” campaign, in which advocates lobbied for direct-care workers in private facilities to receive 90 percent of the wages that similar workers in state-run institutions received, improved wages for nursing home workers. The 1006 Coalition — consumers, providers, worker advocates — successfully advocated for a higher wage floor for employees working in nursing homes. In 2000, Providence worked in alliance with SEIU to prevent cutbacks in reimbursement and maintain wage rates. Now Providence is part of a long-term care coalition that has asked the governor to look at what it would cost to pay all long-term care employees a minimum of \$13/hour. Although the coalition recognizes that this wage increase won't pass the legislature, the campaign has increased public awareness and provided a starting point for debate and discussion.

From his political work, Hawley identified a number of key lessons learned:

- ◆ It's a political process and you have to be politically astute.
- ◆ Go beyond principles. Legislators are looking for practical solutions that can be put in a bill.
- ◆ Understand how rates are set and the incentives inherent in rate setting.
- ◆ Demand that states be “moral purchasers.” The purchasing power of the state is immense in long-term care. Don't get trapped in zero-sum games. Increase the size of the pie.
- ◆ Deal with wage compression. Focusing on the minimum isn't enough. What about long-tenured workers who have never received adequate raises.
- ◆ Choose partners carefully in coalitions.
- ◆ It's never over. Public policy is an incremental change effort.
- ◆ Use the power of your relationships to advocate your position. For example: nurses and direct-care workers can provide powerful testimony. Remember the strength of consumers, their families, and workers.

#### **D. California's In-Home Supportive Services Public Authorities**

**Catherine Sullivan** (SEIU) and **Simi Litvak** and **Hale Zukas** (World Institute on Disability) brought both the union and consumer perspective to their joint presentation on California's union and consumer alliance, which led to the establishment of the In-Home Supportive Services (IHSS) public authority system. The public authorities are consumer-controlled, countywide councils that set provider rates for independent caregivers and provide other services directed at stabilizing the workforce and ensuring consumers receive reliable and appropriate services. In addition, the public authorities act as an “employer of record” for the independent caregivers, allowing them to negotiate collectively to improve wages and working conditions. After the public authority was established in Los Angeles County, SEIU organized 74,000 home care providers in Southern California.

The consumer/union coalition came together around a mutual vision: *the need for a stable, well-trained workforce to provide community-based services*. SEIU wanted the public authorities because they would provide a means for collective bargaining and give workers a stronger voice in the political process. For consumers, the public authorities would make it easier to ensure a stable, high-quality workforce. Not only would the public authority system improve wages and benefits — and therefore expand the pool of workers available to consumers — but the authorities could provide a number of much needed services that would improve both quality of care and working conditions. Consumers looked to the public authorities to: (1) set up a registry to recruit and screen personal care assistants (PCAs); (2) create a system for emergency coverage, (3) provide training for consumers in supervising their workers; and (4) provide optional training for PCAs.

Though the union and consumers recognized their mutual interest in a better-paid, more stable workforce, they had their differences as well. It took many years to overcome these differences and develop trust. In particular, consumers needed to be reassured that the union would not interfere with their right to hire, fire, train, and supervise workers and that workers' rights would not trump disability rights. For example, consumers feared a worker might attempt to rearrange the furniture in a client's home, arguing that the change was necessary to prevent self-injury when transferring the client. Consumers also wanted a guarantee that workers would not strike and leave them stranded without the critical care they need to survive. For its part, the union initially questioned the consumers' commitment to worker protections.

Today, the Quality Home Care 2000 Coalition has over 200 member groups across California working for better wages and benefits for direct-care workers. Public authorities, which are voluntary, have been implemented in a number of key counties, with positive results. Nonetheless, the state-county shared funding formula allows significant wage disparities across counties that have the potential to undermine the system. For example, in San Francisco, one of the wealthier counties, wages and benefits for PCAs have

increased to \$9/hour plus health and dental benefits. This has provided a larger pool of workers in San Francisco, but has depleted the number of workers in neighboring Alameda County, where PCAs are still only receiving \$6.25/hour.

### E. State Ombudsmen Survey Highlights Innovative Responses to Staffing Crisis

**William Painter** discussed some of the results from a national survey on workforce issues in long-term care developed by PHI and NCCNHR. Distributed through state ombudsmen offices, the survey asked detailed questions about the challenges facing the long-term care system and how states were responding to these challenges. Thus far, 35 states have responded, and some interesting trends have been identified.

- ◆ Close to 30 states have set up official taskforces to look at long-term care issues, and many of these taskforces are focusing on the recruitment and retention of direct-care workers.
- ◆ These taskforces, much like unofficial coalitions that are emerging around the country, include policymakers, providers, workers, and consumers.
- ◆ Because of the consumer and worker participation, these taskforces have moved beyond numbers to focus on how to use policy to promote good practice. For example, in some states, civil monetary penalties are being used to support culture change (i.e., reforms such as resident-directed care) in nursing home facilities.
- ◆ Coalitions are bridging the gaps between facility- and community-based care and care directed toward seniors and people with disabilities. This is possible because all the stakeholders are on board.

Painter noted that the full results of the survey would be available in fall 2000.

### Direct-Care Worker Respondents

Following the panel showcasing activities around the country, a respondent panel of direct-care workers offered their views on the challenges they face in the workplace every day. With the exception of Denise Slaughter, all of the respondents were members of the National Network of Career Nursing Assistants.

#### *Panel moderator:*

Genevieve (“Jeni”) Gipson, Director, National Network of Career Nursing Assistants

#### *Panel members:*

Gladys Reeves, CNA, New York Certified Caregivers Association, Rochester, New York

Lorrene Maynard, Home Health Aide (HHA), Virginia Association of Professional Nurse Assistants, Newport News, Virginia

Denise Slaughter, Direct-Care Worker, Markham, Illinois, Local 1232, Council 31, AFSCME

John Booker, CNA, long-term care ombudsmen, nursing assistant consultant, Anaheim, California

In moderating the discussion, **Genevieve Gipson** noted the activities of the Career Nurse Assistant Program, Inc. (CNAP), and its membership organization, the National Network of Career Nursing Assistants (NNCNA). Best known for founding and sponsoring National Career Nursing Assistant Week, the CNAP and NNCNA also foster the development of peer support groups, conduct research related to improving CNA training curricula, and advocate on behalf of nurse assistants. Gipson noted that the program has not been as successful in the public policy arena as in other areas, and she looked to the DCA to bring the voices of nurse assistants to policymakers.



*Genevieve Gipson (left) moderated a panel of direct-care workers that included (left to right) John Booker, Denise Slaughter, Lorrene Maynard, and Gladys Reeves.*

Gipson explained that the nurse assistants in the NNCNA have been addressing five major issues — staffing, education and training, wages and benefits, abuse and neglect, and career advancement. In addition to asking the panelists to speak to these issues, Gipson asked John Booker, a member of the National Taskforce on Male Nursing Assistants, to discuss some of the specific issues that group is tackling.

Below are some of the comments made by the direct-care worker panelists.

### **On caring for patients:**

**Lorrene Maynard:** “Yesterday, I made sure my patient would not have to go without anything for the next three days. That to me is more important than a legislator or all the other stuff we go through to get things done.”

**Gladys Reeves:** “I don’t do anything for my residents and co-workers that doesn’t come from my heart. I try to be patient with my co-workers, and especially my residents, who mean the world to me.”

**John Booker:** Men stay away from becoming nurse assistants because it is perceived as an occupation that is too “sensitive.” But, Booker said, “My father was strong and sensitive. He changed my diaper, fed me, and put me to bed. That’s what a CNA does.”

### **On wages and benefits:**

**Lorrene Maynard:** Maynard told the story of “April,” a CNA in Newport News who had had her lights shut off for nonpayment. April worked the night shift at a nursing home, because she made extra money on that shift. She had three small boys. One night, without electricity, she left an oil lamp burning for the boys. At 5 a.m., she received a call from a neighbor that her youngest son had died in a fire. *Why did this happen?*

April needed to go to work; otherwise she would have had to wait even longer to get her lights back on. Moreover, she didn’t want to leave her co-workers short staffed. She felt responsible to the other workers and residents in her unit.

This story illustrates how hard it is for CNAs and home health aides, who earn even less, to survive. When April was about to be charged with neglect, the Virginia Association of Professional Nurse Assistants (VAPNA) and the NNCNA came to her assistance and ensured that instead she received the support services she needed.

**Jeni Gipson:** Gipson explained that the Career Nursing Assistant Program uses much of its funds to help nursing assistants keep their phones on, to pay for postage, and to support professional development for CNAs by facilitating their participation in events such as the DCA meeting. “We want quality care, but we can’t have it at the expense of workers,” she insisted.

**John Booker:** “We have the greatest country in the world. Our parents are the backbone of this country. For them to be worried about who will care for them is a sad question. We have staffing problems for one reason, because of what CNAs are paid. When you look at the lack of diversity on this panel [three African-American women and one African-American male], it is easy to see the problem. Is the problem gender? Is the problem gender and color? If this was a panel of Caucasian males, we wouldn’t be talking about these issues.”

### **On short staffing:**

**Denise Slaughter:** Slaughter explained that her facility teaches vocational skills to groups of eight to ten disabled adults. When they work short, she said, they combine groups, which means there isn’t time for one-on-one attention. Instead of teaching participants how to brush their teeth, comb their hair, learn their phone numbers, write their addresses, the direct-care workers run arts-and-crafts sessions or take everyone to the park. They can’t provide the individual attention necessary for skill development.

**Lorrene Maynard:** Maynard does home health work because she found it so impossible to work with large numbers of patients in a nursing home. She described her first night as a new aide at the nursing home across the street from her home. “I reported to work on Friday night. It was a floor with 46 people and I was the only CNA there. The LPN said, ‘If they think I’m going to do this by myself again, they’re mistaken.’ I couldn’t believe it.” Maynard was concerned for the residents, who couldn’t possibly get adequate care in that situation. After her shift, she went home and decided it was time to start the Virginia Association of Professional Nurse Assistants.

**Gladys Reeves:** “We’re short four out of seven days. On those days, some patients have to stay in bed. If they misbehave, because they are bored and want to get up, they are overmedicated. They don’t get fed properly. . . .When a person wants to get up and they can’t, it’s very frustrating.”

### **On making change**

**John Booker:** Booker described the work of the male nursing assistant taskforce: Male nursing assistants are looking at changes that will attract more men to the field. It must pay better wages, so that being a CNA offers “career” wages. There needs to be training specific to issues faced by males: for example, how to bathe an alert, middle-aged woman. Men need special training, because they are easily accused of improprieties. They need to know how to handle themselves in sensitive situations. Advertising needs to be more gender neutral to attract males.

In response to Booker’s comments, Gipson noted, attracting more males to the field could both expand the labor pool and help to place more emphasis on increasing wages for all.

**Gladys Reeves:** As a member of the Pioneer Network, Reeves has worked to implement resident-directed care, permanent assignment, and culture change in her facility, which cares for many high-need, long-term care residents. As a result of these “culture change” efforts, she has seen people who didn’t socialize for 30, 40, or even 50 years, begin to socialize. Particularly effective has been the institution of weekly community meetings.

**Denise Slaughter:** Slaughter explained that union organizing in Illinois has brought about important changes in policy. The state has increased required training hours, improved training manuals, implemented more stringent literacy requirements, and has looked more carefully at issues of abuse and neglect.

**Lorrene Maynard:** VAPNA, Maynard noted, has tried to bring about change in Virginia and has had some success. They were able to get town meetings to focus on the issue of direct care and to increase CNA wages in facilities by \$1 per hour. Unfortunately, the increase was poorly implemented and has not been equitably distributed. A similar increase for home health aides was stipulated at “up to \$1” per hour, with most HHAs receiving only 20 or 30 cents. Maynard pleaded, “Those who can bring about change in home health and long-term care must make change, because people are suffering, both residents and workers.”

## PART III: **Keynote Address** Summertime... and the Carin' Ain't Easy

*Keynote Speaker:*

**Deborah Stone**, Independent Scholar, Senior Research Associate at the Radcliffe Public Policy Center, and author of “Why We Need a Care Movement” (*The Nation*, 13 March 2000).

Deborah Stone’s address, read by Karen Love,<sup>3</sup> examined the structure of caregiving as an economic activity in our society and the implications of this structure for building an alliance among providers, consumers, and workers. By challenging the very distinctiveness of the categories “employer,” “consumer,” and “worker,” Stone pushed conference participants to think “outside the box” and reassess their “interests” as stakeholders. In caregiving, Stone noted, an employer may be a nursing home provider or a person in need of care or a family member. But a person in need of care or a family member may also be a consumer. Then again, a family member may be an “unpaid” caregiver, thus, blurring the lines between “consumer” and “caregiver.” Caregiving, an activity that is about relationships, not widgets, she argued, simply doesn’t fit neatly into the industrial model of production.

By posing five traditional “scripts,” embodying generally accepted assumptions about the roles of employers, workers, and consumers in our industrial economy and, then, challenging these scripts, Stone gave participants a chance to re-examine where their interests might intersect with those of other members of the DCA coalition. Stone’s comments are summarized below.

### **SCRIPT 1: “Employers should hold down wages as much as possible.”**

Although most often employers want to pay workers as little as possible in order to increase profits, when the employer is a person in need of care, Stone noted, this rule may not apply. Care consumers, who are often employers, recognize that higher wages improve the stability of the workforce and the quality of care. But consumers can’t necessarily afford to pay higher wages. Thus, building an alliance to demand greater *public investment* in caregiving services benefits consumer-employers and workers. Public investment also benefits agencies and facilities, employers who also need adequate public funds to retain a qualified workforce.

### **SCRIPT 2: “The most important, most skilled, and most valuable work is done by people at the top — the managers, the brains, the executives, the planners, the professionals.”**

As Stone noted, in caregiving, what matters most to care recipients is their relationship with their caregivers, direct-care workers who are at the bottom of the hierarchy — not the top. Because care recipients and their families understand the value of direct-care workers, it is their responsibility to educate managers and policymakers — the people at the top — about the valuable work that frontline caregivers do. Although it is important for individuals to thank caregivers and acknowledge their importance in the care recipient’s life, Stone argued that it is time for consumers to become political — to ensure that public policy acknowledges the critical and highly skilled services of direct-care workers.

### **SCRIPT 3: “Managers with the big picture should have the power to deploy direct-care workers, and professionals with clinical training should have the power to define workers’ tasks.”**

Noting that this is an old script, Stone argued that more progressive industries have recognized the importance of giving workers some control over their jobs. However, she asserted, direct-care workers often have even less control over their jobs than more traditional workers, because they cede control (and rightly so) to the care recipient. To balance the loss of control that workers may feel in relationship to their clients,

<sup>3</sup> Stone was unable to attend the conference due to illness.

Stone maintained that managers should include direct-care workers in decision-making activities such as care-planning meetings, team meetings, scheduling, work assignments, and so on. By empowering direct-care workers, employers make it easier for workers to empower their clients — and thus provide better care.

**SCRIPT 4: “Both employers and workers are better off if they have clear contracts that specify the time, hours, and job tasks in detail.”**

Although Stone acknowledged the importance of rules, she observed that most caregivers go beyond the limits of their job, sometimes even breaking the rules to provide good care. She declared, “Because you are in the care business, you need to acknowledge that good care requires flexibility, judgment, and discretion. And you need to acknowledge openly that a lot of — shall we say? — freelancing happens.” She advised participants to “think together about how best to give workers the flexibility and discretion they need to give good care, while still protecting the health and safety of recipients.”

**SCRIPT 5: “Love and emotion do not belong in the workplace. Workers should be professional, distant, and objective. They should keep work and personal relationships separate.”**

Simply put, we can’t keep the “love” out of caregiving. Though workers are told to keep their distance and “not get involved,” Stone observed, they inevitably say that it’s not possible — it’s not human. In Stone’s final piece of advice to her audience, she suggested that “perhaps the most important thing the DCA can do is to educate the public about this simple idea — the idea that care means CARING. . . . Not only the lay public but also the elite public, the politicians and the policymakers. Someone has to come clean, to come right out and say in public, against all taboos, that caregiving is one kind of work where love is okay. It’s more than okay. We don’t want it any other way.”

# PART IV: Recommendations from Small Group Sessions

## Session I: Building Successful Coalitions

In small groups, consumers, providers, and workers talked about how to build cross-stakeholder coalitions. From their varied perspectives, participants examined their experiences with coalitions, looked at barriers to forming coalitions, and identified critical elements for success.

### Barriers to organizing coalition efforts:

- ◆ Politics: state governments, elections constantly bring a new set of policymakers.
- ◆ Interests are not the same even across a single constituency, for example, among for-profit and nonprofit providers; self-directed consumers and residents in facilities; or facility-based and community-based workers.
- ◆ Every constituency group has an agenda; often these agendas are very narrow.
- ◆ Lack of trust, understanding, shared knowledge, and infrastructure.
- ◆ There are no paid staff to do the work and there is little money; no one is paid to do this work, which makes it particularly hard for low-income workers.
- ◆ The long-term care system is complex, difficult to comprehend and to change.
- ◆ Immigrants are being brought in as a “slave labor” class.
- ◆ The culture doesn’t support aging or living with disabilities.
- ◆ Racism, classism, sexism.
- ◆ Domination of the medical culture/medical bias.
- ◆ Union phobia — caregiver associations are often feared as efforts to unionize.

### Recommendations for building successful coalitions:

- ◆ Have faith in the process, believe, stay hopeful.
- ◆ Provide vision and leadership.
- ◆ Bring all stakeholders to the table, including providers, consumers, and workers across nursing home and community-based care, nurses, doctors, social workers, and educators. Look for common ground and stay focused. Develop shared principles and explore differences before starting a campaign. Trust and respect are essential. “Check guns at the door.”
- ◆ Work to ensure full participation of direct-care workers. Encourage mentoring; ensure that direct-care workers are asked to share their expertise. Also, pay for their time, meet at their workplaces.
- ◆ Look for what you can accomplish in the short-term so your coalition can experience success. Do fun things first.
- ◆ Keep it simple. Have realistic goals that benefit each of the participants.
- ◆ Learn from those who have gone before: for example, the Independent Living Movement.
- ◆ Develop timetables; focus on outcomes.
- ◆ Become sophisticated and knowledgeable about financial issues. Otherwise you will not be able to bring in providers.
- ◆ Be entrepreneurial, take risks.
- ◆ Broaden the coalition to include women’s groups, civil rights groups, living wage campaigns, health care reform groups: humane care is a human rights issue.

## Keys to a successful coalition campaign:

- ◆ Educate the public and key decision makers; use town meetings, develop articulate spokespeople, use PR campaigns, Internet, etc. Get the human stories out.
- ◆ Use empathy: this issue affects everyone, including public officials. Everyone is a consumer.
- ◆ Focus on the decision makers — state government — not facilities. Educate coalition members about effective lobbying. Don't just look to cut up the existing pie — try to enlarge the pie.

## Session II: DCA Products, Activities, and Services

Individual stakeholder groups met to discuss two questions:

- ◆ What products, services, and activities could the DCA offer to meet the particular needs of their constituency?
- ◆ As a coalition, what could the DCA do to promote change that their constituency could not do alone?

This session encouraged each stakeholder group to identify their specific needs and the role the DCA could play in helping their constituency achieve its goals (e.g., workers wanted to promote greater respect for their occupation and suggested that the DCA sponsor a nationwide media campaign).

### Recommendations

#### *Products*

- ◆ Create a clearinghouse and website to disseminate best practices (models of care, training, culture-change models) and success stories, track federal legislation, and provide materials for educational efforts, recommendations to address recruitment and retention, career ladders, and so on. Products might include: information packets, directory of political allies and/or directory of advocacy organizations, a newsletter (distribute electronically), national survey of wages and benefits.
- ◆ Develop press kits, media slogans, video that local groups could use for media campaigns.

#### *Activities*

- ◆ Provide opportunities for cross-stakeholder dialogue. Cross-stakeholder groups might include: self-directed consumers and consumers living in facilities, licensed and unlicensed direct-care workers, family members, elderly, advocates, CEOs of facilities, educators, nurses and physicians, social workers, as well as others involved in long-term care. These cross-stakeholder dialogues could identify tools that could unite us: for example, developing a common language. Sponsor regional meetings for stakeholders. Hold an annual national conference.
- ◆ Help establish state-level DCAs.
- ◆ Advocate for policy and practice changes that will make direct-care work a career. Advocate for parity in pay, respect, recognition, job responsibilities across institutional and community-based care. Recognition of career path that carries across state boundaries. Health insurance for direct-care workers. Living wage campaign. Tuition assistance.
- ◆ Build a “right to care” movement: organize a protest march or a national gathering that promotes dialogue.
- ◆ Establish standards of practice for nurse assistants.
- ◆ Create a Bill of Rights for consumers and workers.



*(Left to right): CNA Sherry Allen from Alvarado, Texas, PHI Development Director Michael Bartus, and CNA Charlene Dreher from Columbia, South Carolina, on their way to the Congressional Briefing at the Hart Senate Office Building in Washington, DC.*

- ◆ Advocate for an ombudsmen for nursing assistants.
- ◆ Help establish/empower a national association of direct caregivers.
- ◆ Work with media to improve image of direct-care workers. Help local groups organize media campaigns.
- ◆ Highlight voices for change: direct-care speakers bureau, letter-writing campaigns, media campaigns.
- ◆ National ad campaign to recruit workers. Regional workshops on recruitment and retention.
- ◆ Develop research agenda; provide resources for action research and program evaluation. Look specifically at impact of public policy decisions. Possibly develop a research council.
- ◆ Address barriers such as racism, ageism, sexism that have an impact on long-term care system.
- ◆ Transform the way care is delivered.

### *Services*

- ◆ Provide training and technical assistance for workers, employers, consumers, and family members. Might include issues such as overcoming cultural barriers, how to work in a resident-directed care facility, consumer-directed care, fundraising, integrated marketing plans for providers, high-quality supervision of direct-care staff, building care teams.
- ◆ Promote exchange visits — visit a site that is engaging in the kind of change you would like to promote in your workplace.
- ◆ Provide direct-care workers with opportunities for networking and support. For example, use website to link direct-care workers through message boards and/or chat rooms.
- ◆ Provide direct-care workers with access to resources: financial, training, mentoring. Support efforts of small nursing assistant groups, don't take over what they are already doing. Possibly establish a fund for small demonstration projects such as newsletters and technical support projects.
- ◆ Develop leadership skills among direct-care workers. Ensure that paraprofessionals are given a place on all policymaking committees, taskforces, and other decision-making bodies.
- ◆ Function as a watchdog organization. DCA hotline where workers could report problems in their facilities. Take legal action against states that don't comply with the law.

## PART V: Congressional Briefing

On Friday morning, June 16, the DCA held a briefing, sponsored by Senator Jeffords of Vermont and Senator Kennedy of Massachusetts. The DCA addressed congressional and government agency staff, policy analysts, advocates, members of the media, and participants from the DCA conference. The DCA organized three groups of speakers, representing long-term care's three primary stakeholders: consumers, workers, and providers (see Appendix for the full testimony of eight of the eleven panelists). Catherine Hawes, Senior Research Scientist from the Myers Research Institute of Cleveland, Ohio, moderated the discussion.

Hawes noted that in a recent survey of long-term care ombudsmen, 90 percent reported that the biggest impediment to providing high-quality care is staffing shortages. Nursing homes are plagued by high staff turnover and an inability to attract quality workers. Commenting on this critical labor shortage, Hawes said, "We must make long-term care work attractive, if we want people to become caregivers." She called the current state of affairs, in which we are unwilling to provide a living wage, health benefits, and respect and dignity to workers who provide essential care, "a national tragedy." *Why*, she asked, *do we honor this work when a family member does it and look upon it with disdain when a stranger does it?*

Following Hawes's comments, Steven Dawson, president of the Paraprofessional Healthcare Institute, introduced the Direct Care Alliance and provided an overview of the critical workforce issues facing the long-term care system. Dawson focused attention on two critical issues: (1) Why we are experiencing this staffing crisis now; and (2) Why it will worsen if we do not respond immediately. He argued that today's staffing crisis can be attributed to:

- ◆ The poor quality of direct-care jobs.
- ◆ The full employment economy, which offers more attractive jobs to workers who once chose direct care.
- ◆ Post-baby boom demographics, which has created a mismatch between the demand for long-term care services and the supply of workers.

After reviewing the demographic changes that can be expected to widen the "care gap" over the next 30 years, Dawson identified four solutions to the labor crisis:

- ◆ Higher wages
- ◆ Health benefits for direct-care workers
- ◆ Higher training standards
- ◆ Improved working conditions in the form of jobs designed around the direct-care worker, career opportunities, and better supervision.

As Dawson noted, to attract high-quality workers in today's expanding economy, the long-term care industry must improve the "price" paid for labor. To do so, however, providers need assurance from policymakers that they are willing to increase reimbursement rates to adequately cover the cost of services.

The three panels expanded on Dawson's comments, bringing the perspective of what it is like "out in the trenches" every day. Members of each panel offered a variety of suggestions as to how the staffing crisis in long-term care could be resolved.

### *Consumer Panel:*

Elma Holder, Founding Director, National Citizens' Coalition for Nursing Home Reform

Marilyn Saviola, Director of Advocacy, Independence Care System

Simi Litvak, Senior Researcher and Policy Analyst, World Institute on Disability

Hale Zukas, Policy Analyst, World Institute on Disability

The consumer panel noted the importance of caregivers to the quality of life of elderly Americans and people living with disabilities. Elma Holder provided a historical perspective on the efforts of the National Citizens' Coalition for Nursing Home Reform (NCCNHR) to establish staffing standards in nursing homes. She then

focused attention on the impact of “short” staffing: poor quality care and, as a result, a poor quality of life for nursing home residents. To address these problems, Holder made several recommendations for changes in the regulation of nursing homes, including:

- ◆ Require minimum staffing ratios that increase flexibly as resident acuity rises.
- ◆ Require facilities to report meaningful staffing data to HCFA on a quarterly basis.
- ◆ Require that nursing services be the largest cost-center for expenditures in the daily Medicare/Medicaid rate.
- ◆ Require surveyors to cite facilities that fail to provide staff needed to provide good care.
- ◆ Require facilities to post the names of the staff on duty for each shift and the ratio of direct-care staff to residents and require HCFA to post this information on its website.

People living with disabilities, Marilyn Saviola observed, feel that having personal care attendants is their right. This right was recently confirmed by the Supreme Court (*Olmstead* 527 US581 [1999]), which ruled that people with disabilities have the right to live in the least restrictive setting possible. The choice to live in the community is only possible if people with disabilities have reasonable access to personal care assistants. These service providers — not “caregivers” since the service provided is not medical care — allow people living with disabilities to live independently, to hold jobs, and to remain productive members of the community. Saviola noted that in order for consumers to be provided with real “choice” as to their living situation, they must be supported by a system that:

- ◆ Pays comparable wages to personal care assistants, home health aides, and nursing assistants regardless of the setting in which they work.
- ◆ Mandates Medicaid coverage for personal care attendants.

Saviola’s comments were supported by those of Simi Litvak and Hale Zukas, who, after describing some of the results (positive and negative) of establishing public authorities for In-Home Supportive Services in several California counties, offered the following suggestions for improving community-based care:

- ◆ Develop incentives in federal policy to encourage states to increase personal assistant wages and benefits.
- ◆ Allow spouses and parents of minor children to be paid providers. This would increase the pool of personal assistants.
- ◆ Require states to provide the full spectrum of services, including housing modifications and assistive technology, which would allow people to live in their homes, often with less need for personal assistance.
- ◆ Modify Medicaid legislation and regulations to correct Medicaid’s bias favoring nursing homes over in-home services.
- ◆ Allow personal assistance users on Medicare who are over 65 years old to “buy in” to Medicaid.
- ◆ Improve working conditions by providing money to states for training of personal assistants and personal assistant service consumers to help them function more comfortably in a consumer-driven, individual provider system.

*Direct-Care Workers Panel:*

Elizabeth Sutton, CNA, Heartside Health and Rehabilitation Center, Local 150 SEIU,  
Milwaukee, Wisconsin

Lorrene Maynard, Home Health Aide, President, Virginia Association of Professional Nurse Assistants,  
and member, National Network of Career Nursing Assistants

Jay Sackman, Executive Vice President, Administrative Office and Nursing Home Division,  
Local 1199, SEIU, New York City

Genevieve Gipson, Director, National Network of Career Nursing Assistants

The direct-care workers made several key points: nurse assistants and home health aides receive inadequate training for the tasks they are required to perform; those who work in facilities are working with sometimes a dozen or more residents at any one time and, thus, no one receives adequate care; among CNAs and home health aides, even those who are most committed are leaving the industry because of overwork, inadequate wages, and lack of respect and recognition. Lorrene Maynard repeated the story she had told at the DCA panel the previous day of a CNA whose son died during a fire caused by an overturned oil lamp. The CNA was forced to leave her children alone in a dangerous situation because she earned so little money that her electricity had been shut off.

In addition to reiterating the recommendations of the consumer panel, Jay Sackman from SEIU suggested that in order to improve the quality of jobs in long-term care, Congress must take the following actions:

- ◆ Hold nursing homes accountable for spending public funds on resident care;
- ◆ Legislate wage pass-through incentives; and
- ◆ Provide grants to improve retention.

Genevieve Gipson focused her comments on improving training for direct-care workers. She pointed out that care needs are becoming more complex, yet there are no national standards by which to determine the presence or absence of necessary competencies to provide high-quality service. Although Congress passed the Nursing Home Reform Law of 1987 requiring 75 hours of entry-level CNA training, there are no requirements for continued competency development. Noting the inadequacy of today's training programs, Gipson cited a recent study in Ohio, in which tasks ranked highest by nursing assistants in "frequency, importance, and difficulty" were also ranked as "learned on my own." Gipson's recommendations included the following:

- ◆ Require at least 160 hours of training for direct-care workers.
- ◆ Improve the curriculum to address skills needed by nursing assistants.
- ◆ Develop a formal learning period — i.e., internships — between the classroom and initial job assignments.
- ◆ Provide greater opportunities for competency development and career growth.
- ◆ Provide stronger preparation for the teaching team.

#### *Provider Panel:*

Rick Surpin, President, Independence Care System, New York City, and President-elect, Home Care Association of New York State

Tom Zwicker, Owner and Administrator, Lakewood Health and Rehabilitation Center, Milwaukee, Wisconsin

Surpin and Zwicker brought home the point that the current staffing shortage in long-term care is by far the worst they have ever seen. Zwicker, whose facility has been recognized as a "best-practice nursing home," noted that he cannot keep direct-care staff, which means that his care teams do not function as high-quality teams. Surpin noted that at a recent industry summit in New York State, staffing issues became the focus. In New York State, short staffing has meant that home care providers are providing shorter hours of service and, in some cases, are simply not providing service at all. Training classes for new workers are also at all-time lows, in part the result of federal welfare reform's "work first" policies that direct welfare recipients looking for work away from any kind of pre-employment training.



*Before the congressional hearings began, the direct-care workers attending the DCA conference displayed their enthusiasm for an event that was bringing their voices into federal policy discussions.*

Surpin and Zwicker made the following suggestions to improve the quality of care for consumers and the working conditions for caregivers in institutional and home settings:

- ◆ Recognition that this is an emerging crisis — and one that is not easily addressed.
- ◆ A paradigm shift:
  - A re-thinking of the importance and complexity involved in caring for our loved ones, particularly as they age and lose mobility or mental cognizance. This involves re-examining our responsibilities as family members, the role of public resources, and our willingness to invest in long-term care so that it can compete for workers with other sectors of the economy.
  - An understanding that the quality of care is not the result of enhanced scientific methods but coordinated efforts on the part of a dynamic team of caregivers.
- ◆ An effort by the various administrative agencies — Labor, Health, and Commerce — to work together to provide direct caregivers with better training, wages, and staffing ratios.
- ◆ Reimbursement levels that allow for the restructuring of jobs to facilitate wage parity with other sectors.

## PART VI: Conclusion

DCA conference participants left Washington, DC, energized and excited about the possibility of building a strong coalition across the major stakeholders in long-term care: consumers, workers, and providers. Everyone felt the conference sessions, which provided opportunities to grapple with the challenges and opportunities of coalition building, were engaging and productive. As is evident by the long lists of recommendations that emerged from the small group sessions, participants agreed that the DCA could play a key role in addressing the critical shortage of direct-care workers, improving the quality of jobs, and demanding quality care.

In this effort to build a coalition, not surprisingly, differences in priorities and questions about the nature of this particular alliance arose. Consumers, particularly those living with disabilities and concerned with self-directed care, felt that the DCA goals and principles were not sufficiently consumer oriented. Some participants felt uncomfortable coming to the table with union activists and feared that the DCA might simply be a union organizing effort, rather than what it intends to be: a multi-stakeholder organization with a strong union presence. Questions were raised concerning the meaning of “worker empowerment”: Is the DCA only about empowering workers or is it about improving the quality of care? All participants, however, were prepared to continue the dialogue. Whether provider, direct-care worker, or consumer, participants recognized the value of a high-quality, stable and committed workforce to achieving their ultimate goal: a long-term care system that provides the highest quality of care, whether in facilities, homes, or community-based settings.

The DCA steering committee, inspired by the success of the initial launch of the coalition, is following up by formalizing its organizational structure and developing an agenda that incorporates the recommendations of participants. Most importantly, the Paraprofessional Healthcare Institute (PHI) has agreed to sponsor the **National Clearinghouse on the Direct Care Workforce**, which will facilitate the exchange of information across stakeholder groups and geographic areas.

The National Clearinghouse will collect and distribute information on best practices, regional coalition development, advocacy strategies, research, and legislative proposals at local, state, and federal levels in order to support state and regional efforts to improve the quality and stability of the direct-care workforce. The DCA will keep key stakeholders, policymakers, and the media informed through periodic mailings, press releases, research reports. In the near future, the DCA hopes to be able to provide technical assistance to stakeholder groups and to sponsor periodic forums that bring the coalition’s supporters together to discuss common interests, areas of disagreement, and creative strategies for ensuring a valued, stable, well-trained direct-care workforce to care for our most vulnerable citizens into the twenty-first century.



# **Appendix** Congressional Briefing on the Direct-Care Workforce in Long-Term Care

June 16, 2000

Hosted by Senator James M. Jeffords (R-VT) and Senator Edward M. Kennedy (D-MA), Chair and Ranking Member, respectively, of the Senate Committee on Health, Education, Labor and Pensions

## **Testimony\* presented by:**

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Rick Surpin, Cooperative Home Care Associates . . . . .	35

\* Although not available for publication, testimony was also presented by Jay Sackman, Executive Vice President, Administrative Office and Nursing Home Division, SEIU Local 1199; Marilyn Saviola, Director of Advocacy, Independence Care System; and Elizabeth Sutton, CNA, Heartside Health and Rehabilitation Center, SEIU Local 150.

## Paraprofessional Healthcare Institute (PHI)

349 East 149th St., 10th Floor  
Bronx, NY 10451

*Testimony presented by Steven L. Dawson, President of PHI*

Good morning... Representing the Direct Care Alliance, we deeply appreciate the opportunity to address you, the staff of the U.S. Congress. We particularly thank Senator Jeffords and Senator Kennedy and their staffs for hosting this briefing.

We are a rare gathering — representative of the three key stakeholders in our country’s long-term care system: consumers, workers, and concerned providers. Although we do not always agree with each other, day and night, seven days a week, we share the experience of trying to make our long-term care system work for our nation’s most vulnerable citizens — those who are frail elderly, chronically ill, and disabled.

And so we would like you to think of this morning as a “report from the frontlines” of your long-term care system.

Because on one point we three stakeholders agree: *our delivery system has begun to unravel*. Staff shortages and high turnover rates among direct-care workers — home health aides, certified nursing assistants, personal care attendants — are causing a true crisis, which requires your immediate attention: Notably, officials in 40 states are reporting dangerously high rates of staff vacancies, and even before this crisis began, annual turnover of direct-care positions averaged 40 to 60 percent in home care, and in nursing homes, between 70 and 100 percent.

Yet I also want to bring this home to you, because this is not an abstract issue for the nation — it is very likely to be a concern for you personally. If you can picture in your mind *any* family member or loved one who is — or who soon will be — in need of long-term care, it is important to understand one central fact: Whether your loved one is cared for in her home, or an assisted living facility or nursing home, *eight out of every ten hours of paid care she receives* will be offered by a “direct-care” aide.

Therefore, from the perspective of your loved one, the more than two million paraprofessionals in this country *are* the delivery system for long-term care. And, thus, this morning we are asking the very personal question: *Who will take care of mother today? next week? every day and night next year?*

In a few minutes, representatives from each of the three key stakeholders will report to you on the critical link between quality jobs and quality care. But before they begin, I would like to focus your attention on:

- Why we are experiencing this staffing crisis; and
- Why it will worsen if we do not respond immediately.

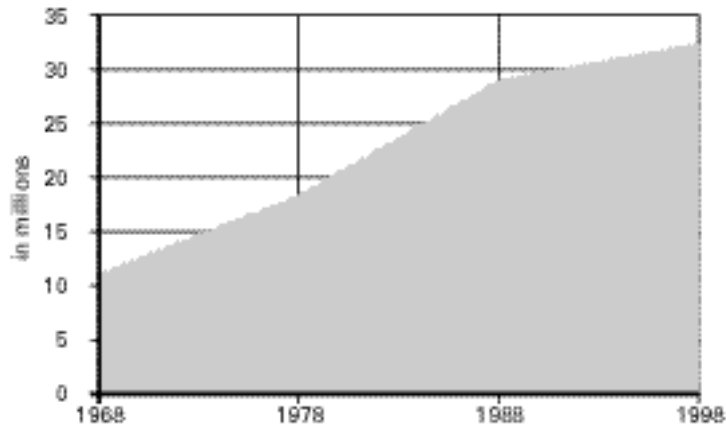
The staffing crisis is hitting now for three reasons:

- 1) The quality of direct-care jobs tends to be extremely poor.** Wages are low (more than 600,000 health care workers return home to families living in poverty) and benefits few — in a bitter irony, most direct-care staff do not receive employer-paid health insurance. CNAs have one of the highest injury rates in the country — more than three times that of coal miners and nearly twice that of construction workers. Home care work typically offers only part-time hours and, thus, part-time pay.
- 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: Offered the alternative of stable and safe food service, clerical or hospitality jobs, compared to the increasingly stressful demands of long-term care, even those who love to assist others are choosing to leave the health field.
- 3) “Post-baby boom” demographics in America have created a mismatch between the demand for long-term care services and the supply of these workers — a “care gap” that will constantly worsen over the next 30 years.**

*I particularly want to focus your attention on this last point — not just the “baby boom” demand for caregivers that you already know about, but the post-baby boom supply of health care workers.*

More than 85 percent of direct-care workers are women. The vast majority of entry-level workers are between the ages of 25 and 44 — these are the workers all health care employers are trying to lure away from clerical and food service positions.

Now, think about what has been going on for women in that age bracket during the past 30 years, when we were designing and building our long-term care system ...



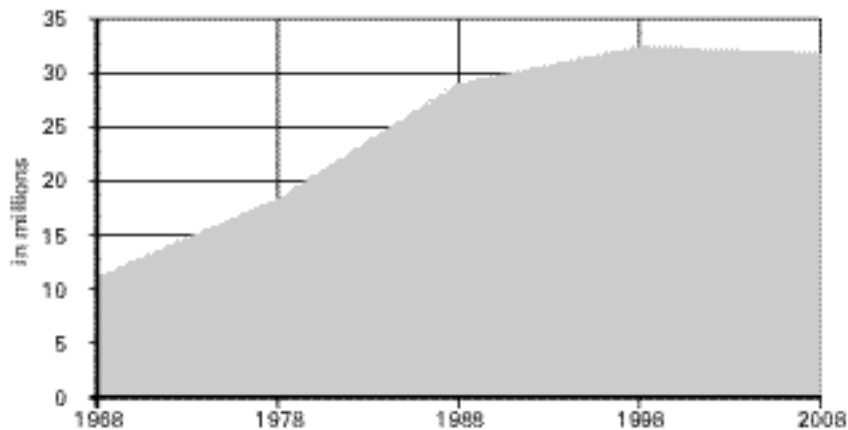
#### **Women Aged 25-44 in the Civilian Workforce 1968 through 1998**

Source: 1968 figure is calculated from US Bureau of Labor Statistics <http://stats.bls.gov/sahome.html>;  
All other data for 1978-2008 are from Howard N. Fullerton, Jr. (Nov. 1999) “Labor Force projections to 2008”  
Monthly Labor Review, Table 5, <http://stats.bls.gov/opub/mir/1999/11/art3full.pdf>.

**The baby boom generation:** This cohort of workers has tripled over the past three decades as a result of two interacting factors: the increasing number women of the “baby boom” generation coming of adult age, and the increasing percentage of those women participating in the workforce (45 percent in 1968, rising to 77 percent in 1998).

Clearly, we have designed our delivery system based on the assumption of an increasing supply of women, who are increasingly willing and able to work.

But this assumption is no longer valid, as is evident in the next graph:

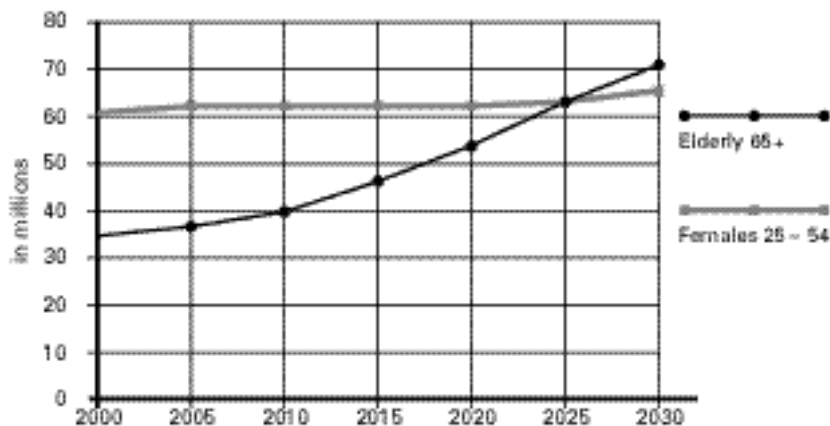


#### **Women aged 25-44 in the Civilian Workforce 1968 through 1998; projected to 2008**

Source: 1968 figure is calculated from US Bureau of Labor Statistics <http://stats.bls.gov/sahome.html>;  
All other data for 1978-2008 are from Howard N. Fullerton, Jr. (Nov. 1999) “Labor Force projections to 2008”  
Monthly Labor Review, Table 5, <http://stats.bls.gov/opub/mir/1999/11/art3full.pdf>.

**The post-baby boom generation.** The “baby boom” workforce has passed through this age range, leaving a smaller workforce to follow, while at the same time the rate of increased participation of women in the workforce is slowing considerably (from 77 percent in 1998 to only 79 percent projected for 2008).

*And we’ve only entered the near side of the problem... Because, looking further into the future:*



### **Women of Care-Giving Age and Elderly in the U.S.: 2000 – 2030**

(Females aged 25 – 54; individuals 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>

The U.S. elderly population is projected to *double* over the next 30 years... while the population of “traditional” female caregivers is projected to grow *by only 7 percent*.

This means that the U.S. population currently includes 1.75 females aged 25-54 per elderly person — when we are already experiencing significant direct-care shortages. Yet this ratio will decline steadily over the next 30 years to a point where there will be *fewer than one woman of caregiving age per elderly individual in the year 2030*.

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 in this age group provide the vast majority of both paid direct-care services *and* family care, this “care gap” in America will increasingly become a double-bind: Families who cannot care for their loved ones by themselves will find, when they turn to the formal system for assistance, relatively fewer paid staff available.

*Because of the link between quality jobs and quality care, the impact of these shortages is incalculable:*

- Less continuity of care
- Less time for each client
- Unsafe workloads...

And worse yet, for the long-term care system, the inevitable result is a *downward spiral*: The fewer the workers, the harder the job is while “working short” — and the harder the job, the more likely it is that workers will leave health care. And the spiral continues...

The result is that your loved one is increasingly in danger of receiving care that is hurried, care that is delayed, and perhaps, even care that is foregone.

Yet, while the demographics are inexorable, the resulting crisis is not: We simply must face that our health care system functions within a competitive labor market — an increasingly competitive one in which demand will continue to rise and supply will no longer keep pace. Any labor economist will tell you that to compete successfully in such a labor market, you must make these jobs more attractive.

Therefore, the “answer” to the staffing crisis is not surprising: We must treat the direct-care workforce for what it has become — a scarce resource — and provide these jobs:

- 1) Higher wages.
- 2) Health benefits — it is unconscionable that we ask the majority of our paid caregivers to go without employer-contributed health insurance.
- 3) Higher training standards.
- 4) Improved working conditions in the form of jobs designed around the direct-care worker, career opportunities, and better supervision.

I will close my remarks with the good news:

- 1) Ironically, this workforce has been ignored for so long, that a range of responses remain available to respond to the staffing crisis. The three stakeholders who will be speaking to you this morning already know how to turn these jobs into decent jobs.
- 2) And by creating decent jobs, you will be addressing two critical goals simultaneously:
  - Repairing our nation’s long-term care delivery system, and
  - Providing decent jobs to low-income health care workers.

For, finally, this is a moral choice.

We already know how to make these jobs decent jobs — and given the most recent federal and state budget surpluses projected over the next decade, we have the resources. We now have an opportunity to forge the link between good jobs and good care. We owe this to our families, and we owe this to those who spend their working lives caring for our families.

## National Citizens' Coalition for Nursing Home Reform (NCCNHR)

1424 16th St., NW, Suite 202

Washington, DC 20036

*Testimony presented by Elma Holder, Founding Director of NCCNHR*

### **The Effect of Inadequate Staffing on Consumers**

*Poor quality of care:* Staff does not have enough time to provide even the basics such as toileting, bathing, mobility, assisting to eat and drink, and preventive skin care, leading to:

- ◆ Incontinence
- ◆ Contractures
- ◆ Malnutrition
- ◆ Dehydration
- ◆ Pressure sores

*Poor quality of life:* Staff does not have enough time to develop and maintain relationships with residents and lack essential knowledge about them, which can lead to:

- ◆ Chemical and physical restraint use
- ◆ Neglect and abuse by staff
- ◆ Lack of choice, control, or autonomy for residents
- ◆ Increase in resident behavioral symptoms
- ◆ Poor grooming
- ◆ Loneliness and inactivity

### **Government Policies that Perpetuate Understaffing**

- ◆ No staffing standard is required for nursing homes participating in the Medicare and Medicaid programs.
- ◆ Federal and state governments do not collect useful staffing and financial data on which to base staffing and reimbursement decisions.
- ◆ Prospective Payment System (PPS) does not require the designated nursing dollars to be spent on nurse staffing (the designated dollars may also be insufficient).
- ◆ State surveyors cited staffing in only 3.8 % of facilities in 1997, although many deficiencies in care are directly attributable to understaffing of nursing assistants and professional licensed nurses.
- ◆ Facilities are not required to post their staffing ratios on a daily basis for residents and families to see, nor does the government post staffing information in a useful way on its website.

### **Public Policies that Would Improve Staffing Adequacy**

- ◆ Require minimum staffing ratios that flexibly increase as resident acuity rises.
- ◆ Require facilities to report meaningful staffing data to HCFA on a quarterly basis with the MDS data.
- ◆ Require that nursing services be the largest cost-center for expenditures in the daily Medicare/Medicaid rate.
- ◆ Require surveyors to cite facilities that fail to provide staff needed to provide good care — whether there is a staffing standard or not.
- ◆ Require facilities to post the names of the staff on duty for each shift and the ratio of direct-care staff to residents and that HCFA post this information on its website as well.

## **NCCNHR's 25 Year History of the Need for Staffing Ratios**

Inadequate staffing is not a new problem. Staffing has been a concern for residents and their representatives for decades. While industry representatives blame the staffing crisis on current high employment rates, staffing in nursing homes has been at crisis levels in times of both high and low employment.

**1975** — (94th Congress. 1st session — Report No. 94 — *Nursing Home Care in the United States: Failure in Public Policy*; Supporting Paper No. 4, *Nurses in Nursing Homes: The Heavy Burden — The reliance on untrained and unlicensed personnel.*) “HEW is committed to establish ratios of nurses and staff per patient.” Later in the report, the following appears: “Significantly, HEW has still to issue ratios of nursing personnel to patients. A judgment of how many nurses are needed by a certain number of patients in a nursing home has been balanced against the availability of nursing personnel and, more importantly, the cost to the operator. Clearly, the intent of the amendments is that this issue be resolved in favor of the patients.” That was never done. We are presently waiting for a HCFA study on the issue. 30 years have passed.

**1975** — (94th Congress. 1st session. Report No. 94, *Ibid.*). The report refers to a quote from Reverend William T. Eggers, who as President of American Association of Homes for the Aging presented testimony in July 1969 before the Moss Subcommittee. Rev. Eggers said to the committee: “The association has consistently deplored the fact that national standards and many state standards for skilled nursing facilities have not established a number of significant ratios between patients and staffs and between supervisory staffs and nursing personnel ... Despite the acute problem in establishing these ratios, it is the Association’s contention that the solution is urgent and wholly possible.”

**1978** — NCCNHR’s first study was titled, *The Plight of the Nurse Aide in American Nursing Homes: An Obstacle to Quality Care*. One strong message of this study was that there must be enough nursing assistants to provide quality care in each facility.

**1985** — NCCNHR, with funding from HCFA, Robert Wood Johnson, AARP, and Retirement Research Foundation, produced the report entitled, *The Consumer Perspective on Quality Care: The Residents’ Point of View*. Focus groups of residents were held all across the country to find out how they defined “quality care.” What was the most important element? The need for enough nursing assistants who are well trained, kind, and well supervised.

**1987** — The Nursing Home Reform Law was passed. The staffing issue was the only element of good care that the participants in the Campaign for Quality Care — a group of about 50 national organizations representing consumers, providers, and professionals — could not agree on. Although consumer groups advocated for higher standards, the law requires only one RN on the day tour of duty, one licensed nurse around the clock, and enough staff to meet each resident’s assessed needs (a standard that is rarely enforced).

**1997 and 1999** — At two NCCNHR annual meetings, Jeanie Kayser-Jones, Ph.D., spoke of her research showing that the most important, but not the only, cause of malnutrition and dehydration in nursing homes is lack of well-trained, well-supervised staff. NCCNHR staff chose that subject specifically to help assure that the public would understand that a shortage of staff means that “Mom isn’t being fed.”

**1998** — HCFA Administrator Nancy Ann Min de Parle and an official from the Department of Labor came to the NCCNHR annual meeting. At an official “listening session,” the two department heads heard from family members, residents, and paraprofessional staff about poor working conditions, wages and benefits, and how these conditions result in poor quality care. For the first time we heard a HCFA official state in public that “ratios” could be considered — depending on the outcome of the pending HCFA staffing study.

**1999 and 2000** — In over 30 states, consumer advocates have been successful in raising the staffing issue with state legislatures, leading to important staffing reform measures in several states.

**2000** — The Abt/HCFA study of the staffing issue is being reviewed by HCFA and is due for release this summer.\* Continued public pressure will assure the report’s release and implementation of any consumer friendly recommendations.

\* This study, released in July 2000, indicated that 54 percent of nursing homes are so seriously understaffed that they are causing harm to residents.

## World Institute on Disability (WID)

510 16th St., Suite 100  
Oakland, California 94612

*Testimony presented by Simi Litvak, Senior Researcher/ Policy Analyst & Hale Zukas, Policy Analyst, WID*

*We prepared this testimony together. Hale is a Personal Assistance Services (PAS) user and a policy analyst for the World Institute on Disability (WID). Simi is a senior researcher and policy analyst at WID. We are going to discuss the impact of wage and benefit levels on the availability of personal assistants (also known as personal care attendants) in the San Francisco Bay area.*

During the past decade, the course of California's In-Home Supportive Services (IHSS) program — the largest PAS program in the country — has been affected by the overall state of the California economy. In 1991, the state was in a severe recession and was faced with a budget crisis: revenues in 1991-92 were projected to be 25 percent (\$14 billion) less than expenditures. A number of steps were taken to address this shortfall. For one thing, the counties' share of cost for a number of programs, IHSS among them, was increased. A taskforce was also established to investigate ways of delivering long-term services in a more cost-effective manner.

Among the recommendations of the long-term care taskforce was that California implement the Personal Care Option under Medicaid, which would bring hundreds of millions of new federal dollars into the IHSS program. (There had been widespread opposition previously, because it was thought that Medicaid funding could only be used for highly medicalized services provided through agencies. A 1990 WID study found, however, that Medicaid allows great latitude and that the degree of user control allowed in Medicaid-funded PAS programs varied enormously from state to state.) The result of all this was that roughly one-third of IHSS funding is federal, four-ninths is state, and two-ninths is county. (We will not go into the byzantine details of how these figures are derived.)

In the early '90s, disability and senior advocates and the Service Employees International Union (SEIU) became increasingly concerned about the deficiencies in the IHSS program — the chronic shortage of quality personal assistants (a problem which was widely thought to be exacerbated by the low wage level and lack of benefits), the lack of emergency services, and the lack of management supports to assist those who, due to their cognitive, emotional, or dementia-related disability or simple inexperience, need assistance in managing their PAS.

SEIU was interested in improving wages and obtaining benefits through collective bargaining, but because of a deliberate vagueness over who was the employer of IHSS workers, there was no entity with which to bargain. SEIU hit upon the idea of county-level public authorities, which would be the employer for bargaining purposes. At the same time, these public authorities would be a vehicle for providing management assistance and training to consumers and basic independent living philosophy training to new individual providers.

Public authorities have been established in several Bay Area counties over the last several years. With one or two exceptions, though, progress in raising wages has been very limited. One probable reason for this slow progress is that the state refused, until very recently, to pay its proportionate share of any increases above minimum wage (\$5.75 in California). This meant that any county that increased wages had to pay the entire non-federal share (about 65 percent) of the cost of the increase, rather than the 22 percent it would have had to pay if the state had kicked in its share.

In San Francisco, which is one of the strongest union towns in the country and where there have been significant budget surpluses in recent years, workers' wages have been increased sharply to \$9 an hour, and medical and dental coverage have been added. There is now no shortage of workers in San Francisco. However, there is a *downside* to San Francisco's achievement. San Francisco is now attracting attendants from nearby counties, making the already critical shortage in those counties even worse.

For example, in Alameda County, where we live, just a 15-minute drive across the bay, wages have been only \$6.25 an hour with no benefits. Very few people can afford to work for such a low wage, particularly given the outrageously high rents in the area. The shortage of attendants is so severe that the Berkeley PAS emergency service, which is meant to serve people who are in a bind when an attendant on occasion does not show up, is badly overloaded. People are overusing the emergency service because they can't get regular attendants.

Meanwhile, just as the recession of the early '90s produced the largest budget deficit in the state's history, the economic boom in the late '90s produced the largest projected surplus in history — \$13 billion — for FY 2000-2001. This prospective surplus no doubt played a large part in loosening the state's purse strings during budget deliberations this spring. For the first time, the state agreed to pay its share of wage increases (only in counties with public authorities, though) of up to \$1.75 above minimum wage. Soon after, SEIU and Alameda County, which had been negotiating a new contract for several months, reached agreement to raise worker wages to \$7.82/hour, effective August 1, 2000. It is of course too early to tell how this increase will affect the supply of attendants in Alameda County.

Federal policymakers could improve this situation in several ways:

- 1) Develop incentives in federal policy that encourage states to increase personal assistant wages and benefits.
- 2) Allow spouses and parents of minor children to be paid providers. This would increase the pool of personal assistants.
- 3) Require states to provide the full spectrum of services, including housing modifications and assistive technology, required to allow people to live in their homes, often with less need for personal assistance.
- 4) Modify Medicaid legislation and regulations to correct Medicaid's bias favoring nursing homes over in-home services.
- 5) Allow PAS users on Medicare who are over 65 years old to "buy in" to Medicaid.
- 6) Improve working conditions by providing money to states for training of personal assistants and PAS consumers to help them function more comfortably in a consumer-driven, individual provider system.

## National Network of Career Nursing Assistants (NNCNA)

3577 Easton Road  
Norton, OH 44203

*Testimony presented by Genevieve Gipson, Director of NNCNA*

*The following comments are drawn from the perceptions and recommendations of nursing assistants from many organizations, facilities, and agencies across the country.*

Nursing assistants and other frontline workers provide as much as 90 percent of the direct care in nursing homes, home care, and other long-term care settings. It follows that the quality of care actually received by the resident or client is highly dependent on the skills, perceptions, values, and decision-making abilities of the nursing assistants. Yet little is known about this important worker, and few resources are directed toward developing competencies that are needed to perform daily tasks of care.

Also, we know little about how the nursing assistant learns to adapt classroom learning to the individual needs of clients, or how she/he actually recognizes and responds to situations and individual needs. In addition, no national standards exist to determine the presence or absence of necessary skills, and no measures exist for determining what is adequate, inadequate, or outstanding performance for either the nursing assistant or the trainer who provides classroom and clinical instruction. Further, we don't know the extent to which either makes decisions based on formal preparation or common fallacies or perceptions.

A critical question being asked today is, "How can I get adequate care for Mom?" The population served by long-term care is growing older and increasing in numbers, and the demand for capable competent frontline workers is increasing in response to this shift. Care is becoming more complex and requires a greater level of skill by daily care providers. Frontline workers are the largest investment that the health care system will make. The reality is that a facility or agency must be able to prepare workers to provide not only the very basic services, but also services for those with increasingly acute and complex care needs. This requires skills beyond those learned in basic, entry-level training.

Official recognition of the importance of nurse assistants came in the passage of the Omnibus Budget Reconciliation Act of 1987. This legislation mandated that nurse assistants complete 75 hours of prescribed training. This legislation focused only on entry-level training and ignored the necessity of continued career growth or development of competencies. The legislation required only 12 hours of in-service training per year.

The lack of adequate training was clearly demonstrated in a recent study in Ohio that showed that tasks ranked highest by nursing assistants in "frequency, importance, and difficulty" were also ranked as "learned on my own." These issues affect not only the quality of care received by the client or resident but also the morale, well-being, and retention of the worker.

In order to provide adequate training the following factors must be addressed:

### **1) Preparation of the teaching team**

The people who are most likely to influence the new nursing assistants are the trainer, the mentor nursing assistants, and the supervisor. They need training on how to support nursing assistants on the job and how to help them become proficient in the tasks of care.

- ◆ Each member of the teaching team needs to meet a specified level of competency in areas such as: teaching methods for adult learners, methods of evaluation, fostering teamwork, and energizing trainees.
- ◆ Clinical trainers must be prepared with skills that will enable him/her to teach the nursing assistants how to apply and adapt basic information to a myriad of different care situations.
- ◆ The new trainer needs a mentor, a period of internship as a trainer, and periodic competency evaluations.

- ◆ The nursing assistant who serves as mentor needs to know the content that was taught in class. Prior to working with a new nursing assistant, the mentor nursing assistant must receive a teaching plan that clearly outlines the competencies to be developed, methods to be used, how these skills are to be evaluated, and what to do if the new trainee is unable to reach the anticipated level of competency.
- ◆ Nursing assistants who mentor should be released from other duties to allow time for mentoring.

## **2) Development of curriculum content**

- ◆ All nursing assistants must be able to read and write at a minimum level with a provision for remediation for those who are unable or need refreshers.
- ◆ Basic preparation needs to include at least 160 hours of preparation in the tasks that nursing assistants will actually be expected to perform. A minimum of 80 hours should be allocated to guided and specified clinical practice.
- ◆ Curriculum content needs to reflect the current priorities for assuring adequate fluid intake, prevention of abuse and neglect, and preventing falls.
- ◆ Nursing assistants make many minute-to-minute choices about care practices. Nursing assistants need to understand how these choices affect the care given, the client or resident, and the caregivers.

## **3) Development of a formal learning period between classroom and state testing**

- ◆ An additional two-month internship is recommended during which time the assignments would become increasingly complex as the trainee gains confidence and experience.
- ◆ This period should provide time for orientation to the practical aspects of the job, mental preparation for what is involved in compassionate caregiving, information about how the unit and the facility operates as well as the care-planning process, and an introduction to each resident.

## **4) Opportunities for competency development and career growth**

- ◆ Entry, on-going, and advanced competency must be well researched and clearly defined.
- ◆ Standards of Practice should be created to guide nursing assistants in their chosen profession as caregivers.
- ◆ Legitimate career ladders should be developed based on Standards of Practice and a hierarchy of skills actually performed by nursing assistants.
- ◆ Pay scales should be based on demonstrated levels of competency.
- ◆ Facilities should have a skill lab to allow nursing assistants to refresh their knowledge of skills.
- ◆ Competency testing and remediation should be provided for all new hires.

## **Virginia Association of Professional Nurse Assistants (VAPNA)**

5114 Huntington Ave., Suite 2

Newport News, VA 23607

*Testimony presented by Lorrene Maynard, President of VAPNA and member of the  
National Network of Career Nursing Assistants*

As a certified nurse assistant for 20 years, I have worked consistently, without a blemish on my record, but I have not received benefit for my work. Mostly my career is in home health, simply because I find it impossible to serve more than five patients in an eight-hour shift. In the few long-term care facilities where I have worked, I was asked to work with at least ten patients, and with all the extra things that needed to be done, at the end of the shift, I felt like I just saw faces, without really having any kind of interaction with those faces.

My motivation in nursing all these years has derived from the Ten Commandments, *Do unto others as you would have them do unto you*. The seniors of today have put their blood, sweat, and tears into this country and deserve to have kindness as well as competence at their bedside of longevity. There is a lot to be learned from these elders, if only we had time to listen.

The old school that I received my training from taught me to listen and observe because I am the eyes and ears of the doctor and the nurse. I spend more time with the patients than any other health care worker. Should that time be in vain, should it be just for a paycheck, or should the elders be my primary concern?

As founder of my own organization, the Virginia Association of Professional Nurse Assistants, and a member of the National Network of Career Nurse Assistants and the Direct Care Alliance, I hear of all kinds of experiences from nurse assistants, but one stands foremost in my mind, and I would like to share it with you because it can happen to any of us, but it has happened to a colleague.

“April”\* lost her youngest son due to a fire that was sparked from an oil lamp that she left burning in her apartment, because she had no electricity. She could not afford to pay her overdue utility bill with the salary she was earning as a nurse assistant. When asked what she was thinking, she replied that she worked night shift simply because her facility offered a night differential, and she need the extra income to care for her three children. She also felt compelled to work these hours because she did not want her unit to be short staffed.

NBC “Nightly News” reported that businesses are beginning to look at more time off for their employees, to prevent worker burnout. I only wish that the health care industry would follow the example of those companies that seem to care about their workers and their performance. We work for poverty wages, we have no health benefits, and we enjoy no paid vacations. Almost every day we work short-staffed, or we are forced to endure the pain of leaving our patients/clients with their essential needs unmet.

It is no wonder that the most committed and experienced direct-care workers — people like myself, who have devoted years to their clients/patients in this profession — are now leaving the long-term care industry in droves. This is a tragedy. I hope you will help us address these important issues.

\* The CNA's name has been changed to protect her privacy.

## **Lakewood Health and Rehabilitation Center**

2115 East Woodstock Place  
Milwaukee, Wisconsin 53202

*Testimony presented by Tom Zwicker, Owner of Lakewood Health and Rehabilitation Center*

Today, I had a certified nursing assistant look me in the face and ask me this question: “Tell me, Mr. Zwicker, could you live on my wages?” I considered her question for a moment, looked her straight in the eyes, and said, “Frankly I could not.” That is why I am here today.

I am thankful for the opportunity of holding this briefing to educate congressional staff about the critical issues facing our nation’s direct-care workforce and the clients they serve.

I am Tom Zwicker, a licensed nursing home administrator and owner of Lakewood Health and Rehabilitation Center in Milwaukee, Wisconsin. I have been a licensed administrator since 1977 and have personally overseen or directed well in excess of 100 different nursing homes. Importantly, I started my career as a nursing assistant while I earned my college degree in the mid 1970s. These experiences, as a nursing assistant to nursing home administrator, represent the basis for my comments as well as my membership in the Direct Care Alliance.

In 1998, Lakewood, a 246-bed Title 18 Medicare and Title 19 Medicaid nursing home joined the Eden Alternative Reform Movement. In that same year, Lakewood was invited to join the Pioneer Nursing Home Movement, which was formed by the National Citizens’ Coalition for Nursing Home Reform in response to the need to identify those pioneering organizations that, as we often say, were “getting it right.” Since that time, Lakewood has shared its experience with many new members in the Eden Alternative as well as the Pioneer Nursing Home Movement. Recently, the Center of Health Systems Research and Analysis at the University of Wisconsin recognized Lakewood as a best practice nursing home.

More significantly, in 1998, I admitted my father and mother to Lakewood and, in doing so, started the long and painful process of understanding the significant problems in nursing homes from the perspective of a family member. I honor my father by offering testimony today as to the breakdown in the nursing home industry and, most specifically, the challenges of the direct-care workers.

As I previously stated, I have been involved in the nursing home industry for 20-plus years. I want to state with certainty that the shortage of direct-care workers currently experienced in today’s marketplace is the most significant in my lifetime.

Since the start of the new millennium, some four months ago, Lakewood has recruited 54 CNAs or, as we call them, CEOs (Chief Elder Organizers). Lakewood has a long-established history of high retention in comparison to other nursing home providers, but these historical levels have been dramatically altered in the last four months. With reference to the 54 CEOs, I am saddened to say that only 31 percent remain in employment at Lakewood. To say that these are devastating numbers is an understatement. The continuation of this pattern will ruin Lakewood as a reformed nursing home for the mere inability to form meaningful and high-performing teams. It is an important distinction to note that a nursing home, as it relates to the care provided our loved ones, is a labor intensive and team-performance organization.

This is a national crisis that can only be solved by rethinking the models used in developing elder living environments. What were we thinking some 30 to 40 years ago when we created the long-term health care system under the assumption that nonskilled workers (certified nursing assistants) could provide inexpensive health care services under the direction of a few registered nurses? This concept of leveraging the skills and abilities of nurses has contributed to our nursing home crisis. The truth of the matter is our direct-care workers render the majority of hands-on services while the nurses handle planning, assessment, and paperwork.

We view nursing homes as step-down hospitals. What people really need are highly functioning and highly skilled teams of people. For example, I am a Green Bay Packer fan. I understand that this game is not about

the Green Bay Packer organization but instead a game about the players playing for the Green Bay Packers. The distinction here is that we confuse the nursing home industry with the people who are actually providing the care and services to our loved ones. We seem to understand in sports that it is players that make the game, but we fail to have a similar understanding with regard to nursing homes. It is this distinction that has led me to join forces with the Direct Care Alliance and to develop common ground between workers, concerned providers, and consumers.

What I propose needs more than money. It needs a rethinking of the importance and the complexity involved in caring for our loved ones, particularly as they age and lose their mobility or mental cognizance. What is needed is research that centers on the people actually offering the care not on what others might want to evaluate with regard to clinical aging issues. What is needed is the understanding that quality of care is not a result of enhanced scientific methods but the result of coordinated efforts on the part of a dynamic team of caregivers. Please consider this paradigm shift, and direct the various administrative agencies (Labor, Health, and Commerce) to work in collaboration in providing our direct caregivers with better training, wages, and staffing.

Thank you for your time and consideration of this important matter. We must all (workers, concerned providers, and consumers) work together to answer the direct caregiver's question, "Could you live on my wage?"

## Cooperative Home Care Associates (CHCA)\*

349 East 149th St.  
Bronx, New York 10451

*Testimony presented by Rick Surpin, President of CHCA and Chair-elect of the Board of Directors of the Home Care Association of New York State*

### **The home health care industry is facing strong competition for our workforce from other occupational sectors, in health care and outside, where:**

- ◆ Wages and benefits are often better.
- ◆ There are more opportunities for stable, full-time employment.
- ◆ Working conditions are better – e.g., there is typically one workplace.
- ◆ Opportunities for advancement are increasingly available.

*The competition is due to both:*

- 1) The full employment economy; and
- 2) Demographics – there is no longer an endless supply of workers and there is an increasing number of elderly and people living with disabilities.

At the recent Annual Summit of the Home Care Association of New York State, workforce issues dominated the agenda, overshadowing the new Prospective Payment System. This was not conceivable when planning for the event began nine months ago.

The impact of the competition differs by region in the state, although the more suburban and rural the area, the worse the shortage.

- ◆ Some regions have as many as 20 percent of their patients being denied care due to worker shortages.
- ◆ Other regions are forced to triage on weekends and holidays.
- ◆ Most regions have very small training classes for new workers.

States, including New York, are increasingly looking, at wage pass-through legislation but its value will be diluted in agencies that are blending Medicaid *and* Medicare funds, since Medicare will not do pass-throughs.

Employment and welfare policy have moved away from supporting home care aides as an occupation. The Job Training Partnership Act typically stipulated wage levels at placement that were too high for the industry; TANF's emphasis on "work first" means that recipients often no longer can train as a home care aides even though training is short-term and leads to immediate placement on a job.

### **If We Had the Money What Could We Do?**

- ◆ Re-structure jobs to compete with other sectors
- ◆ Wages – parity with other health care paraprofessionals; \$10 – \$15 an hour is a family wage
- ◆ Benefits – especially health insurance
- ◆ Full-time work
- ◆ Opportunities for advancement
- ◆ Support Services
- ◆ Transportation
- ◆ Child Care

This is what we do with professional positions like nurses; we must now do the same for paraprofessionals.

\* CHCA is a worker-owned home care agency in the South Bronx, employing over 600 home health aides.

### **We Won't Have the Money Until We:**

- 1) Recognize that this is an emerging crisis – and one that is not easily addressed.
- 2) Recognize that current health, job training, and public assistance policy work at cross-purposes today or bypass the problem entirely and that state and federal policy often do not intersect. We must figure out how to get everybody aligned.
- 3) Recognize that this is a long-term issue that will only get worse over time. We need to build consensus, as we answer these questions:
  - ◆ *What is our personal/family responsibility?*
  - ◆ *What should public resources provide?*
  - ◆ *How do we make best use of each?*
  - ◆ *How do we invest appropriately in the paraprofessional home care workforce to ensure its competitiveness with other sectors and its ability to do its job under changing conditions?*



**Our Mission:** To improve the quality of care for consumers through the creation of higher quality jobs and working conditions for “direct-care” paraprofessional workers. The DCA promotes recognition that direct-care paraprofessionals are the foundation of good care, particularly for long-term care clients.

**Our Purpose:** Consumers, workers, and concerned providers — who have often held divergent viewpoints — have joined together to ensure a stable, valued, and well-trained workforce to meet the urgent demand for high-quality paraprofessional caregiver services. Our coalition believes that every American is a stakeholder in ensuring that older adults and people with disabilities have access to high-quality paraprofessional care.

Through advocacy, education, and public awareness, the DCA works to achieve fundamental change in direct-care industry practice as well as in both legislative and regulatory policy.

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