

Working Paper

***Supporting Caring Caregivers:
Policy and Practice Initiatives in Long Term Care***

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Introduction

This working paper was produced from the transcript of a spring 2002 MIT Workplace Center seminar given by Susan C. Eaton and Barbara Frank on April 11, 2002. Barbara Frank and Susan Eaton study policy and practice and the links between the two.

Susan Eaton is an Assistant Professor of public policy at the Kennedy School of Government of Harvard University. She teaches human resource management and healthcare management to master's students and also teaches in their executive program. Her research interests and her publications span work organization and redesign, particularly in healthcare, relating them to quality of care issues. She has a special interest in recruitment and retention of front line caregivers. Before becoming a scholar and a teacher, Susan worked for twelve years as a union negotiator, trainer, and top-level manager for the Service Employees International Union (SEIU). She holds a PhD in management from the Sloan School at MIT and an MPA from the Kennedy School at Harvard.

Barbara Frank is the Massachusetts policy director for the Paraprofessional Healthcare Institute (PHI). PHI is a national advocacy organization that works for the creation of quality jobs for low-income individuals within the health care system and the provision of high-quality long-term care. PHI has been involved in a number of activities in Massachusetts: a Direct Care Workers Initiative, which is a policy initiative, and many employer-based activities including the Extended Care Career Ladder Initiative, which is the subject of this working paper. Barbara has worked on national and state health policy. For sixteen years she directed policy and program work for the National Citizens Coalition for Nursing Home Reform and then she served for four years as Connecticut State's Long Term Care Ombudsperson. Barbara has an MPA from the Kennedy School of Government.

An MIT Workplace Center working paper¹ reports on 40 interviews in the healthcare sector in Massachusetts and identifies five key problems. Frank and Eaton focus in the long term care industry on the very problems identified in that working

¹ "Workforce Issue in the Greater Boston Health Care Industry: Implications for Work and Family." Mona Harrington, Ann Bookman, Lotte Bailyn, and Thomas A. Kochan, November 2001.

paper: poor quality jobs including short staffing, inflexible schedules and difficult working conditions, the implications of financial problems in the healthcare sector on workers and patients, and emerging opportunities to reorganize care giving and workplace practices.

Defining the Problem: A Crisis in Care Giving: Barbara Frank

Direct care workers provide hands on care to elders and people with disabilities who live in nursing homes or in their own homes. They are certified nursing assistants in nursing homes, home health aides,

personal care attendants, or homemakers who are providing services to people at

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home. In order to give quality care to people receiving long term care services, we need to provide support to those who give the services. Many direct care workers need two or three jobs to make ends meet, don't have health insurance coverage for their family, lack adequate training to get started in the job, and face workloads and understaffing that force them to rush through caregiving tasks. All these circumstances have a direct effect on workers' ability to provide good care.

The care giving relationship between people who receive care and those who give it frames the work of the Paraprofessional Healthcare Institute. Anyone who has had personal experience needing services knows that it is this caring relationship that makes all the difference. We have lots of clinical indicators to measure quality, but the warm human touch and the caring that occurs at the human level is what is at the heart of quality care for people. Many aides work in nursing homes where their assignments vary from day to day, and they aren't able to develop personal relationships with the people they're caring for. That means that every day frail older persons must introduce themselves anew to a caregiver and, if they can, explain how they need to be helped, cared for, and assisted to be moved about. This is an overwhelming burden for someone receiving care.

Many people choose to work in long term care despite the poor quality of these jobs because they want to care for others – it is what is in their hearts. But when they see their co-workers leave, and they then face increasingly unmanageable assignments that

don't allow them the time for caring, their jobs become very difficult. Under these conditions, they have no time for the tender loving caring – what they came to this work to do. As the jobs get worse, more staff leave and this creates a downward spiral.

In addition to not having time for caring, the caregivers often aren't respected for what they bring to their work, what they know and what they do. This makes work even harder, and their morale that much lower. The following is an excerpt from *Heartwork*, a 40 minute video that gives voice to the experiences of direct care workers, in their own words. The video is a play that six home health aides in Philadelphia put together to capture their life and work experience. They performed this play in six locations, including at the State House in Boston.²

² *Heartwork* is available from Paraprofessional Healthcare Institute (781) 402-7766 or www.paraprofessional.org.

Just an Aide

“Hey Mom, the girl’s here, you know the maid.”

“You’re just a glorified house keeper.”

“I want you to remember one thing -- I’m the nurse – you’re just an aide!”

“You’re just an aide” “You’re just an aide” “You’re just an aide”

These hands, they feed and dress my clients.

These hands position my clients so they don’t get skin sores.

These hands do their care shaving and fixing hair.

These hands transfer my client from bed to chair and from chair to bed.

These hands wash tons of laundry, scrub many floors.

These hands get tired with age and you say, *“I’m just an aide”*?

These hands have wiped away tears, have comforted loved ones.

These hands have held the hands of patients who were dying and you say, *“I’m just an aide”*?

These hands are my client’s hands. They do what she can’t do. Scratch, if she gets an itch, brush her teeth, prepare her food, wash her floors, and become her TV remote. These hands are my client’s hands, and you say, *“I’m just an aide”*?

These feet have done a lot of walking to get to my clients.

These feet stop patients from falling down stairs with their walker.

These feet have walked to the grocery store.

These feet have carried laundry baskets of clothes to the laundromat.

These feet have danced to make my patients laugh!

These feet have peddled my bike when the buses were on strike, walked through many snowstorms when no one else can get there but me.

These feet are sometimes so tired; they can’t wait to get home. It feels like rocks and needles are in them, but these feet keep on because I’m just an aide.

This heart is a caring heart; you have to care to be an aide.

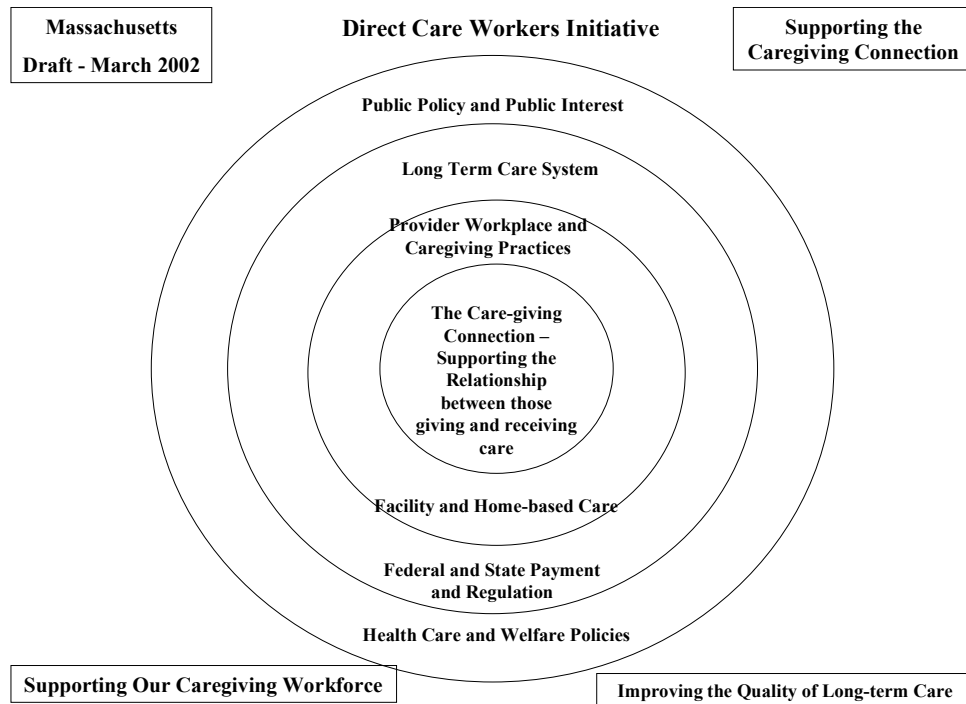
This heart becomes attached to many patients even though they tell us not to, but this heart bleeds when I see anyone mistreated or abused. It hurts me when people don’t appreciate what we aides do, but this heart is big enough to feel love even for those who put us down.

These are the hands of an aide!
These are the feet of an aide!
This is a heart of an aide!

We are so much more than just aides.
We are the heart of homecare.
We are the heart of homecare!

With this in mind, what can we do about the workplace environment to support that caregiving relationship? What kinds of workplace practices support the caregiving connection? (See Figure 1)

Figure 1



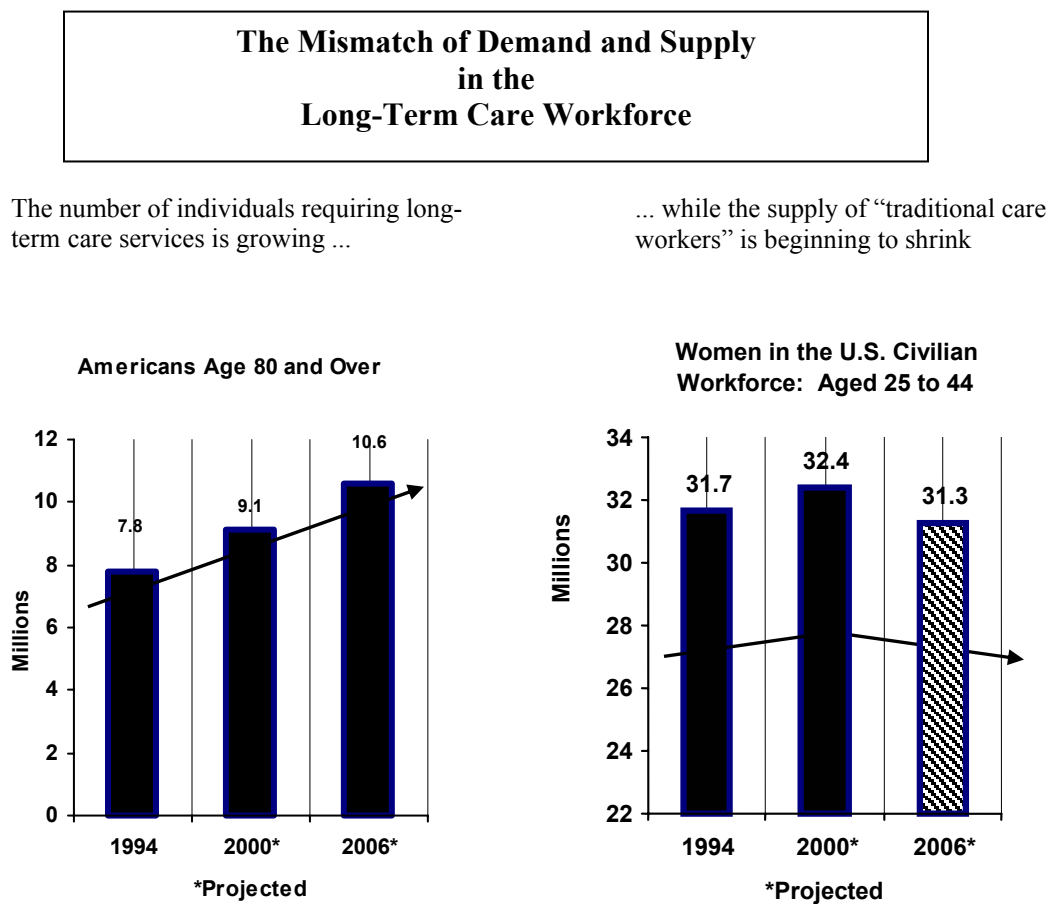
In Massachusetts, the Direct Care Workers Initiative (DCWI) is a coalition of consumer advocacy organizations, labor unions, and health care provider trade associations – groups that have been at odds with each other in the past. What these groups have in common, despite different perspectives, is needing to provide an environment that supports caregiving workers.

The DCWI has worked to improve job quality in order to support people who work as caregivers. We work to improve both the very tangible ways of being valued – wages, benefits, and workloads – and the intangible ways of being valued in the workplace environment – being supported, listened to, brought into the decision-making process, and invested in.

For a number of years, pre-September 11th, Massachusetts and the rest of the country had been experiencing a dramatic labor shortage in long-term care. Massachusetts had a 2.5 percent unemployment rate. In that tight labor market, workers had a lot of choices about employment. Many opportunities existed for work besides

long-term care, such as in the food services or hotel services industries. Even if these other options weren't necessarily people's first choice, if they paid better, offered better benefits, or were less stressful than long term care, people were drawn to alternate work that allowed them to provide better for their families. Vacancy rates in long term care jobs were up to 15-20 percent in Massachusetts because long-term care employers could not compete with other employment sectors. Now we are in a temporary reprieve since the economy has taken a shift. In fact, some people laid off from the airline, food service, and hotel industries have come to long-term care. When the economy turns around and people have other options again, the key question will be whether the long-term care sector can keep these workers.

Figure 2



We also need to look at the kind of pressures that are going to be on our long-term care system in the future. (See Figure 2) The population of elders in our country is dramatically increasing. We expect a doubling in the number of elders in the next 20-25 years, meaning an increase in the need for long-term care services. Despite the increasing need, we expect a shrinking of the population that normally provides this work. The population of women aged 25-55 will decrease over that same period of time. This will lead to a decrease in the supply of workers. The decrease would have been more significant had it not been for the increase in immigrant workers in Massachusetts. Given the decrease in the supply of labor, the long-term care system will need to take action to ensure that it has a workforce to meet the impending increases in demand – (1) improve job quality in order to compete in the labor market, and (2) improve job supports in order to support immigrant workers coming into caregiving.

Policy and Practice Initiatives: Susan C. Eaton

Forty-eight states have activities underway to address the shortages of healthcare workers, paraprofessional workers, and nurses. A number of activities are also being considered at the national level. A variety of approaches to the problems of recruitment and retention are arising because even with the poorer economy making recruitment less of a problem, keeping people is still a big issue. The average turnover rate in this industry for aides is 100 percent per year. For licensed practical nurses it is 50 percent and for registered nurses and directors of nursing it hovers between 40 and 50 percent. The national average for all jobs is approximately 17 percent.

One initiative that has been tried in several states is wage pass-throughs, but these can be problematic. (See case example, next page.) A wage pass through is typically supposed to go to frontline workers, but for many reasons, including administrative issues at the facilities, it doesn't always happen. In Michigan, however, there was a study with baseline data and a follow-up study five years later that showed that wage pass-throughs of approximately five percent did reduce the turnover rate somewhat.

Case Example

A Wage Pass-Through in Massachusetts: Barbara Frank

A coalition of groups called the Coalition of Organizations to Reform Eldercare (CORE) campaigned for a raise for every certified nursing assistant in Massachusetts. The legislature allocated \$35 million in FY01 and continued funding to maintain the increase in subsequent years. The formula for distribution of the funds was complex and the state issued three sets of regulations governing its use and the audit process. Despite complications in trying to implement the raise, we saw, on average, an 8.7 percent increase in CNA wages. By the second year of implementation, compliance rates were up to 98% -- facilities were getting the money to their workers. For the first time in years, the vacancy rate in CNA positions has dropped, largely because of the wage increase and other measures that made up the Nursing Home Quality Initiative³, including free entry level training for those entering caregiving, and workplace educational opportunities for ESoL, basic educational needs, and skills courses to support career advancement.

Although the increase was significant, the gap between what people need and what they get is so great that a one year wage increase of 80 cents isn't going to make enough of a difference over the long term. Many years of under funding have made the gap bigger and bigger. This increase helped stabilize vacancy rates in the short term, but we need to continue to increase wages if we hope to keep nursing home jobs competitive for the long term.

Increased staffing ratios (of nursing staff to patients or standards of minimum nursing hours) have passed in a few states, California being one, but these have also been problematic so far. It is not clear that they are being enforced, or that they are high enough, nor is it clear that a staffing ratio itself is the answer to the problem. There is, however, good solid research that says that a basic level of staff is needed in order to be

³ Mark Montigny, Chair of the Senate Ways and Means Committee, designed the Nursing Home Quality Initiative to address the staffing crisis on a broad scale. The initiative was first introduced in the FY 01 Budget, and maintained in FY 02 and FY 03. It provided funds for a wage pass-through, the Extended Care Career Ladders Initiative, and the Direct Care Workers Scholarship Fund.

able to do adequate care giving. This research was funded by the U.S. Centers for Medicaid Services and can be found on its website (www.hhs.cms.gov). A dramatic decline in resident health occurs below that basic level, which is about 2.9 hours of nursing aide care per patient day or 4.2 hours of total nursing care per patient day. Nine out of ten nursing homes in the U.S. currently do not have that basic adequate level of staff.

DCWI and CORE tried to get an increase in staffing ratios here in Massachusetts and instead won a commission to look at what staffing ratios should be. The cost to require more people working creates a struggle because it means paying for more hours of service. There has been a very effective grass roots coalition that has been fighting very hard through a group called CORE –Coalition of Organizations to Reform Eldercare – to be able to increase staffing levels in nursing homes.

The Direct Care Workers Initiative (DCWI) is about to embark on a series of conversations around the state with direct care workers, their employers, and with the consumers of long term care services to find out how to construct a policy initiative that would provide greater

One in four direct care workers in nursing homes and home care settings doesn't have health insurance.

access to health insurance coverage for our caregivers. One in four direct care workers in nursing homes and home care settings doesn't have health insurance.⁴ Even though most employers offer health insurance, many workers are either ineligible or can't afford it under the conditions with which it is offered.

A practice initiative that the Bush Administration put out for public comment in May 2002 is the use of single task workers. Single task workers don't require any training, would be hired for tasks like helping to feed people at mealtime, and could be paid even less than certified nursing assistants. Certified nursing assistants are now required to have at least 75 hours of training. As a comparison, your hairdresser probably has to have 1,400 hours of training!

⁴ Marcia Hams, et al. Health Insurance Access Survey of Direct Care Workers in Nursing Homes and Home-Based Care Agencies in Boston, New Bedford/Fall River, including surveys of employees and employers. Spring 2002. Direct Care Workers Initiative and Paraprofessional Healthcare Institute.

Another Bush Administration initiative is promoting volunteers at nursing homes. Quite a lot of people volunteer in nursing homes already, and their support is invaluable, but volunteers are not a reliable major source of labor.

The Department of Health and Human Services (DHHS) recently responded to the Phase 2 staffing study with an initiative saying that consumers should have more information about nursing homes. Six states are taking part in a pilot project where additional information will be available to people about the quality of the care, the deficiencies surveys found on annual inspections, and the kind of clients or residents that are in the facilities. One problem with this is that nursing home beds are 85-90 percent filled, so having more information doesn't necessarily allow you to make a better choice. It is also very hard for people to move once they are in a facility. In addition, very often the nursing home is chosen by the hospital social worker and nine out of ten facilities do not have enough staff to guarantee good care. It is not clear how more market information on their deficiencies will help solve these basic problems.

Extended Care Career Ladder Initiative: Susan C. Eaton

The hardest thing to achieve through policy initiatives is to restructure work place dynamics and create career ladders – something Barbara Frank's organization is trying to do. Restructuring work involves changing the culture of the work place, allowing people to have more control to respond to individualized needs of residents, thus allowing them to give real care. One way to conceptualize this is to use a typology like that in Table 1.

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Table 1 *A Typology of Nursing Home Work and Care Organisation for Nurse Aides* ⁵

	<i>Traditional*</i>	<i>Semi-skilled semi-autonomous*</i>	
	Low Service Quality medical-custodial	High Service Quality medical-rehabilitative	"Regenerative community"
	<i>1.</i>	<i>2.</i>	<i>3.</i>
Work Patterns	Rigid, traditional	Teams	Neighborhood units
Worker Input into Service, Delivery and Quality	Individual only Not welcome; actively discouraged	Flexible, adaptive Welcomed and solicited in systemic way	Resident assts. Built into Not work structure in "neighbourhoods"
Information Shared	Little to none	Most	Virtually all
Industrial engineering or time and motion studies	No, staff at legal minimum	No, but can complete work	No, but staff responsible for complete patient
Supervision and Control formal procedure	For tasks only; Compliance w/	For outcomes; help to do job	Coordination; resident choice
Assumptions re: Workers	Theory X	Theory Y	Community members
Staffing ratio: day Nas	Ten + residents	Seven to nine	Five to seven
Wages, avg. NA	\$5.50+	\$7.00+	\$6.50 +
Turnover, annual	More than 80%	30-80 %	20 to 40%
Career paths for Nas	Little or none	Senior NA; Scholarships	Cross-training evolving
Ownership or Reimbursement	"Medicaid mills," for profit chain, 'mom & pop'	Non profit; special chain high-end for profit	Non-profit, religious, or high-private profit
Labour Relations	Mostly non union	The most unionized	Mixed
Cost Structure	Low to average	Average to high	Average to high
Philosophy of Care	Medical-custodial	Medical-rehabilitative	"Regenerative"

This typology distinguishes custodial care, which is found in the majority of long term care facilities, from medical-nursing care, from regenerative communities of care.

See the following case example.

* Note: See Herzenberg *et al.* 1998 for further explication of these categories in other settings; they were jointly developed as regards nursing homes in preparing this analysis for an Office of Technology Assessment (OTA) (Eaton 1995).

⁵ Susan C. Eaton, "Beyond 'Unloving Care:' Linking Human Resource Management and Patient Care Quality in Nursing Homes" International Journal of Human Resource Management, June 2000.

Case Example

Changing the Culture of the Workplace: Barbara Frank

The Pioneer Network is an organization that works to change the culture of caregiving through the transformation of traditional institutions and practices into communities in which each person's capacities and individuality are affirmed and developed. Culture change transforms demoralized, dispirited staff into productive teams and dispirited, isolated elders into active members of engaged communities.

Sue Misiorski, a registered nurse on staff at PHI, is the President of the Pioneer Network. She has been working on culture change in nursing homes for years. Culture, in this context, involves core values: how time and space are organized; how relationships are nurtured or not; what language people use; how care is provided; and the ways that we celebrate and grieve. Misiorski works to transform nursing homes into places where people are proud to work, where there are communities of caring grounded in positive relationships, and the potential of each employee and resident is respected. The real challenge of this vision is how do we get from what exists now, to this ideal. To accomplish this, caring relationships need to exist at all levels -- between staff and residents; between staff and supervisors; between certified nursing assistants and nurses. The possibility for and the reality of caring needs to be built into every level of these relationships.

In the traditional nursing home culture, tasks drive care; for instance, an aide is told to give a bath, or feed a person. It is command and control -- go do this -- go do that -- pick up the pace -- answer that bell. It is depersonalizing for residents and for workers. The notion of offering support to employees, as they struggle with on-the-job and off-the-job challenges, is new to most nursing homes. Instead, it is typical to see strained relationships in a task-focused culture.

In the caring culture, assignments and systems are organized to support individualized care for residents and a more humane work environment for staff. Workplace and caregiving practices are guided by questions like, how can CNAs work with residents to help them feel at home, encourage them to have a good meal, get a good rest, engage in life? How can supervisors coach workers, support their development, and engage in a participatory approach to designing and delivering care? Management

figures out how to match staff and residents to ensure good caregiving relationships. This builds on the natural affinities between people and has a big impact on the workplace culture. The key is to support relationships – between residents and their caregivers, between caregiving staff and their supervisors.

The Extended Care Career Ladder Initiative (ECCLI) is developing career advancement opportunities and supports for direct care workers. I am a member of a university-based team that is evaluating ECCLI for its funding agency, the Commonwealth Corporation, which is a quasi-public workforce development group that gives out training contracts, in this case, to a variety of nursing homes. Fifty long-term care and three home healthcare facilities are involved in this initiative. Approximately 1,500 people work in the nursing homes involved in ECCLI and about 350 have been directly touched by this program since 2001. ECCLI's mission is to improve quality care and quality of jobs by bringing workforce development initiatives into long-term care. It involves basic training classes and in some cases, organizational and work process change that leads to quality improvement. The work design changes result both in better outcomes for workers and for the work itself. The initiative is beginning with developing career ladders and will move to care practice changes. The leaders of ECCLI are trying to make long term care a job that has a future. They are also looking at specialty training in Alzheimer's care or rehabilitative care so that workers not only improve their own skills, but can improve their caregiving in ways that will improve quality care.⁶

ECCLI's mission is to improve quality care by bringing workforce development into long-term care.

The following are the components of ECCLI.

- **Career Ladders and Cross Training**

Through ECCLI, career ladders are developing to provide career steps into specialty areas for current CNAs. Cross training can occur, for instance between home health and certified nursing assistant work, which can help individual workers get enough hours to make a decent living. This means a home health aide could get certified as a nursing assistant and she could fill in her hours at a nursing home if she doesn't have enough hours in her home health job. These jobs are quite different – a nursing home compared to caring for someone in their home – and cross training gives people the

⁶ Eaton, Susan C., Amara Kamanu and Randall Wilson. 2002. Extended Care Career Ladder Initiative (ECCLI) Round 2: Evaluation Report. Kennedy School of Government Working Paper #RWP03-006. URL: <http://ksgnotes1.harvard.edu/research/wpaper.nsf/RWP/RWP03-006>

chance to see what each environment has to offer. Kitchen, laundry room, and housekeeping staff are receiving English for Speakers of Other Languages (ESoL) and pre-certification classes to prepare them to be able to train for CNA jobs.

- **Labor Movement Involvement**

ECCLI has also involved the labor movement. Currently five of the 50 facilities participating in ECCLI are organized by unions and one project is led by a union-organized education project team, the Worker Education Project affiliated with SEIU Local 285.

- **Training, Education, and Mentoring**

Basic adult education and English as a Second Language (ESL) courses are much in need. ECCLI is making available pre-GED (Graduate Education Diploma, or high school equivalency) classes, “customer service” and communication classes, and classes on dementia care, death and dying, and the nature of aging.

Ninety percent of participants rate the training as positive. Training on-site works best because transportation is an issue for many of these workers. Flexibility in the topics covered in training is important, too. Diversity training has succeeded in many settings. People have learned about each other’s cultures and some of the tensions that existed between aides and supervisors mainly because of different backgrounds have fallen away.

- **Supervisory and Leadership Training**

Most nurses do not get any supervisory training, particularly LPNs, and they supervise large numbers of people. The expected enrollment for one introductory management class was eight people, but 20 people came for every class! Many managers have been supervising people for years with no training.

- **Coordinating between Facilities**

Scheduling and childcare issues are areas of difficulty for many direct care workers. Two facilities recently cooperated to make a schedule work for an employee. They arranged for a transfer for a worker who had childcare issues so that she could work on a different shift at another facility. This would never have happened without ECCLI. She would have been fired from the one facility and then had to try to find another job on her own.

- **Workforce Development Agencies**

Most workforce development agencies do not know a lot about long-term care, but with ECCLI's help this is changing. Workforce development involves family and employment supports and assistance with adult basic education, entry-level training, and opportunities for advancement. Workforce development and healthcare are two different publicly funded systems that serve people. The healthcare system serves elders and people with disabilities and provides long term care services. The workforce development system supports low wage workers who need help getting stable employment and to advance in their careers. Many low wage workers are employed in long term care and so ECCLI has been able to create an intersection between those two efforts.

Accomplishments and Challenges of ECCLI

ECCLI participants report higher morale in nursing homes and many CNAs report feeling more respected. Several facilities reported fewer people resigning. One home's turnover rate went from 100 percent to 54 percent – this is still pretty high, but it is a big improvement! One facility said their CNA jobs were fully staffed for the first time. Another says they have a pile of applications (partly due to the economy, but also because people are beginning to want to work there). Career ladders are becoming a recruitment tool. The use of pool staff or agency staff has decreased, saving the facilities money and improving quality. People have been getting raises, although these were not required by the program. In Gardner, Massachusetts the facilities decided on a 50 cents an hour wage increase. This is significant to a nurses' aide. It is not enough, but it's a lot. Most of the actual wage increases were smaller, three percent, or about 30 cents, upon completing training.

We have also documented some difficulties. Changes of practice have been the hardest to implement (see below, The Culture Change Movement and Care Practice Changes). Access to data for researchers is very limited because of privacy and other administrative problems. Even giving us the information about how many workers have been trained in what topics appears to be almost too much administrative work for the facilities. The program has cost more than estimated. Staffing during the classes is another problem. People are supposed to go to class an hour before their shift ends – who

is going to cover their shift? Many times employees don't get released and then they don't come to class, or an emergency will arise during the training and they have to leave. Another hurdle is space. Nursing homes typically don't have training space.

The Culture Change Movement and Care Practice Changes: Barbara Frank

Despite the caring nature of this work, long-term care workplaces operate within a structured system. The long-term care system is publicly financed with numerous federal and state regulations that set out in great detail standards of care and how services are paid for. Resources for long-term care are dependent on the public will and commitment to spend on healthcare, education, elder care, and services to people with disabilities. So, the larger system that we operate in – and whether or not we have enough resources – affects whether or not a nurse aide has enough time to be at the bedside or to help someone to the bathroom.

Nursing homes can be very rigid environments considering that they are there to care for people with a wide range of needs. This is a result partly of the medical culture, steeped in documentation, procedures, and hierarchy around scope of practice and who is allowed to do what. It is a regimented world where mistakes have a real cost and where public funds pay for care, so there is

significant oversight and regulation. People are sometimes so driven to do something because someone else has said so and thus they live two realities – the reality of what they're supposed to do and the reality of what is natural to do as a human being.

People are sometimes so driven to do something because someone else has said so that they live two realities – The reality of what they're supposed to do and the reality of what is natural to do as a human being.

Part of what the culture change movement is trying to do is to heal that split and find ways that are within the spirit of the medical and government rules, but are not so rigidly constructed that they obstruct human caring. If caregiving is supposed to be about caring and some rule is being interpreted in a way that drives you away from caring, then how that rule has been interpreted has missed the point and has to be looked at in a different way. For instance, about 15 years ago the use of physical and chemical restraints in nursing homes began to be rethought. Inordinate numbers of people were physically tied into their chairs, unable to move, and they often were medicated so they

wouldn't resist. This was a common practice and nobody thought that he or she was doing something harmful. Nurses thought that they were protecting people's safety – preventing people from falling and from wandering. Then people started to look at how much physical and psychological damage was being done if people sat tied in one place for hours on end. It became clear that if they got to know each person, they would figure out ways to structure caring without tying them down in a chair, most likely incontinent, hungry, and distressed. This new awareness opened up a whole different kind of conversation around caregiving – the importance of getting to know residents, assessing their needs and abilities – finding ways to take an individualized look at each person – to get to know their strengths and capabilities, their deficits, and how they could be supported. That led to establishment of the Pioneer Network, a group of practitioners who have pioneered new caregiving practices.

One person who is a leader in the Pioneer Network is a nurse named Joanne Rader from Oregon. She turned the notion of difficult behaviors on its head. Residents got labeled as having difficult behaviors – it could be a person with dementia who has lost her ability to communicate in words and so communicates by actions and by calling out and so gets labeled as “difficult”. If a caregiver is told that someone has a difficult behavior, that person will focus on trying to stop the behavior. Rader says we have to understand behavior as a form of communication. If we restrain behavior, we will never know what is being communicated to us. If we can understand why a person is crying out, we can respond to her need, instead of restraining this expression. Rader eliminated almost all restraint use and the use of psychotropic drugs in her facility. Incontinence declined as people were able to get up and go to the bathroom. Food supplements were eliminated because people actually had an appetite again and ate. Physical and emotional well being improved significantly.

At the time Rader was making these changes, the federal nursing home reform law (OBRA 1987) put some of these best ideas into a policy frame that supported quality of life and individualized care. Some of the nursing homes that had been moving toward restraint-free care and toward these

... if something is a miserable experience for a resident, it's also a miserable experience for her caregiver.

innovations came together and shared their ideas and experiences and helped to stimulate

what they call a change in the caregiving culture to make nursing homes better places to live and to work.

Improving care for residents also improved work for caregivers. If something is a miserable experience for a resident, it's also a miserable experience for her caregiver. Joanne Rader brought this home with her recent work on bathing. She recognized that one of the most frequent causes of injury to residents and workers is the bathing process. Bathing in nursing homes is almost like a car wash – very dehumanizing and traumatizing. Residents naturally fight back, push away, fall. Staff get punched in the face, get bit, and Rader tried to understand this. To do so, she asked her best nursing assistant to take her through the process. She was put in a hospital gown, transferred out of bed and into a chair, and wheeled down the hallway in front of everybody with nothing but a hospital gown for privacy. She was taken into an industrial sized shower room with silver walls, wheeled around, and sprayed. She later videotaped one particular patient's experience and the woman pleads, "Don't do this to me, don't do this to me! Stop, stop, stop." The woman curses and fights back until finally one of the aides screams because she's been bitten! Another aide tries to come in and the woman says, "I'll bite you, too!" Scenes like these are daily occurrences in nursing homes.

While there are federal and state regulations that say good hygiene needs to be maintained for people in nursing homes, Rader started thinking about other ways that people could be bathed. The second part of the video she had made shows that same aide and the same resident. The aide says, "I'm coming to give you a bath," and the woman says, "Oh no! Not that again! I don't want a bath." The aide says, "I'm going to leave you here in bed and let me put these warm towels on you...how does that feel? The patient says, "That feels good." And the aide says, "I'm going to massage your leg here with this warm, wet towel. Okay?" At one

That's culture change -- maintaining all of the responsibilities that are needed, but doing it in a way that is humane.

point in the video the woman says "I don't know if I have the money to pay you for this" and the aide says, "That's okay, you don't have to pay." They just murmur away until the bath has been given and the work has been done. That's culture change – meeting caregiving needs, but doing so in a way that is humane. We don't need a cost benefit

analysis to know that this is actually going to improve care and is going to be a better situation for everybody.

Nursing homes that are changing their caregiving and workplace practices are attracting and keeping good workers. Efforts to change the workplace culture and to provide concrete supports to workers are beginning to demonstrate positive results. As the long-term care system faces the need for more workers, it will need to make these changes in public policy and workplace practice to support and expand its caregiving workforce.

For further reading:

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Eaton, S. C., C. Green, R. Wilson and T. Osypuk. "Extended Care Career Ladder Initiative (ECCLI): Baseline Evaluation Report of a Massachusetts Nursing Home Initiative." Kennedy School of Government Working Paper # RWP01-035, July 2001.

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Frank, B. and S. Dawson, Health Care Workforce Issues in Massachusetts. June 2000. The Massachusetts Health Policy Forum.

Hams, Marcia, et al. Health Insurance Access Survey of Direct Care Workers in Nursing Homes and Home-Based Care Agencies in Boston, New Bedford/Fall River, Including

Surveys of Employees and Employers. Spring 2002. Direct Care Workers Initiative and Paraprofessional Healthcare Institute

Refer to www.directcareworkforce.org for other tapes and information. National Clearinghouse on the Direct Care Workforce, 349 E. 149th St., Bronx, NY 10451, 718-402-7766

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