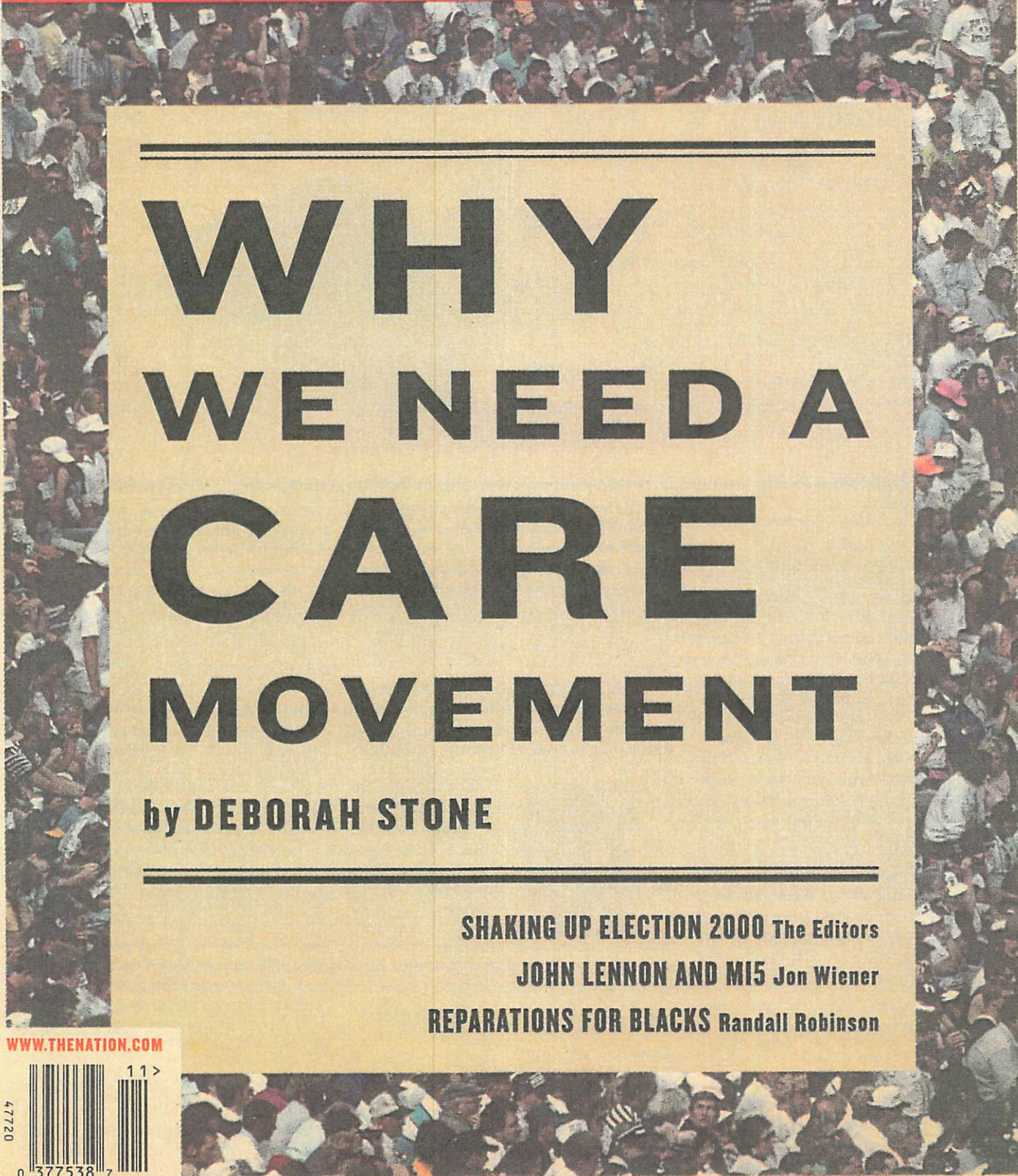


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## WHY WE NEED A CARE MOVEMENT

by DEBORAH STONE

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## ARTICLES

## WHY WE NEED A CARE MOVEMENT

by DEBORAH STONE

**W**e have the Bill of Rights and we have civil rights. Now we need a Right to Care, and it's going to take a movement to get it.

Care is as essential as the air we breathe. Two centuries of myth-making about rugged individualism will not yield easily to the painful fact that dependence is the human condition. In addition to the 38 million children under age 10 who need looking after, we now have somewhere between 30 million and 50 million people who need help with the basic tasks of daily life to be able to lead decent lives.

It took a movement to re-envision air and water so they didn't appear to be free and inexhaustible resources. By one recent estimate, 27 million people—more than 11 million of them men—are providing an average of eighteen hours a week of informal care to someone over 18. According to the National Alliance for Caregiving, caregivers to the elderly who also work in the paid labor force frequently turn down promotions, take leaves of absence or early retirement, or even give up their jobs to accommodate their caregiving. We need a movement to demonstrate that caring is not a free resource, that caring is hard and skilled work, that it takes time and devotion, and that people who do it are making sacrifices.

We need a movement because caregiving is a class issue and a labor issue as well as a social-welfare issue. Working alongside the informal-care brigade is an army of underpaid and overworked formal caregivers. While the rest of the economy is downsizing, caregiving jobs are booming. But these new jobs pay minimum wage or a little more, and usually lack any kind of security, benefits or possibility for advancement.

We need a care movement because this is how the left can and should reclaim family values from the right, which blames families for neglecting their responsibilities and castigates poor women for balking at below-subsistence wages in care work. The left must highlight all the ways society thwarts the primeval urge to care.

### Three Rights to Care

**R**ights are not magic wands for curing social problems, but they are a splendid device for mobilizing a movement. By demanding the right to care, we can point out just how inhumane many current policies are.

*A right to care means, first, that families are permitted and helped to care for their members.* Contrary to all the conservative rhetoric about families shirking their responsibilities, most families are making heroic efforts to care for themselves in the face of huge obstacles society puts in their way. The entire system of paid work is hostile to family responsibility. Rigid schedules, long hours, changing shifts, mandatory overtime, the near-universal lack of leave time to take care of sick relatives—all block workers from caring for their families.

The reformed welfare system won't tolerate (much less support) women who choose to be full-time mothers. Such women are deemed irresponsible parasites, while—perversely—when they take care of other people's children for pay, as daycare workers or home health aides, for example, they are considered virtuous.

Most elders dread the nursing home and most families want desperately to keep them out, but with the advent of sophisticated, high-tech home medical care, keeping a frail parent at home often requires outside help and the money to buy it. Yet in 1997 Congress slashed Medicare's home healthcare budget, forcing many families to put their elders in nursing homes.

*A right to care means, second, the right of paid caregivers to give humane, high-quality care without compromising their own well-being.* As states and counties privatize social services, they are pushing care workers into shaky, independent-contractor status, where they have zero security and benefits. Most states subsidize childcare for low-income women, but they pay such low rates that many full-time childcare providers are themselves eligible for some public assistance. Home health aides and aides in mental health facilities are often similarly ill paid. With hourly wages of \$6 to \$9 per hour and usually no guarantees of full-time work, most are kept near or below the poverty level.

When health insurance plans pick up the tab for care, whether public or private, they don't want to pay for non-essentials. In the name of efficiency, they're squeezing out the social time, the time it takes to treat a person with dignity and compassion instead of as a body with only physical needs. Caregivers often must disobey rules to provide decent care.

*Last, a right to care must mean that people who need care can get it.* Culturally, we are a nation that shudders at the very idea of dependence. We pretend that only the lazy and the poor need help, and that they get it. Meanwhile, people with the most utterly normal and ordinary dependencies cannot get the care they need. The litany is familiar: more than 44 million people without health insurance, a whopping shortage of daycare for children, thousands of children languishing in foster care, unaffordable and uncovered home care, a shameful incapacity to treat the mentally ill.

The left should continue to champion this third right to care, the right to receive care, but it's time to emphasize the first two rights, which are rights to *give* care rather than to receive it. One reason the right wing has been so successful on social issues is its one-sided portrayal of social aid as an entitlement, as all taking and no giving. We must show that the right to care is the right to be a decent person, to feel love and loyalty, and to act on those feelings without being ground down or punished. The care movement must recapture the nobility of care.

## What Kind of Movement?

It will take a movement to join the three corners of the care triangle: people who need care, families who care for and about their members, and people who give care for a living.

Each corner already has its grassroots beginnings, but they rarely make common cause. They are split by their relationship to the problem—whether they are users and buyers of care, or people who make a living at caregiving. Consumers want affordable, low-cost care, but people who care for a living must have livable wages and benefits. Care interests are split again by the sector of the service world they inhabit—childcare versus eldercare, chronic illness and disability versus acute illness, physical health versus mental health. Then, they are split yet again by the sector of the economy that presides over the resources they need—multiple levels of government; private agencies and firms that provide services and employ caregivers; and employers everywhere that control employees' time and may or may not provide fringe benefits crucial to meeting family care needs.

The way out of this impasse can be glimpsed in efforts like the disability-senior-labor coalition in California that is helping home health workers upgrade their pay and working conditions, while helping consumers get better-qualified and more reliable caregivers. A year ago, Service Employees (SEIU) Local 434B won the right to represent 74,000 homecare workers in Los Angeles County. It was the biggest influx of new union members in a single vote since 1941, and it was a long time coming. Home healthcare workers get paid from a mix of federal, state, county and private money, and when they first tried to organize, courts said they were independent contractors (who aren't allowed to organize) and that even if they were in a position to organize, they didn't have a single employer with whom to bargain.

To get around the courts, a coalition of labor, seniors, disability activists and other advocacy groups got state legislation authorizing counties to create Public Authorities to run the state's large In-Home Supportive Services (IHSS) program. The authorities serve as employers of record for homecare workers.

Many consumers were afraid of the new model. "We did not want to see IHSS become like an HMO, where companies come in and dictate the hours, what's to be done and for how long," says Lillibeth Navarro, a disability activist and consumer representative on the governing board of LA's Public Authority. "I myself had those misgivings," she admits, "but I also knew that we consumers were affected by the situation of our homecare workers. They had no health insurance, and we needed them for our survival. If they were sick or had a loss of health, we suffered." Verdiana Daniels, president of 434B's executive board and a homecare worker for twenty-two years, adds that consumers became union allies "when they saw they couldn't keep their providers; the providers had to leave homecare and get other jobs because they couldn't support their families."

When homecare workers started to unionize in earnest, leaders of the disability community feared they would be out-organized. So they went into low-income housing units where there were clusters of seniors and people with disabilities. "A lot of seniors

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