

WAKING UP THE CARING MAJORITY: WHY WE ALL NEED TO CARE ABOUT THE AGING OF AMERICA

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This is a transcript of the 21st Annual Sheinberg Lecture delivered by Ai-jen Poo at NYU Law on April 8, 2015. Ms. Poo's lecture, entitled "Waking Up the Caring Majority: Why We All Need to Care About the Aging of America," discusses the need to create a caregiving plan for America's aging population.

The writer George Saunders at the 2013 Syracuse University commencement gave one of my favorite speeches of all time. In speaking to the young graduates, Saunders helped them anticipate their futures. He said, "the things we regret most in life are not the things you might expect, but rather failures of kindness. Those moments when another human being was there, in front of us, suffering, and we responded sensibly. Reservedly. Mildly. To look at it from the other end of the telescope: Whom, in your life, do you remember most fondly, with the most undeniable feelings of warmth? Those who were kindest to you." Saunders goes on to admit that kindness is not easy. But he believes that kindness becomes more natural with age. He quotes poet Hayden Carruth, who wrote near the end of his life that he was "mostly Love, now." Saunders wished for the graduates to embrace this awareness early – avoiding failures of kindness, and instead striving to be ever more kind and connected to others, and ultimately, mostly love.

I come from an immigrant family and had the great gift of growing up with my grandparents. I don't know if they grew to become mostly love but that's certainly what they were by the time I entered the world. They showered my sister and me with kindness. They cared for us, laughed with us, offered important perspective on life. From my grandmother, I learned how to appreciate and cultivate laughter, and how to use the potty – which has proven very useful. From my grandfather – I learned hard work and discipline, I learned Tai Chi, and developed a deep appreciation for the hidden strategies of Wheel of Fortune. I feel so fortunate to have been cared for by both of them. Two extraordinary people, on different sides of my family, but similar experiences of early life defined by poverty in China, war, migration, hard work – each a full life of hardship and triumph.

And then their stories diverge.

My paternal grandfather lived to the age of 93, a long and, for the most part, healthy life. However, the final months will haunt me forever. After my grandfather's vision and other functions deteriorated, my father was unable to find appropriate home care support for him and had to place him in a nearby nursing home against his wishes. I visited him there, and even now my memory of the visit gives me shivers. My grandfather's bed was in a dark room with half a dozen other people, some completely still and unmoving, others wailing with pain and suffering. It smelled of mold and illness. When I found him, it was clear my grandfather hadn't slept or eaten for days. Though he was alive enough to tell me he was not afraid, I knew he was dying inside. He passed away after just three months in that frightening facility.

On the other hand, my maternal grandmother is still alive, and she turned 89 a few weeks ago. I visited her for lunar New Year – celebrating the year of the sheep. She lives in her own apartment in Southern California across the street from a Chinese grocery, not far from a Chinese hair salon. She goes to church twice a week, and even sings in the church senior choir. She and I play mahjong together, and on occasion she lets me win so that I keep playing. She's living life on her terms. It brings me a lot of peace to know that she's living well now, after caring for so many of us.

Two grandparents, both made of strong stock, both loved by their family dearly. So what made the difference?

Mrs. Sun. Mrs. Sun is the home care worker who looks after my grandmother. A few times a week, Mrs. Sun comes and assists with the things that have become more difficult for my grandmother over time: things like lifting, cleaning, sometimes cooking – although cooking's usually a team effort, something they do together, buying groceries and all that. Our last big scare was when my grandmother slipped and fell as she was rushing to catch the bus to church. Now Mrs. Sun or her husband always make sure that my grandmother gets to church on time.

Mrs. Sun is an immigrant from China, and has become a key part of my family's care team, her own family of two grown sons and a husband, have also become like extended family. Like so many families with aging relatives, we didn't have a plan. That lack of a plan and lack of options proved painful in the case of my grandfather. A few years later, in the case of my grandmother, we were just fortunate to find Mrs. Sun. Having her has changed everything, especially my grandmother's quality of life.

What's become clear to me is that we as a country don't have a plan either. Whether you're an overstretched family caregiver, or you cannot afford the care you need, or you can't find the right long-term care option for your family. You're not alone. It's all of us.

And it's gotten to the point where — as individuals, as families and as a nation — we simply we can't afford not to have a plan. Every 8 seconds, someone turns 65 in America. This year 4 million Americans will reach retirement age. By 2030, 20% of our population will be over 65. The Baby Boom generation is aging – the advances in health care and medicine that have extended our life expectancy by nearly 20 years since 1930. The combined effect is what some call the Silver Tsunami, though I prefer the term Elder Boom.

Whatever you call it, what this means is that by 2050, 27 million Americans will need long-term care or assistance. But for the vast, vast majority of those 27 million people, care doesn't mean living at home with the help of a Mrs. Sun. For most, elder care will mean a nursing home, just like for my grandfather, unless we do something different.

The dark ending that my grandfather faced is too costly – there's the emotional cost of what he endured, and our feeling of failure, but then there's also a financial cost. The average private room stay in a nursing home costs \$87,000 per year. That's unimaginable for 27 million people and literally not possible.

So then perhaps the solution is simple – if we had more caregivers like Mrs. Sun – the more than 90% of us who would much prefer to age in a place connected to our families communities, and to actually age the way we want to. It’s that easy, right? Instead of spending \$87,000 per year on nursing homes we could spend that money on quality, trained home care workers like Mrs. Sun, right?

Well, not exactly. Because the more than 2 million women who currently work as home care workers, personal care aids, and domestic caregivers today can barely sustain in their jobs. It’s the kind of job that people don’t even recognize is a real job. It’s called “companionship, or help.” We’re still fighting for inclusion in basic worker rights protections. And many of the workers in this workforce are undocumented immigrants, trapped in the shadows. The wages are unfathomably low, with average wages less than \$9 per hour—so low that the women, mostly women of color and immigrant women, we count on to care for our loved ones can’t afford to care for their own families. It’s to the point where 30% of home care workers must rely on public assistance for food security. And many live in fear of being separated from their own families as a result of our immigration policies.

Myrla Baldonado is a Filipina immigrant caregiver in Chicago who helps elders in the community lives independently. She’s had over 20 clients, working 24 hour shifts, 4 days a week, lifting her clients in and out of bed, bathing, administering medicine, helping do physical therapy, plus cooking and cleaning around the home. For this work, Myrla takes home between \$5 and \$9 an hour. And what does Myrla do? Because she’s also a parent, she sends some of that precious money to support her five children living back home in the Philippines. But with that plus the cost of rent for the room she lives in, some weeks Myrla barely has any money left over. On several occasions, Myrla has gone for weeks eating nothing but hard-boiled eggs and bananas. She simply can’t make ends meet.

So we can stay on this same, dark path — the unsustainable home care wages and working conditions, which reinforces an unsustainable overdependence on nursing homes that no one wants to live in. Or, we can seize upon a moment of opportunity to create a whole new system to care for our families *and* care for the workers, too.

Think of this as a “care grid,” like the grid of infrastructure that once brought water, electricity, and maybe someday the Internet to every home in America — we need a care grid to bring caregiving options to every home in America.

And if we look closely enough we will start to see the seeds of what’s possible all around us. We have Naturally Occurring Retirement Communities and the Village Movement, designed as communities for older people to pool resources and purchasing power, and share services that enhance their quality of life, including caregivers.

In Hawaii, champions will be introducing the first state social insurance program for long-term care in this legislative session. The state of Washington has created the country’s top training facility for home care workers, training 40,000 professional caregivers per year, in 12 languages, utilizing the most cutting edge training content and methodology. This facility has elevated the quality of care for the people of this state, and the quality of jobs. And as a result, Washington State is among the most prepared for what’s to come in the nation. And in the last four years,

domestic workers have won state-wide legislation to establish basic rights on the job in four states, with Massachusetts passing one of the strongest bills to date in 2014, including maternity leave for caregivers.

These examples are just the beginning of what's needed. The care grid of the future must be a connective lifeline of creative solutions and choices our families, communities, legislatures and entrepreneurs create together. It will support choice in how we receive and access care, it will make quality care affordable, while bringing poverty wage jobs out of the shadows and transforming them into millions of good jobs for the future. This is our moment to take caregiving, what has been a private, and often isolated conversation, into the national public policy conversation about the future of this nation.

Erlinda, another caregiver, shared a story about a client she called "my lady," who always asked her to sing to her. One particular day, rather than ask her to sing, she said, "give me your hand," and Erlinda knew right away that she was going to transition. She called the family together and stayed with them. She was proud that she could be there for that moment that she could ensure "her lady" was in good hands and surrounded by love. Just as the family remembers Erlinda's kindness, Erlinda thinks of "her lady" often.

We remember in life, and ultimately rely on at the end of our lives, those who are kindest to us. We need a care system that is mostly love. A care grid that channels dignity. And enhances choice and respect and health and self-determination and fairness. And love.

Especially as more and more of us age, and hopefully grow in kindness, we need a care system that cares for all of us, including the workers. And in creating such a system, we will begin to lay the foundation for an economy and a democracy that honors the full diversity of who we are and who we are becoming – opening up jobs, with real pathways to opportunity and citizenship and new supports for workers, immigrants, and our elders, people of all generations and walks of life.

And to be clear, the demographic changes in this country are profound. By 2040 we will be a majority people of color nation, and over 20% of the population will be over the age of 65 – the older population will be significantly whiter, and the younger population will be significantly more of color, particularly immigrant. We could run the risk of becoming the kind of country where our interests are constantly polarized or pitted against one another along the lines of race and generation, if we don't present an alternative vision for the country – one where we actually take care of one another.

It will be up to us to make it clear, that there is shared vision for healthy, secure American families that benefits all of us, and that coming together toward that vision will ultimately make the country more whole and connected. Care can connect us all. A vision for a more caring and just future for all of us. And it will take all of us to create.

Now because we're at one of the premiere public interest law schools in the nation – I want to say a few words about politics, policy, and the social contract. We live in a moment when inequality is at all time high, and our democracy is in jeopardy – with unprecedented amounts of corporate money flooding into elections and corporate lobbyists defining the realm of the politically possible. With only a

few exceptions, low-income and working families are for the most part on the defensive. We've been struggling to defend the gains of the 60's and 70's. If we're not careful, we'll soon be forced to defend the gains of the 30's.

Now what does that mean in the lives of people? When the New Deal was being negotiated more than 75 years ago, Southern members of Congress refused to support the labor laws – the National Labor Relations Act and the Fair Labor Standards Act – if two groups of workers, farm workers and domestic workers who were of course largely African American at the time, were included. So in a concession to southern Dixiecrats, those laws were passed, explicitly excluding those two groups of workers. To this day, farm workers and domestic workers live and work in the shadow of racial exclusion. Poverty wages, long hours, unsafe conditions, at the bottom of our economy.

Over many generations, farm workers and domestic workers organized and sought to change those exclusions. In 1974 domestic workers successfully gained inclusion in some minimum wage protections under the fair labor standards act. It took organizing and advocacy. But there was a loophole that remained in place – something called the “companionship exemption,” again excluding caregivers for the elderly and people with disabilities.

Now, this current generation of the domestic workers movement has been fighting to change these exclusions once and for all. Since 2009, when the first group of domestic workers went into the Department of Labor to push for a stronger enforcement of domestic workers rights, we have been working to bring the nearly 2 million caregivers who are still excluded, under minimum wage protection. And I'm proud to say, that in one of the most important victories for women and low-wage workers of this Administration, we were successful. On January 1, the new rule to ensure minimum wage and overtime protections for home care workers and caregivers went into effect.

Unfortunately, however, the home care industry lobby which does not want to pay minimum wage and overtime, filed a lawsuit to try to stop the rule from going into effect. And a DC District Judge that heard the case vacated the rule change. Now the Department of Labor is appealing the ruling and it's being fought out in the courts. And we're actively organizing in states to push for states to adopt the change in their state budgets, so that the rule can be implemented smoothly without any negative impact on how services are delivered, and we create a climate of inevitability for fair wages.

It's an ongoing struggle – for basic wage protections. And I'm sure many of you are following the litigation against the President's executive action on immigration. These basic changes, so minimal and so far from what we actually need, even they are under severe attack.

And the truth is, we are and will be fighting on every front in this way – both defensively and offensively, because our movements are relatively weak, in relation to what we're up against. And our old models and institutions that have anchored progressive power & social change are outdated – from trade unions to old models of electioneering. We simply haven't kept up with a changing global economy, all the new alignments and concentrations of wealth and power; we haven't built the power to define the future in our new context.

But I feel incredibly hopeful. Because change is happening around us, in the economy, in the nature of work, in the structure of families, in our demographics, in our popular culture, and in American political life. Amidst change, there is more room for new protagonists, new alignments, and new convergences of communities and movements. And the experiences that have existed in the margins are becoming increasingly defining of the whole. Domestic workers used to be considered a shadow, a marginal workforce. Today, the conditions that are associated with domestic work are increasingly defining of the whole of the American workforce. More and more people can identify with caregivers and domestic workers. More and more people can identify with the formerly incarcerated, as more experience being locked out of real opportunity in an unusually unequal, cruel economy. And, if we are to look back at the New Deal – even the gains of the 30s and 60s were full of holes – they were not gains that benefited all of us. There were profound exclusions, with profound implications.

So what gives me hope and energy is that in the midst of the change that's happening all around, we have the opportunity to put into place a new framework for public policy; a new social contract – a long overdue new social contract – one that learns from past errors and exclusions. It will be this generation – you – who will lead the way in shaping what that new social contract looks like. And just as law students right here at NYU worked alongside domestic workers to craft the breakthrough domestic workers' Bill of Rights, my hope is that all of you will work alongside the many movements for change today, to develop that new social contract.

With one major caveat. Building power must be a focal point of that work. We must build a significant force behind our values, if we want our values to shape the future of the social contract. We must achieve an entirely new level of power and impact in our social movements, to open up the political space to win what our communities and our children deserve. The new social contract must NOT be defined by what's considered politically possible today. We must build the power to fundamentally redefine what's politically possible. It's fundamentally a question of power.

Now there is a path to power, and where it's unclear, we just need to get out there and create it as we go – through elevating new protagonists, like domestic workers and other low-wage workers, through building powerful movements, with integrated strategies, where policy, litigation, narrative, and culture change, organizing, and civic engagement are part of a shared strategy to build and exercise the power of real people.

We need to be dreaming boldly and organizing broadly. We must be prepared for a long-term journey. And we must always remember that at the end of the day, what is politically possible – and ultimately what is considered justice – will be defined by how powerful our movements for human rights and dignity become.

It's up to us. We can start building the caring majority we need to live and work with dignity in this country. I hope you will join us.