



CARING ACROSS
GENERATIONS



**Building Towards the Future
of In-Home Care:** Consumer Voices
Supporting a Roadmap to Citizenship





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Caring Across Generations is a multi-faceted campaign that is changing the way America cares for seniors, supports people with disabilities, and values caregivers and in-home care workers. The principle that consumers and workers should be treated with dignity and respect underpins all of our work.

Lack of an immigration status and ability to work legally in the U.S. are significant barriers for many domestic and home care workers, making them vulnerable to exploitation and abuse. Caring Across Generations supports a roadmap to citizenship for all undocumented workers. In the absence of fair and humane immigration reform, the creation of a roadmap to citizenship for home care and other private household workers is a core element of Caring Across Generations' federal policy vision.

This storybook highlights the voices of some of the many consumers who support immigration reform.

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JEANNE IMAI

Age: 65

Location: San Anselmo, CA

After working as a high school career counselor while raising two children, Jeanne Imai retired to support her aging mother. Jeanne's mother, Jane Davis, passed away in February 2013 at the age of 94. Until her mother's death, Jeanne spent a significant amount of time managing the intricate web of care and support that allowed her mother to remain independent and live at home.

"We employed five different care workers to support my mom from 9 am to 9 pm everyday," Jeanne explains. "We are so grateful for their services, but more than that, their care. They went beyond just taking care of mom's daily needs. They really became an integral part of her life, making sure she aged with dignity."

One care worker in particular meant a lot to Jeanne and her family — a single mom with two young daughters who was originally from Fiji. "She's told me that as a culture, Fijians really respect their elders, and that is the basis for the kind of care that she gives and for her outlook on caregiving," Jeanne says of her mother's aide. "And to me, this really showed. She was so conscientious and thoughtful, and so sensitive to mom's needs. She just went above and beyond." The high quality support was essential to Jeanne's mother's quality of life, especially in her final months and days.

Reflecting back, Jeanne is deeply aware of the role played by immigrant care workers who not only contribute to our communities, but who are also provide invaluable support to many American families. And yet the way immigrants are treated today reminds Jeanne of the horrible way that Japanese Americans were treated during World War II. People who simply work hard and contribute to America are disrespected and denied the most basic of rights. Then, as now, we need a fair immigration policy for America.

"There has been no common sense immigration policy, instead deportations are tearing families apart and those here with papers are often kept from uniting with their families for far too long. People need to feel that there is a place for them, not live in fear of being forced to leave their families. Immigrants are a part of the fabric of the United States like everyone else," says Jeanne. "I just think it's fair to create a roadmap to citizenship for America's immigrants."



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JUDITH FELSENFELD

Age: Senior

Location: New York, NY

Judith Felsenfeld has been supported by domestic workers throughout her life because, like so many Americans, her life and her family simply needed more help.

Judith's mom, an immigrant from Poland, and her father both worked full-time and relied on a nanny to help them raise Judith. Decades later, Judith and her husband hired a nanny to help them raise their own son when Judith went back to work. And later still, Judith and her family relied on the support of an in-home care worker to support her mother-in-law, Clara.

At 92, Clara had lived by herself for 30 years, ever since her husband died. She was doing her own shopping, balancing her checkbook, and taking the bus to meet friends for lunch. But increasingly, Clara needed support. Clara hired an immigrant domestic worker, Dalia, to clean her apartment once a week. Slowly, her job expanded to helping Clara with groceries, handling her prescriptions, and assisting her with showering.

As Clara's need for support increased, Judith worried about what might happen next - especially because Clara, like many seniors, wanted to stay in her own home. Fortunately, they met and hired Joyce, an immigrant elder-care worker. With Joyce's help, Clara lived six more years in her own home. She remained comfortable and independent until she passed away at the age of 98. After Clara died, Judith paid Joyce severance and helped her find more work.

"I realize that my family has been incredibly lucky," says Judith. "My mother-in-law could afford to pay the workers for the support she needed." Judith argues that all people and families in America should have the support they need to age at home with dignity. And the care workers who help make that possible should have good wages, decent benefits and, for those who are aspiring Americans, a road to citizenship.

Judith is very clear that her fortunate story is an exception in America today, but it shouldn't be. "Our job is to make stories like mine—those where in-home care workers truly bring respect to the seniors they care for—the standard, the norm, no longer the exception."



“I realize that my family has been incredibly lucky. My mother-in-law could afford to pay the workers for the support she needed. All people and families in America should have the support they need to age at home with dignity. And the care workers who help make that possible should have good wages, decent benefits and, for those who are aspiring Americans, a road to citizenship.”

KURT SHAFFERT

Age: 83

Location: Chevy Chase, MD

Born to Jewish parents in Vienna, Austria, Kurt Shaffert's family escaped just before Germany invaded Poland at the start of World War II. Kurt was just nine years old when his family immigrated to the United States with the support of the Hebrew Immigrant Aid Society. Kurt thrived in his new homeland, graduating from the Bronx High School of Science, City College, and eventually NYU Law School. He worked first as a chemical engineer and then, for most of his career, as a lawyer.

Kurt's first experience with care workers came during the last year of his mother's life in the 1990s. "At that time, the recent immigrant population was African, largely refugees and other immigrants from Liberia. To me, their stories were so parallel to the Polish refugees of the 1900s, and to my own escape from Hitler: there was strife and trouble in their homeland, and some of them escaped, particularly the young people. We all did what we had to do to survive." He hired three Liberian immigrant women to care for his mother during the last months of her life. Their support enabled her to stay in her own apartment and not go to an institution, which she feared.

Today at age 83, Kurt has Parkinson's Disease and relies on immigrant care workers to support him as he lives independently in an apartment building with other seniors. "There are many analogies from my early life to the caregivers I have here," Kurt recognizes. "There has been a good stream of people that came here escaping something at home. They've struggled to make it here and re-establish their lives. They live in areas in where previous immigrants have come and settled. They have communities."

And yet Kurt notes that there aren't as many social service agencies or support systems now as back when his own family immigrated. It seems harder for new immigrants to navigate their new country alone with the lack of social support, a challenge that's compounded by jobs with low wages. "Their income is quite low, really at the bottom of the ladder," Kurt says.

"To not be institutionalized, to be able to stay in my own home and have caregivers here, is important," Kurt explains. "I like where I live," he adds. "I feel welcome here. I feel independent here." Kurt supports immigration reform because he believes that the workers who support him should have access to all that America has to offer – in the same way that he has since he arrived in the New York harbor so many years ago.



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LISA HILL

Age: 52

Location: Grovetown, Georgia

When Lisa Hill was 38 years old, her mother was diagnosed with cancer. Soon after, Lisa's father fell and broke his hip. As their only daughter, Lisa was suddenly faced with the daunting task of caring for her parents.

Without knowing how to care for both parents, Lisa confided in a hospital nurse and asked for help. Fortunately, the nurse knew a man named Armond, a Filipino caregiver living in Miami who happened to be searching for work. "By the grace of God, he agreed to come to Russellville, Arkansas along with his parents," said Lisa. Armond and his entire family moved into Lisa's family home. Armond and his mother both began taking care of Lisa's parents.

"There is no way I could have cared for my parents on my own – absolutely no way," says Lisa. "Armond and his mother helped them with bathing, medication, food – they needed round-the-clock care," which was more care than what Lisa, with her own job and other family responsibilities, could manage.

Without Armond and his mother, Lisa's parents would have had no choice but to live in a nursing home. "Neither of my parents wanted to go into a facility," says Lisa. "My father was a proud man who would have died if he couldn't stay at home. Really, he wanted nothing more than to stay at home."

For four years Armond and his family stayed and helped Lisa and her parents. During that period, Armond was diagnosed with cancer. Lisa's family helped him receive treatment—both families ultimately helped each other. Due to the close relationship the families created, Lisa wrestles with the fundamental injustices that Armond and his parents face.

"I always asked myself – why was I fortunate enough to be born in the US and have the privileges that comes with US citizenship?" asks Lisa. "Caregivers like Armond and his mother are a part of the fabric of so many American families like my own. It's only fair and right that they be able to thrive here and live with the same dignity they help our families to live with."



"I always asked myself – why was I fortunate enough to be born in the US and have the privileges that come with US citizenship? Caregivers like Armond and his mother are a part of the fabric of so many American families like my own. It's only fair and right that they be able to thrive here and live with the same dignity they help our families to live with."

MARCIA MAYER

Age: 67

Location: Syosset, NY

In 2003, Marcia Kramer Mayer found herself in an unfamiliar situation, but one that millions of Americans face: caregiving. Marcia's parents were getting too old to drive, do basic chores, and take care of themselves on their own. Initially, Marcia drove the 14 miles from her home to theirs to help but eventually it became too difficult to balance all of her commitments. Marcia hired Kristina, an immigrant from Poland, to help care for her parents.

"Literally, her first day on the job, my father collapsed and had to go to the hospital, leaving my mom all alone. My mother's back went out — she was in terrible pain. So we brought her to the hospital as well." While Marcia's father was quickly released, her mother's stay lasted three weeks, followed by an additional five weeks in a rehabilitation facility. Kristina cared for Marcia's father while driving him daily to visit his wife.

By the time Marcia's parents returned home, their health was rapidly declining. "They both needed walkers and my father started to show signs of dementia," says Marcia. Within a few months, they needed round-the-clock help. Marcia hired Daphne, who had originally emigrated from Jamaica, to provide additional support. "Daphne and Kristina cooked, cleaned, took my parents to doctors' appointments and most of all, provided constant, high quality personal care," says Marcia.

"A few years later, my husband was diagnosed with terminal cancer," Marcia says. "He was home for about five months before he died. Sometimes, I would hire Kristina or Daphne to help me with my husband when I needed a break from the constant care he required."

Kristina and Daphne not only supported Marcia practically but also emotionally. "They had been through this with many older people — the process of caring for someone as their life comes to an end," says Marcia. "I feel I was very lucky to have their support." When Marcia's father was later diagnosed with cancer, Kristina stayed at the hospital caring for him while Daphne cared for Marcia's mother in their home. Before he passed away, Daphne and Kristina helped make it possible for him to spend his last days at home with his wife.

"Both Daphne and Kristina are an intimate part of my life," says Marcia. "These two immigrant women — who left their own mothers behind in their home countries — have cared for my mother in ways I simply could not." Recognizing the value of their work and the need of Daphne and Kristina to care for their own families, Marcia always paid them not only a decent wage, but overtime when appropriate, and has even paid for health insurance. "That has really benefited us since it meant they could stay with us and not seek other career opportunities," Marcia says.

"Immigrant caregivers are central to my life, my family, and our entire country," says Marcia. "Immigration reform allowing millions of caregivers to gain citizenship will only make our country stronger and help more people like my parents and husband live with dignity at home."



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NICOLE BROWN-BOOKER

Age: 45

Location: Oakland, CA

Nicole Brown-Booker was diagnosed with juvenile rheumatoid arthritis at the age of two. She has used a wheelchair ever since. But now, at age 45, Nicole lives independently and works with the support of personal assistants.

At age 18, Nicole hired her first attendant when she went away to college. With the support of her attendants and with a lot of hard work, Nicole earned a master's degree in psychology and currently works as a counselor supporting families who have children with disabilities. She continues to rely on the support of care workers.

"I need helpers on a regular basis to do things like get me out of bed in the morning, help me shower, prepare my meals and drive me to work," says Nicole. "In the evening, they help me get home, eat dinner, and get into bed."

The impact of the support Nicole receives reaches the people and families she is able to help through her counseling work, not to mention the broader economy and community in which she lives.

Furthermore, quality home care is more cost effective than institutional options. "Without this help," says Nicole, "I would end up in a nursing home, which not only costs far more than independent living but would keep me from working, paying taxes, and being an active member of my community."

Immigrants have and will continue to play an integral role in caring for Nicole and many other people with disabilities. Nicole believes that "It's time we care for immigrant workers and give them a path to citizenship."



“Without this help I would end up in a nursing home, which not only costs far more than independent living but would keep me from working, paying taxes, and being an active member of my community. It’s time we care for immigrant workers and give them a path to citizenship.”

RAHNEE PATRICK

Age: 39

Location: Chicago, IL

When Rahnee Patrick was eight years old, she developed psoriasis, a chronic immune disease that affects the skin. By age 10, Rahnee developed severe arthritis, and by age 16, she was also experiencing severe depression. Through all of her trials and tribulations, Rahnee has been supported by care workers, most of whom are immigrants. She knows all too well how vital these jobs are — and how hard they are to fill with someone you can rely on.

Today, at age 39, Rahnee employs two immigrant care workers, Maria and Elaine, who support Rahnee's daily needs. "They both help me with so much — putting lotion on my skin, washing my hair, fixing meals, washing dishes, helping walk my dogs," says Rahnee. "Maria even comes with me when I need to travel."

Because of Maria and Elaine's support, Rahnee is able to get to work — at her job where she helps other disabled people. As the director of Independent Living at the organization Access Living, Rahnee supervises a team that helps people with disabilities develop independent living skills. This gives Rahnee a unique vantage point, as someone who relies on care workers herself and helps find care workers for others.

"As someone who works to help people find caregivers, I can tell you that providing legal status to more workers would help tremendously in stabilizing the workforce and in increasing the number of workers we can rely on," Rahnee says.

It's hard enough being a U.S. citizen trying to make a living from low-wage domestic work. "Immigration status is another layer to this," says Rahnee. "If workers are under stress, if they can't afford their own health care, or they don't show up one day because their relative was deported, it's really hard on us, the clients."

Meanwhile, Rahnee notes that because care workers paid by Medicaid or Medicare are required to have legal work status, the absence of a clear road to citizenship means there are not enough documented workers to fill the disability community's needs.

Fortunately, both Maria and Elaine, Rahnee's care workers, have immigration papers — they have to, since Rahnee's care is paid for by the state. But when she thinks about the many qualified and loving care workers who are undocumented, Rahnee thinks about her own mother who immigrated from Thailand in 1970. Rahnee's mother was able to become a United States citizen because Rahnee's father was a U.S. citizen. "My mother was lucky, but we cannot leave the needs of people with disabilities up to luck. Many people like me who live with disabilities need help every day. We need a stable workforce of caregivers."



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SUSIE JARRELL

Age: 95

Location: Nantucket, Massachusetts

Susie Jarrell was married to her husband Oscar for 61 beautiful years. After Oscar survived several strokes, he required round-the-clock care. And, Susie was determined that she and her husband would spend their last days together in their dream home near the beach where they had retired.

“I desperately needed help,” says Susie, who turned to her housekeeper for ideas. The housekeeper helped Susie find Marcia, a Jamaican immigrant who moved in with Susie and Oscar for three months and helped Susie provide Oscar with the care he needed. Marcia’s help not only meant that Oscar could live at home, but that Susie and Oscar could spend time simply being with each other.

“It is very expensive to have full-time care,” says Susie. “It’s a real problem! But workers shouldn’t have to suffer. Care workers need time off, vacation, and a living wage.”

After all, while Marcia was helping Susie care for Oscar, Marcia was also supporting her family back home. “I knew she needed this job to be able to send money back home to Jamaica,” says Susie. “So many immigrant workers are physically caring for people in their jobs while financially caring for their families from a distance.”

Today’s immigrants deserve a roadmap to citizenship, says Susie.

Both she and Oscar are descendants of immigrants who came to America in search of opportunity and a better life. It’s the same dream that Marcia and other immigrants seek today. “And care workers,” Susie emphasizes, “do the most incredible work of caring physically and emotionally for those who need support. How can we not grant them a place in our country?”

When Oscar died, it was Marcia who helped Susie pack up their belongings and clean out their home. Endorsing citizenship for Marcia and other immigrant care workers, Susie says, “No family should be separated.”



“So many immigrant workers are physically caring for people in their jobs while financially caring for their families from a distance.”

JUDITH FRIEDLANDER

Age: 68

Location: New York, NY

Silvia Friedlander, the daughter of Russian Jewish immigrant parents, came of age in New York during the Great Depression. Like many unmarried women in her community, she became a high school teacher, something she continued to do after marrying and having children. In the 1950's, when other women gave in to social pressure, and stopped working, she was still teaching, going to graduate school, while also fulfilling her responsibilities as a traditional wife and mother in suburban Long Island. How did she do it? With a great deal of help from other women!

At first, Silvia hired African American women fleeing the segregated South; then working-class German immigrants from war-torn Europe. When political violence shifted to Latin America in the 1970s, Silvia hired domestic workers from El Salvador.

As the years went by, her daughters grew up and left home. In 1974 her first husband died; in 1988 she lost her second. In 1996, at the age of 85, Silvia sold the family home and moved into Manhattan. Soon even a small apartment was too much. Just before her 90th Birthday, Silvia finally agreed to hire a Jamaican immigrant eldercare aide named Elaine.

“Within a couple of months the two had developed a deep bond, and our mother got the expert care she needed so badly but had been resisting for well over a year,” says Silvia’s daughter Judy. “They talked politics together, both American and Jamaican, and they cooked together, sharing recipes ranging from curried shrimp to gefilte fish.” Elaine gave Silvia the kind of daily companionship she hadn’t had in years.

A few months after her 92nd Birthday, Silvia had a stroke and began needing round-the-clock care. Elaine came to the rescue. Drawing on her extended network of homecare workers from her immigrant community, Elaine and two other friends took care of Silvia for the remaining weeks of Silvia’s life, each working eight-hour shifts.

Judy looks back on Silvia’s last years with mixed feelings: “On a human level the experience for the entire family was precious. On the social and economic level, the system was entirely broken. In 2004, we paid highly skilled women between \$12 and \$15 an hour. For Elaine and her friends, these wages were not enough to make ends meet in New York City, particularly given the fact that they could not rely on this compensation for any length of time.” But for Silvia, the cost was breaking the bank.

“Women like Elaine deserve to earn a living wage and have benefits. Congress needs to address the problem on at least two fronts: first and foremost by passing legislation that will ensure a common sense immigration policy so that currently undocumented immigrant in-home care workers will have the right to hold their heads high and demand a living wage. Second, Congress needs to reform Medicare and Medicaid so that elderly Americans like our mother can afford to pay these workers a living wage.”



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PAMELA HALL

Age: 48

Location: Bronx, NY

As a college student in 1994 in South Carolina, Pamela Hall was in a horrible car accident. Pamela experienced serious head and spinal injuries. She made an almost full recovery, but years later, Pamela's legs gave out underneath her while she was walking to work. Pamela went for an x-ray, figuring one of her injuries from the accident had resurfaced. Instead, Pamela was diagnosed with multiple sclerosis.

"I was shocked. I had been so proud of my recovery from the car accident, finally feeling like I could get my life back together," says Pamela. "And then this!"

Soon after, Pamela started using a wheelchair to get around. By the time she moved to New York in 2009, Pamela relied on personal attendants to help her live on her own.

"My independence is what it is because of the care workers who support me. They help me with so much – cleaning, food shopping, personal care, cooking, escorting me to social events and so much more," Pamela says.

Two of the workers Pamela employs are immigrant women. Christina fled war in her home country of Sierra Leone and came to the United States at age 21, seeking the promise of opportunity and freedom. Norma escaped from violence in El Salvador and came to the United States when she was 25, leaving her whole family and homeland behind to pursue a safe future.

"Neither Christine nor Norma had immigration papers when they got here. But they had no choice but to come in search of a better life," Pamela says. "We have talked a lot about how hard it was for them being here – alone, without their families, scared they would be caught without papers."

Ultimately, Christina and Norma were able to become citizens. Pamela is focused on supporting the many other care workers who are undocumented. Pamela says, "It is time for a common sense immigration policy that works for people with disabilities – and the workers who support us to live independently."



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PAMELA LEE

Age: 48

Location: Bronx, NY

Pamela Lee's parents were born in San Francisco's Chinatown in the 1920s. They both worked low-wage jobs, mainly as a result of the widespread discrimination against Chinese Americans during that period. After years of struggle, Pamela's mother eventually got a job in a California state agency and Pamela's father became an engineer in Silicon Valley. They joined the middle class, bought a house, and eventually retired — grateful to a nation that allowed opportunity for all.

Now, at age 88, both of Pamela's parents require full-time care. "My mother has dementia and probably Alzheimer's, and my father had a bad bacterial infection that has left him very frail," says Pamela. "They both need help getting dressed, taking showers, cooking — really they need help with everything." Caring for her parents is a task that Pamela simply cannot do alone.

Pamela employs four immigrant workers to care for her parents. All four care workers are from the Philippines. "They are here because of the economic and political situation in the Philippines. They are some of the millions of Filipinos who are caring for families around the world," says Pamela. Pamela describes her parents' care workers with warmth and admiration: one sits with her mom and sings her songs, while another gives Pamela's father healing therapeutic massages.

Because of her desire for the people caring for her parents to be able to care for their own families too, Pamela ensures fair payment of the legal minimum wage in California to all of her workers. But \$10.55 an hour, without benefits, still amounts to over \$8,000 a month in costs for Pamela and her family. Even with long-term care insurance, Pamela and her parents are still left with an enormous financial burden. "Each month, I dip into their savings since my mother's pension doesn't cover it all," explains Pamela. "Eventually the money will run out."

The care workers not only help Pamela's parents in physical terms, but they also help honor her parents' dignity. "When my parents got sick," says Pamela, "they both said quite clearly they wanted to stay at home. So that's what you do!" Pamela wants immigrant care workers to be treated with the same respect and dignity they show her parents every single day. "I know that our society can do better — passing immigration reform that includes a true path to citizenship is one of the most important ways we can recognize the value of this immigrant labor."



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