

CAREGIVER NARRATIVE PROJECT:

Caregiving as an Act of Resistance and a Common Good



CALIFORNIA
Work & Family
COALITION



WHO WE ARE

The California Work & Family Coalition is a groundbreaking alliance of community organizations, unions, and nonprofits working together to pass laws and promote workplace policies that help parents, caregivers, children, and families thrive. We envision a world where all people have the time, resources, and support systems to care for themselves and their families and lead meaningful, healthy, and happy lives. Our mission is to organize communities to realize equitable, family-friendly workplaces and to expand the social safety net in California through policy, advocacy, and education.



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Photos by Immanuel Leka

Cover Photo: Kiran and her mother at the care facility where her mother lives. Kiran cared for her mother and father for 16 years and now continues to care for her mother who has dementia. Kiran spends time with her mother daily and takes care of her grooming, basic needs, and makes sure she has her favorite foods.

Caregiver Narrative Project

BACKGROUND

In 2021 and 2022, the Coalition received funding from the Robert Wood Johnson Foundation to identify and lift up narratives that reveal the importance of care, caregiving, and the dignity of both paid and unpaid family caregivers. We focused on bringing Coalition members together to study and discuss current popular perceptions of caregiving, and to listen and learn from each other to see how our own thinking about care shifted during the life of the project. In Phase One, Coalition staff led a hands-on process with members and allies which started with our hiring the [Berkeley Media Studies Group](#) to lead an investigation of current narratives and help organize a study group to identify themes we wanted to highlight and explore further. This led to the formation of a moving and transformative learning circle/photography project with Coalition members in Phase Two.



Arianne at her desk at home. Arianne is a single mom and caregiver to her son, Colin. She works at the airport and on the day of the photoshoot, she was balancing caregiving and getting her car repaired.

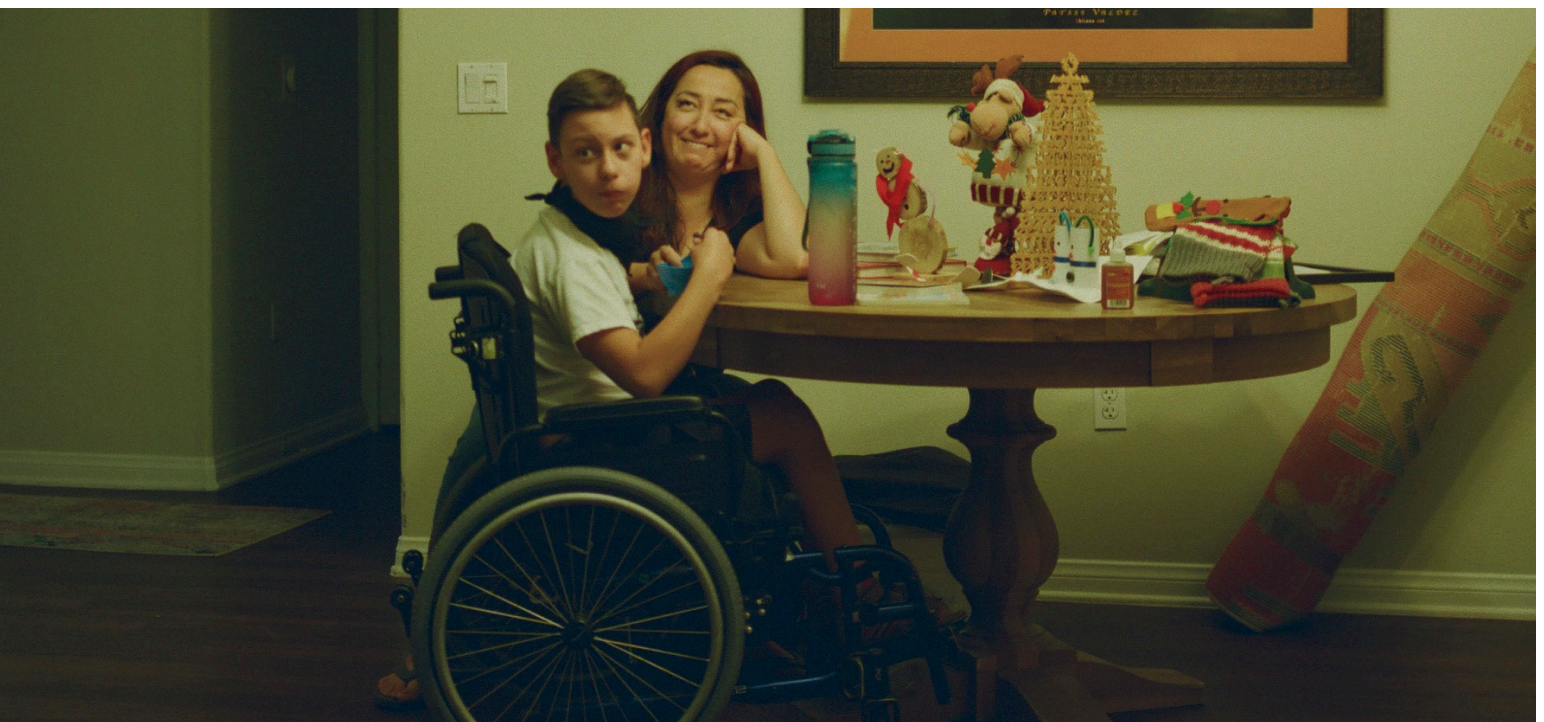
Phase One: Studying the Caregiver Landscape

Through a landscape analysis, Berkeley Media Studies Group identified dominant and emerging themes in media and the nonprofit and policy sectors around care. These included the invisibility of the act of caregiving rooted in racism and sexism/ gender oppression and a tension between the idea of caregiving as an individual problem and the concept of caregiving as something that is necessary for the common good and should be a shared societal responsibility.

At the start of Phase One, Coalition staff shared an open invitation to members and allies to join us in a study group where we could read and discuss current writings about caregiving. Fourteen members mostly from child care and eldercare-focused work joined and the number of people in the meetings varied from week to week. The study group became a space where members discussed current cultural narratives and art depicting the caregiver experience. Most Coalition members who participated said they appreciated the safe discussion space and the opportunity to take time out of hectic work lives to

discuss the ideas inspired by the political readings and visual art. A virtual visit to the Smart Museum of Art (Chicago University) *Take Care* exhibition sparked a moving discussion. The study group especially responded to [Song Yongping's series My Parents](#) in which the photographer captures stark and moving photos of family and care that we found both beautiful and heartbreakingly raw. The readings, viewings, and discussions in the study group helped surface the themes we focused on in Phase Two, the Caregiver Learning Circle:

1. The invisibility of caregiving rooted in race, gender, and family responsibility, and how we make the invisible visible
2. Pushing back against the idea of caregiving as an individual problem and looking at it as a shared/ societal responsibility and benefit
3. The inherent worth of care and caregivers apart from their monetary value or output
4. Caregiving as an act of resistance / a radical concept



Arianne and Colin

Phase Two: The Caregiver Learning Circle

FORMING THE LEARNING CIRCLE

We identified 15 participants from diverse backgrounds and organizations. Learning Circle participants ranged in age from early 20s to mid 60s. The group was made up of Coalition members in child care, legal services, unions, breastfeeding advocacy, caregiving, and disability rights. Participating members also included a retail worker, a college student, a photographer and a small business owner. Job titles ranged from entry level intern to executive director and department director. Learning Circle group members identified as African American/Black; Filipino; Asian; Latino/x; and White. Fifty percent of the participants were immigrants or the children of immigrants. As in the Coalition itself, the Caregiver Learning Circle was made up of a majority of people who identified as women, with 4 men and 11 women participating. A small percentage identified as caregivers at the start of the process and more started to see their connection to care and caregiving as we moved forward.

Coalition staff took special care to organize the Learning Circle project in a way that ensured ease of participation by a range of people and groups:

- ✓ We identified 15 Coalition members from diverse backgrounds and organizations and invited them to participate.
- ✓ Each participant made a commitment and signed an MOU.
- ✓ We provided each participant/organization with a \$1,000 stipend for taking part in the four 1.5 hour Learning Circle meetings.
- ✓ We hired a facilitator so that staff could participate freely in the discussions.



Colin and Jarod, from the Coalition/photo-shoot team, taking a selfie. Colin has visual impairment, so pictures and zooming onto the photo help him see what Jarod looks like.

- ✓ We held four Learning Circle meetings over a four month period.
- ✓ As a group, we established ground rules and community agreements in order to create a safe space to learn from each other and explore new ideas.

Since we found the “Take Care” photography exhibit especially moving, we decided to use photography to visually represent the themes we would be exploring in Phase Two of the project. We hired a freelance photographer who took part in the Learning Circle from the start, and Learning Circle participants helped us identify caregivers to photograph at the end of Phase Two.

MEETING 1: THE INVISIBILITY OF CARE ROOTED IN RACE, GENDER AND FAMILY RESPONSIBILITY

We started the first meeting of the Learning Circle by sharing our own experiences with giving and receiving care. We discovered that we all had been caregivers, received care, or anticipated giving or receiving care in the near future.

Some participants spoke about their experiences as immigrants growing up. One young woman said, “The expectation is that you care for your family members, but this does not necessarily have a name.” Many participants grew up with the idea of care as a responsibility, kept within the family, and not always talked about outside the home.

We explored the idea that the invisibility and marginalization of paid caregivers is based on race, gender, and immigration status and on who does the care in our state and country. Some noted that even within families the role of unpaid family caregiver often falls to one person and that the general invisibility of this role and work makes it harder as there is little support or compensation.

Facilitator Maria Loya led a visualization of a future in which caregiving is not just recognized but honored, awarded, and applauded. The majority of the group members shared that they found it uncomfortable to imagine themselves being called out onto a stage and receiving a standing ovation for being caregivers. But many resonated with the earlier part of the visualization where it was a sunny day and time with family members and care were woven into a workday without added stress or negative consequences.

“Caregiver: I think that a lot of people don’t necessarily identify with that word, that they see themselves as just being a good daughter or spouse or parents, but not that they’re doing something that is called providing care.”

—LEARNING CIRCLE PARTICIPANT, MEETING 1



Kiran explains how arthritis has caused swelling and pain in her mothers hands.

MEETING 2: CAREGIVING AS A COMMON GOOD—A SHARED/SOCIETAL RESPONSIBILITY AND BENEFIT

In the second Learning Circle meeting, we focused on the idea of normalizing care and lifting it up as a common good, not something that should be a private, individualized matter. One participant said, “We need to shift our culture to value interdependence more than independence. It helps to start to connect care to larger issues like housing, healthcare—the things we need in order to survive and thrive.” There was agreement around the idea that what human beings need to survive and thrive should not be commodities that one must be able to afford and that the people providing care and the cared-for all need support. In envisioning a world where caregiving is a shared societal responsibility, participants shared ideas of how this would look:

- » The infrastructure that makes caregiving possible is visible and available; there are places to go for support and respite, and everyone knows how to find them.
- » Professional caregivers feel valued and respected and have resources and time for themselves and their own families.
- » There is less shame attached to needing care and more ease in providing care.

One Learning Circle participant pointed out how the “personal responsibility trope” negatively highlights the idea that caregiving is difficult in part because the caregiver is financially unprepared; yet, in reality, most people are not ready when the need to provide care arises and struggle to afford taking time off from work. Another participant said, “We need care normalized for both the giver and receiver. The receiver should not feel different, wanting, a burden, or weak and the giver should not have to second guess taking time to care or that giving care ‘looks’ a certain way.”

“I have a vision of the future where my partner or loved one does not feel like a burden and where we both get the support and care we need. It’s a vision of neighbors flowing in and out of the home offering help—seeing people in the kitchen, laughing, talking, me feeling at ease—in community.”

—CAREGIVER, LEARNING CIRCLE PARTICIPANT

Another member noted that it was positive and normalizing for her son to see her caring for her mother-in-law. “It’s good role modeling for children to see that providing and needing care is a part of life.”

“Care is vital to our survival; we would literally die without it!” a Learning Circle member said. We all will need to receive care at certain times in our lives, from childcare to elder care. A culture shift acknowledging the centrality of care could spark the societal changes we need.

“If there were societal support, caregiving could be a viable and well compensated career path, something to aspire to instead of something to fall into—invisible and unsupported,” said one participant. Another added that she’d like to see care as a common good, normalized and respected so much that children would say “I want to be a caregiver when I grow up.”

MEETING 3: VALUING CARE AND CAREGIVERS SEPARATE FROM THEIR ECONOMIC CONTRIBUTION

In the third Learning Circle meeting, we explored the idea of valuing care and caregivers apart from their economic contribution or value. Immediately we grappled with the tension that exists in the nonprofit world and beyond between seeing certain work as “invaluable” and paying fair wages for that work. In other words, something that is considered invaluable is seen as being too important to hold monetary value; this idealized view of caregiving contributes to undervaluing the work—and underpaying the caregivers. This perception is out of touch with the reality that caregiving, while uniquely personal and often rewarding, is hard work that needs to be fairly compensated. More than one person noted that under capitalism, we often measure value in terms of cost and payoff. One participant noted that this plays out in advocacy work: “So much of how we advocate for why we need to invest in families and children and seniors is that they won’t need other publicly funded supports later in life—it pits the current need and future need.”

While recognizing the economic contribution that caregiving provides can be validating, centering the conversation around money/productivity can make us lose sight of the worth of caregiving that can’t be measured. One participant elaborated, “One of the values of caregiving is that it gives people compassion and patience, and allows knowledge and emotions to transfer across generations.”

“Keep moving forward, no matter what. To always take steps forward, even if it’s slowly, is resistance”

—CAREGIVER, LEARNING CIRCLE PARTICIPANT

“Too often we undervalue the ‘invaluable.’”

—LEARNING CIRCLE PARTICIPANT

Overall, however, the response to this theme varied based on participants’ own experience, linking it to the first theme of invisibility and gender in racial inequality. Caregiving in a family setting is often unappreciated, isolating, and uncompensated. Shifting to a world where caregivers are paid a living wage was at the top of participants’ minds. One member noted, “We can’t really think of this theme without understanding that real material exploitation is happening today. Quantifying care apart from the monetary value does not seem like something that many of us resonate with.”

MEETING 4: CAREGIVING AS AN ACT OF RESISTANCE

In the last Learning Circle meeting, we talked about how turning our focus toward caregiving is, in itself, an act of resistance that goes against the grain of a society focused on individuality and quick profits. As one participant put it, “Our society is focused on how to produce economically. How radical it would be if we focused on human needs instead.”

Another member added that supporting marginalized and vulnerable communities is a form of resistance to the structures that keep them in precarity and financial distress. Participants shared examples of how this could be seen during the pandemic—where communities would form mutual aid programs to support each other’s needs. From sharing funds to grocery drop-offs, or sharing information on how to navigate resources, many people were finding a way to form care networks during a time of isolation and financial strife: “We were almost reverting back to a time before care was commodified. We are going back to why it matters to care. That is radical.”

Reflections on the Caregiver Narrative Project: Lessons Learned, Takeaways, and Next Steps

The Caregiver Narrative Project, especially the Learning Circle phase, helped focus a core group of Coalition members on the importance of care and the idea that it should be valued and treated as necessary as the air we breathe. Our discussions united us in the conviction that we need to profoundly shift our culture to one that actively supports caregivers and care recipients for the benefit of all. The Learning Circle also pointed us toward the idea of care as a common good—one that everyone contributes to and benefits from both economically and socially.

Another important takeaway from the Caregiver Learning Circle was that stepping outside of our day-to-day work to explore new ideas and themes together is vital. Participants said that creating a safe space enabled everyone to think more expansively and creatively about caregiving and caregivers. The process was helpful in getting us out of the pragmatic, incremental thinking our state policy landscape often requires of us. As one member said, “These discussions help us stay strong internally.”

Another member expressed that this format was perfect because it “engages the heart and the mind.”

One challenge for us as advocates, however, was staying focused on the process of changing the narrative. We leapt from shifting the narrative as a vehicle for change to envisioning a future where all the change has happened and care is central, visible, and valued and where caregivers and care recipients have emotional and economic support.

Another takeaway was that it was important to have the photographer take part in the Learning Circle meetings in Phase Two even though it was challenging to keep the photography connected

“The Learning Circle deepened my commitment to working for a world where everyone has the choice to care from a place of security, safety, and support.”

—LEARNING CIRCLE PARTICIPANT



Arianne and Colin talking

to the Learning Circle in a seamless way. This was true mostly because it took place after the last meeting. The photographer said that being part of the discussions helped him and his team approach the sessions with “curiosity and compassion.” As one team member put it, “It was about creating an authentic, kind, and nurturing environment while being together.”

Continuing the Work

In the months since the last Learning Circle meeting, the Coalition has heightened our focus on caregiving in our legislative and education work. As we work on bills that expand the rights of caregivers in the workplace and lead caregiver trainings, we share the inspiration from the Caregiver Narrative Project by shining a light on caregivers and their stories to educate decision makers and remind other caregivers that they're not alone.

Members of the Learning Circle describe being more aware of caregivers and caregiving responsibilities in the families they support. One member who works with African American families with new children said the Learning Circle experience helped her see the different roles fathers and other family members play and gave her ideas of how to better support them as well. A workplace organizer who took part in the Learning Circle said it opened her eyes to the ways workers are currently able and unable to take care of each other. And other Learning Circle members shared that they felt their whole orientation around caregiving has shifted. One member said, "I used to see caregiving as a problem and an obstacle; now I see it as an opportunity and a positive."



Kiran helping her mother



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Learning Circle staff and participants: Alisha Ko; Angelica Andrade; Arissa Palmer; Charlette Flanders; Daniel Nesbit; Donna Benton; Immanuel Leka; Jarod Caceras; Jenya Cassidy; Karina Laigo; Karina Soto; Katie Duberg; Kayla Shore; Lydia Boyd; Natasha Castro; Nina Weiler; Ricardo Alonzo Ugalde; Sarah Diaz; Sharon Terman; Sukhdip Purewal Boparai.

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