

Co-Creating a Financially Sustainable Future for Caregivers

2024 Caregiver Coalition Report



Table of Contents

Page	Section
3 - 4	Executive Summary
4 - 8	Background
8 - 14	Methodology
14 - 18	Findings
19	Recommendations and Next Steps
20	Acknowledgments

Executive Summary

Over the past several years, the U.S has [increased its efforts](#)¹ to address the sustainability and well-being of caregivers across the country. Public health events like the COVID-19 pandemic amplify the critical role that caregivers and care workers play in the fabric of our society, especially in communities of color. Blacks Americans are [30% more likely to be caregivers](#) than their white counterparts and spend almost 13 more hours each week in caregiving activities.² Yet, despite their importance, caregivers are [too often excluded from the creation](#)³ and implementation of the very policies that impact them most.

To begin addressing this gap, Health Leads, with the support of the Lucile Packard Foundation for Children's Health, established the National Caregiver Coalition in 2023, following its inaugural [National Caregiver Summit](#). The Coalition, composed of family caregivers, care workers, care receivers, and organizational partners, developed advocacy priorities aimed at enhancing caregiver financial sustainability. Convened and facilitated by Health Leads, the Coalition designed **a communications tool with specific calls to action aimed at key stakeholders** - including employers, healthcare systems, and policymakers - who have the power to ensure caregivers have the resources they need to thrive and continue their important work of keeping communities healthy.

Through a unique, equity- and community-led process grounded in design justice, Health Leads uncovered several key learnings that we recommend teams apply to both future caregiving advocacy and other Coalitions fighting for systems change:

- **Enhance outreach to incorporate the perspectives of care receivers in advocacy efforts aimed at sustainable caregiving.** Effectively incorporating the lived experience of care receivers ensures that any proposed care strategies resonate with their unique contexts as well as those of the caregivers themselves. During the Coalition recruitment process, we learned that prioritizing caregivers in our outreach efforts may have inadvertently diminished the opportunity to elevate the voices of care receivers as well. Upon reflection, we realigned with our partners in the recruitment process and successfully onboarded two care receivers to the Coalition. If we were to repeat this process, we would create distinct recruitment materials for care receivers and intentionally engage organizations that work closely with them.
- **Ensure Coalition members are adequately paid for their expertise.** Despite our careful planning, budget constraints and the challenges of an hourly payment

¹<https://www.whitehouse.gov/briefing-room/presidential-actions/2023/04/18/executive-order-on-increasing-access-to-high-quality-care-and-supporting-caregivers/>

² <https://pubmed.ncbi.nlm.nih.gov/11129751/>

³ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9626797/>

arrangement limited our ability to fully engage Coalition members and contractors at various times. In the future, we will explore offering a monthly stipend to account for the flexibility needed to do this work effectively and respond to the cohort's needs.

- **Allow ample time for pre-planning, and processing with stakeholders, not only for project execution.** Health Leads planned four foundational sessions for grounding the Coalition in shared language, values, and understanding of key concepts. Each topic area was allotted a single 90-minute session. When we found additional time was needed, we added additional sessions to meet the needs of the group. Given the diversity of the cohort, we realized in the process that an additional session would be needed to align on critical definitions that framed our work. In hindsight, it is clear that more time should have been allotted upfront for this phase of the work.

The Health Leads Caregiver Coalition successfully demonstrated the power of a diverse cohort with lived expertise in identifying and designing solutions for the future of this critical field. It was further proof that communities themselves are best suited to advocate for the progress that would make the greatest impact and that creating the time, space, and resources to uplift those voices is a critical first step. This report will lay out our process and approach as well as insights gained in our aim to design a caregiver-driven solution to caregiver financial sustainability. Looking ahead, the Coalition aims to launch a communications campaign around their tool, to both raise awareness and advance advocacy efforts for caregiver sustainability.

Recruitment & Composition

The Caregiver Coalition was established in 2023 in response to guidance received from caregivers who designed and attended the inaugural summit. A collective of caregivers (accounting for the majority of the members), organizational partners, and care recipients, this group included those who support individuals with special health needs and/or disabilities ranging from children and adolescents to adults, as well as caregivers for seniors and military veterans, among others.

Our objective was to **assemble a diverse and inclusive group of caregivers**, encompassing both family caregivers and care workers, including compensated and uncompensated individuals, organizational partners, and care receivers who would work together for 16 months to **incubate a solution for caregiver financial sustainability**. We also considered factors such as the type of care recipients the caregivers supported, geographical location, race and gender.

To attract applicants, we engaged former Summit design team members to either apply themselves or disseminate the opportunity within their professional networks. We utilized various social media platforms and communicated with Health Leads' networks and partners, which included healthcare organizations, community organizations, advocacy groups, and philanthropic entities. A media toolkit, including flyers and email templates, was distributed to our networks to facilitate the sharing of this opportunity. The materials were provided in both English and Spanish. We clearly articulated the expected time commitment, ensuring that potential applicants could assess how the role would align with their schedules. Key terms, such as "caregiver," were defined to help individuals determine their eligibility. Lastly, we encouraged individuals to reach out with any inquiries, emphasizing our preference for questions over potential applicants opting out due to uncertainty.



Coalition members later reported:

- 18.8% or 3/16 members discovered the Coalition through the flyer;
- 25% or 4/16 members discovered the Coalition through a Health Leads employee;
- 56% or 9/16 members discovered the Coalition through a variety of ways; including LinkedIn, hearing from other organizations, talking with a coworker, etc.

Recognizing that caregivers have limited time, we were determined to make the application process as easy and low-effort as possible, while still allowing us to get to know the applicants.

Application Process: Round One

Applications were open for round one for 5.5 weeks to allow enough time for word to spread and those interested to apply. This gave us some flexibility to adjust the recruitment process, if needed, and have enough time for application review and a second round to connect with applicants more deeply.

For round one, we asked general questions that all applicants answered, followed by specialized questions for caregivers, organizational stakeholders, care receivers and those applying to be co-leads. The general questions included demographic information, relationship to caregiving, availability, role for which they were applying, and general

views on equity and caregiver advocacy. There were no right or wrong answers; this information provided us with a clearer understanding of the cohort and allowed us to build the foundational sessions around their needs. Applicants also had to choose if they were applying to be a Coalition member, Coalition co-lead, or if they were open to either position.

We spent a week on application review and employed practices such as blind application review, where reviewers of applications did not see the name or demographic information for applicants, only an identification number. Each application was [reviewed](#) and scored by two Health Leads team members. The review rubric included a bias call-out box, allowing reviewers to self-identify any notable biases they may hold, so the core team would be aware.

Upon reviewing the 52 applications, the core team recognized a bias toward the perceived writing ability of applicants – those with a more academic writing style were ranked higher. The core team decided to retain some of the lower-scored applications, focusing primarily on the unique perspectives the applicants would bring to the Coalition. Attracting care recipients, however, proved to be the most challenging aspect of our recruitment strategy.

We advanced 24 applicants to the second round.

Application Process: Round Two

For the second round, we encouraged participants to submit their responses to the provided prompts either in writing, audio, or video. We used a similar rubric for evaluating the submissions for the final round, and highly encouraged applicants to submit a video or audio file to create a more equitable process. The provided prompts were designed to give us a deeper understanding of what each applicant would contribute to the Coalition. For those who expressed interest in being co-leads, we considered their ability to meet the time commitment and their recognition of the key role others play in caregiving as we believed these individuals would more naturally create community among the diverse cohort of caregivers. Out of respect for the applicants' time, they were compensated \$75 for completing the application, which was well-received and appreciated.

The Coalition recruitment process included:

- A simple, **easy application process** and blind application review, where reviewers of applications did not see the name or demographic information for applicants, only an identification number.
- A process for **recognizing and accounting for bias** during application review, which revealed a bias toward the perceived writing ability of applicants. Those with a more academic writing style were ranked higher.
- A second round of accepting **answers to prompts** via writing, audio, or video, to give us a deeper understanding of what each applicant would contribute.
- **Compensation of \$75** for completing the application.

Through this process, Health Leads selected [16 members for the Coalition](#). We ensured caregivers made up at least 51% of the Coalition, thereby amplifying their voices. We exceeded this goal, with 63% (10 of 16 members) of Coalition members bringing the caregiver perspective, 12% (2 of 16) care receivers, and 25% (4 of 16) organizational partners. Notably, while 63% of participants identified as caregivers, one care receiver and three out of four organizational partners also had caregiving roles, resulting in 87% (14 of 16 members) of the Coalition having direct caregiving experience.

Among the family caregivers cohort, 31% (5 of 16 members) cared for children and youth with special health care needs, 25% (4 of 16 members) for children without such needs, 25% (4 of 16 members) supported older and disabled adults, 6% (1 of 16 members) cared for military veterans, and 6% (1 of 16 members) assisted disabled adults.

The Caregiver Coalition defined a *family caregiver* as any family member, friend, or neighbor who provides any kind of support including: social and emotional support, transportation, errands, medical tasks, as well as, helping with organizing care, managing finances, and making health care decisions. Proximity of family caregivers can range from living with the care recipient to living nearby or in a different state or country. While some family caregivers are compensated for the care they provide, this role is often unpaid.



In the care workforce, 25% (4 of 16 members) were community health workers, with an additional 6% (1 of 16 members) consisting of home health aides, peer support specialists, and doulas. The Caregiver Coalition defined *care workers* as someone who provides care and is usually associated with a formal service system. This support can be provided in the care recipients' home, community, or an institution. Formal caregivers often work closely with family caregivers to optimize care for the care recipient. Examples of formal caregivers include, but are not limited to home health aides, peer support specialists, community health workers, and doulas. Too often these roles do not provide a living wage.

Additionally:

- Both care receivers involved are/were youth with special health care needs.
- The organizational partners represented various sectors, including philanthropy, academia, health plans, advocacy, nonprofits, policy, and employers.

- Geographically, Coalition members represented the East, West, South, and Midwest, covering 12 states.
- 19% (3 of 16 members) were male and 81% (13 of 16 members) were women.
- 50% (8 of 16 members) were black and 50% (8 of 16 members) were white.

Compensation

We aimed to provide a fair compensation rate for Coalition members, demonstrating our value for lived expertise. Coalition members were compensated \$100/hour for up to 4 hours per month, while co-leads were compensated \$150/hour for up to 8 hours per month. The difference in pay accounted for the varying responsibilities assigned to each role. Coalition members were asked to attend bi-weekly 90 minute meetings, complete post-surveys, and review occasional pre-reads. Co-leads were required to attend and facilitate meetings, and support the Health Leads team in incorporating feedback from Coalition members into the planning of sessions.

Recruitment Feedback

Overall, Coalition members provided positive feedback about the application process, describing it as easy, fair and thorough. They appreciated the options for submitting responses, especially the video response. As a result of this process, we assembled an extremely diverse group of caregivers, organizational partners, and care receivers. A majority of the Coalition (14/16) members feel the recruitment process (two rounds) was adequate.

Methodology: Goal Setting & Strategy

Over 16 months, Health Leads led the Coalition through a comprehensive process to evolve and work towards core goals that were established by caregivers from the inaugural summit:

- **Strengthen a united caregiver voice, while broadening the caregiving advocacy community.** Coalition members noted the transformative impact of dismantling silos, reducing isolation and fostering collaboration among caregivers. They also stressed that achieving meaningful change requires the involvement of organizational partners, such as health systems, payers and funding entities, as well as care receivers.
- **Offer solutions for caregivers, by caregivers.** A key tenant of Health Leads' approach to designing solutions is that those who are most impacted by the barriers must not only inform but drive the solutions we design and test. Caregivers remained the primary decision-makers and drivers of the Coalition.

- **Build a mobilizing advocacy platform focusing on caregiver financial sustainability.** The group overwhelmingly agreed on centering on improving the quality of life for caregivers, including equitable compensation, paid leave and self-care.

The Coalition's co-leads worked closely with each other and the Health Leads team to integrate caregiver perspectives into the planning, strategies and facilitation. This partnership was vital for maintaining accountability in our mission to build power. One co-leader was a parent of two, including a child with complex medical needs, while the other co-leader was a community health worker who also cared for their parents. Their contributions were pivotal in planning and executing Coalition meetings, offering essential insights and guidance.

To facilitate Coalition members in developing a solution to improve caregiver financial sustainability, we structured the process into key phases: *Foundational Sessions*, *Defining the Problem*, *Brainstorming Solutions*, *Designing a Model for the Idea*, and *Testing the Ideas*.

Foundational Sessions

The Caregiver Coalition first convened in January 2023 and embarked on foundational sessions focusing on empathy, relationship building, language alignment, policy analysis and innovation to deepen understanding and address biases within caregiving. Health Leads constructed these sessions around key content:

- Establishing community agreements on how we would work together and care for each other in our shared spaces.
- Reaffirming our commitment to our community agreements at the start of all subsequent meetings (see [Appendix A](#)).
- Engaging in relationship-building activities so that members could learn about one another, both as individuals and through their caregiving journeys.
- Examining the historical context of caregiving and the systemic causes of caregiver inequities, including a deep dive into language (defining terms like equity, racism, sexism, and ableism), and aligning on key terms including “caregiver” and its various subcategories. The Coalition decided to develop their



own definition to capture the breadth of caregivers' roles (see [Appendix B.](#))

- Understanding the role of innovation, with a comprehensive overview of design justice, emphasizing the importance of driving solutions that are both meaningful and practical from the perspective of those who will be most impacted.
- Exploring policy with a panel of four speakers representing family caregivers, home health aides, community health workers and doulas.

With the table set for collective action on caregiver sustainability, the group moved into problem definition.

Defining the Problem

During this phase, the group started by applying the first step of design thinking and empathy mapping, which involves visualizing the thoughts and experiences of the people for whom we are designing solutions. Coalition members drew on their personal experiences, insights from the foundational policy session, and their research to gain a deeper understanding of the problem of caregiver financial sustainability. The Coalition's analysis:

- **Caregivers are vital to our care system and economy.** If caregivers are forced to step away from their roles due to a lack of financial sustainability and other support, it jeopardizes well-being of those for whom they care, as well as their entire family.
- Compensation for caregivers is unfair **compensation.** The current institutional systems often fail to fairly compensate caregivers, and in many cases, they are not compensated at all for the care they provide.
- There is a **growing shortage of caregivers.** There is a critical shortage of caregivers, as many are moving to other sectors like retail and food service for better compensation and benefits.
- **Everyone is impacted.** Both the immediate and downstream consequences of a caregiver shortage affect everyone's health and well-being.

The Coalition also identified the complexities of achieving financial sustainability:

- **One size doesn't fit all.** While caregivers share similar experiences, there are unique aspects and societal expectations for different types of caregivers.
- **Existing solutions aren't adequate.** While Medicaid plays a role in caregiver compensation and reflects government involvement, it cannot be the only solution.
- **No unified national solution.** Caregiver support varies by state, with many programs available only at the state level, and funds don't always flow directly to the caregiver.
- **Temporary nature of existing funds.** Some caregivers such as community health workers, are compensated through temporary channels like grants.

The group explored several key questions focused on five areas: incentives and pay, caregiver value, partnerships and organizing, shifting the narrative, and guiding principles. Most questions centered on incentives, pay and caregiver value, leading to the Coalition's final key question:

How might we ensure all types of caregivers are valued as an essential and vital part of the healthcare system and are provided adequate support and fair compensation?

Brainstorming Solutions

The Coalition aimed for a unique solution and participated in activities designed to help them generate ideas. The brainstormed opportunities fell into four categories:

1. **New Measure.** Develop and test a new measure to capture the impact of caregiving that isn't currently being recognized.
2. **New Communication.** Establish a new way of communicating the financial impact of caregiving in a way that resonates more broadly.
3. **New Action Tool.** Create a tool to support peer action, overcoming barriers in implementing and communicating known financial impacts.
4. **Data for Change.** Analyze existing datasets in a way that highlights the desired impact and share the results.

Health Leads led Coalition members through several creative and collaborative activities to explore and determine the feasibility of each idea. For example, Coalition members designed skits to illustrate their ideas; they acted out these ideas with the understanding that if it couldn't be acted out, it likely wasn't practical for the group to pursue.

Ultimately, the group chose to create a **novel communication tool** focused on the care receiver's perspective to advocate for caregiver financial sustainability, believing that mindset change was an essential starting point.



The Coalition began a comprehensive review of existing caregiver-related content, including music, literature, documentaries, films and television programs. They analyzed these materials to validate their idea's value proposition and identify the strengths and weaknesses of the current offerings.

Health Leads supported the Coalition’s determination to not conform to the status quo. They distinguished their content from existing materials by:

- Incorporating the care receivers’ viewpoints to underscore the importance and multi-faceted impact of caregiver financial sustainability;
- Highlighting what works well and its impact, versus only focusing on the barriers and deficit (a more asset and strengths-based narrative);
- Integrating humor with the seriousness of caregiving situations;
- Illustrating the intersectionality of perspectives.

The value proposition for this idea includes the opportunity to humanize caregivers and care receivers, present solutions that advance the conversation around financial sustainability, and foster a sense of belonging. As a result, the Coalition developed a communication tool titled “[A Day Without A Caregiver](#),” hosted and narrated by care receivers.

The series aimed to showcase the consequences of care receivers being without a caregiver and the benefit of receiving quality care. It also illustrated the domino effect of having versus not having quality caregiving on the individual, family, employers, providers and others in the care ecosystem. The Coalition identified several priorities for the storylines:

- **Calls to Action.** Each storyline should include clear calls to action, including those aimed at fostering systemic change.
- **Data and Mythbusting.** Incorporate relevant data and debunk common myths.
- **Contrast.** Highlight the differences between having and not having a caregiver.
- **Unexpected Relationships.** Explore relationships that might not be immediately obvious.
- **Quality of Life Moments.** Emphasize moments that improve the quality of life for care receivers and caregivers.



With these details established, the Coalition moved to the prototyping phase.

Designing the Model of Idea

The objective of this phase was to develop a tangible representation of the Coalition’s novel communication tool. The team created a journey map that visualized a typical day for a caregiver. The map was divided into morning, afternoon, evening, and late evening. The late evening was included to dispel the myth that caregivers can rest during this time,

highlighting how many caregivers are still engaged in their caregiving duties late into the night.

It was important to caregivers that the storylines be based on true stories, so they shared their personal experiences. As they documented their days, the Coalition mapped elements of the storylines to a customized tool that tracked how well they aligned with the unique attributes they developed. For some, sharing their stories was cathartic, as they found common ground with other caregivers. However, others experienced vicarious trauma, making it difficult to relive and share their experiences. The group often leaned on their community agreements to care for themselves and each other.

As the group identified their experiences, storylines began to emerge. Coalition members were divided into three separate groups to further develop their storylines, each with a unique caregiver and care receiver focus.

Group A - Further evolved a storyline that highlighted a youth with special healthcare needs being cared for by their mother with support from a neighbor. Coalition members highlighted the experiences of the care receiver and caregiver throughout this storyline. In doing so, they highlight the role employers could play in supporting caregivers and the vital role that care workers, like home health aides, play in supporting families. It reminds us that these care workers are often caregivers themselves and notes the need for better pay and benefits for them. They reveal the domino effect of not caring for our caregivers, both family and care workers.

Group B - Developed a storyline that highlighted an older adult being cared for by one of their children, then caregiving suddenly shifts to the other child. Coalition members further developed the experiences of each of these individuals as they navigate these changes. They highlight the role healthcare could play and how care workers like community health workers are an important part of the solution.

Group C - Created a storyline that notes the experiences of a woman giving birth for the first time. The Coalition highlighted the need for addressing the overall health of the expectant mom - physical, mental and emotional health. They highlight the critical role that doulas play in improving maternal health outcomes, with a specific focus on effectively integrating doulas into the care team.

Once the storylines were developed, Coalition members prepared to share them with individuals in their trusted network. We referred to these individuals as research participants.

Testing the Idea

Coalition members invited their networks to review the storylines and provide feedback. The Coalition determined that those who participated would be compensated \$100 for engaging in the process. Coalition members also provided input on the [feedback guide](#), and some co-led the feedback sessions. Input was gathered from research participants via virtual interview style conversations. The first round of feedback sessions allowed the Coalition to test the assumptions and value propositions. The innovation framework focused on three key areas:

- **Desirability:** Creating something people want to use.
- **Feasibility:** Designing within our resource capabilities.
- **Viability:** Ensuring sustainability over time.

After analyzing demographic data, including the experiences of those we interviewed (e.g. youth with special healthcare needs, caregivers of older adults, employers) with the Coalition we highlighted key perspectives that were missing. An example is the male caregiver point of view. We conducted two additional rounds of feedback to capture key perspectives. The group conducted three rounds of testing in total.

After each testing round, we synthesized our learnings (noted in the following section) to refine the working model. This iterative and flexible approach allowed us to continuously enhance our mockup and pinpoint areas where we fell short of our objectives. In total, 21 research participants from diverse caregiving backgrounds and locations across the country contributed their insights.

Findings

Once testing was complete, the Coalition collaborated with our graphic designer to bring the storylines to life. Preparing for the Caregiver Summit 2024, the team enhanced the presentations with better graphics, voiceovers, and music to help attendees visualize the storylines as real videos. Testing revealed:

- **Demand for storytelling:** People are hungry for content on the topic of caregiving that prioritizes authenticity and the human aspect.
- **Overemphasis on academia:** Many research participants feel there is an excess of content grounded in academic frameworks, which can strip the human experience from caregiving narratives.
- **Preference for concise impact:** There is a desire for shorter, impactful content and many told us that they don't have time for the longer form content.
- **Emotional connection:** Research participants resonated with our storylines and felt acknowledged and understood.

We unveiled "A Day Without A Caregiver" at the 2024 Caregiver Summit to an audience of 167 attendees, and this was our fourth round of feedback. Audience feedback revealed that the communication tool was uniquely powerful and useful. Nearly 70% of respondents 'strongly agreed' and 31% 'agreed' that the stories could be used to start or advance conversations to advocate for caregivers' needs.

Summary of Storylines & Calls to Action

The Coalition created a mock up of three storylines that highlight the experiences of caregivers and care receivers with calls to actions that can be taken at the individual, organization, and/or systemic level. Legislative actions were designed to make systemic impact and built off of existing calls to actions. There are many caregiver and care worker organizations with a specific focus on advocacy. The Coalition was intentional about supporting existing efforts rather than disrupting or distracting from these efforts.

'Domino Effect: A Day Without A Caregiver,' shows Ana, a family caregiver who is caught between deciding to stay home to care for her young adult son, Javier, or going to work after learning their home health aide is unavailable to come to their house to care for Javier. As the day continues to unfold, Ana is offered a promotion that becomes yet another tough choice - this is a promotion that Ana has been working towards, but it's not a given that she can accept it due to the nature of managing both the responsibilities that come with her professional role and caregiver role. This storyline highlights the challenges family caregivers often face when balancing the demands of their career while caring for a loved one.

Individual Call(s) to Action: Get informed and share knowledge about the resources available to caregivers and share with other caregivers. This would include a resource bank, similar to one provided by [Family Voices](#).

Organization Call(s) to Action: Create a safe and supportive space for caregivers at work. Examples include:

- Create an uplifting space: Design an affinity or resource group for caregivers or anyone who might find the conversations, information, and resources useful (like someone who might be a caregiver in the future).
- Provide family caregiver days: Distinguish this time off from PTO or sick / wellness time so that employees who also have caregiver responsibilities are supported.

Legislative Call(s) to Action: Create and/or support legislation that invests in family caregivers and direct care workers, examples include:

- [Paid Leave for All](#) advocates for paid and medical leave for all working people.
- Adopt the [VA Program of Comprehensive Assistance for Family Caregivers](#) as a federal policy.
- [Social Security Caregiver Credit Act](#) would allow caregivers who are forced to

leave the workforce to continue to build toward their retirement.

In "*The Collision of Responsibilities*," a healthcare professional, Michael, debates approving a family caregiver education program, recognizing its value but ultimately rejecting it due to competing priorities. Yet, when Michael unexpectedly becomes a caregiver themselves after a family accident, Michael faces the harsh reality and challenge of inadequate training and support, underscoring the vital necessity of caregiver education and resources in healthcare. This storyline emphasizes that caregiving can be a universal experience that touches everyone at some point in their lives and the importance of adequately preparing and supporting caregivers.

Individual Call(s) to Action: Be or continue to be role models:

Through your daily actions, emphasize that caregiving is a precious community resource that we all contribute to and take from throughout our life span.

Organization Call(s) to Action: Invest in community based workforces:

This includes, but not limited to community health workers/promotoras, doulas, home health aides, and peer support specialists. Ensuring patients have consistent support from the point of entry to point of stabilization, will help family caregivers feel better equipped and support better outcomes for care receivers.

Legislative Call(s) to Action: Support legislation that invests in community health workers/promotoras, examples include:

- [Change physician fee schedule through CMS](#) this will provide reimbursements for CHW/Ps providing education to family caregivers;
- The [Community Health Worker Access Act](#) would provide for Medicare reimbursement of CHW/Ps and community health representatives and create an optional Medicaid benefit to cover preventive services to address social needs furnished by CHW/Ps and community health representatives.

“Operation White Coat: The Dance for Healthcare Excellence” highlights the importance of doula integration into the clinical care team. Data has proven that doulas are part of the solution in improving health outcomes for black birthing people. Women with doula care are 58% less likely to experience postpartum depression and anxiety.

This storyline shows the barriers that doulas often face in supporting their clients - a lack of understanding and appreciation of their role by the clinical team. We see what is possible when a provider champions the integration of doulas in the care of their patients.

Individual Call(s) to Action: Share knowledge. Talk to friends and families about the role of doulas during prenatal, birth, and postpartum care and how doulas drive positive birthing outcomes.

Organization Call(s) to Action:

- **Build a Pipeline.** Health systems can build relationships with local doula organizations and implement a formal referral process to connect birthing people with doulas.
- **Educate All Members of the Clinical Care Team.** Include information about doula care in the training and onboarding materials for clinicians, and provide education and skills training for collaborating with doulas. Ensure that staff understand the benefits that doula care offers to the birthing person, their child, and members of the clinical care team.

Legislative Call(s) to Action: Support legislation that invests in the doula workforce and maternal mental health. [Black Maternal Health Momnibus Act](#) includes 13 individual bills that support black maternal health, specifically:

- *The Perinatal Workforce Act* will increase the number of maternity care providers and non-clinical perinatal health workers who offer culturally congruent care and support during and after pregnancy.
- *The Moms Matter Act* will make investments in programs to support moms with maternal mental health conditions and substance use disorders. It also provides critical funding to grow and diversify the maternal mental and behavioral health care workforce.

Coalition Engagement

Health Leads tracked several measures to ensure the Coalition was highly engaged in their charge to incubate solutions for caregiver financial sustainability, maintaining an average monthly attendance rate of 88%. We were diligent about meeting Coalition members where they are, recognizing that they have very busy schedules and may need to perform caregiving duties unexpectedly.

To support engagement and attendance as part of the recruitment process we collected availability then confirmed that the selected date and time would work for the Caregiver Coalition. Meetings occurred at a regular cadence and time, so everyone knew when to expect meetings. Health Leads sent calendar invitations and an email days prior to the meeting to remind the cohort of the upcoming meeting, they also included an agenda. An accommodation that we found helpful for some members to participate was sending the materials and questions that would be posed ahead of time, so they could prepare accordingly.

Coalition members were communicative with the project team about meeting attendance. For those who were unable to attend they knew how to access the materials to review, provide input (as needed), and be up to speed for the next meeting. If someone was missing at the start of the meeting and did not inform us that they would be absent or late we reached out to them via their preferred communication method, which we collected during the onboarding process, this included phone calls and text messages. Coalition members appreciated having these reminders from time to time.

We followed up with members who were experiencing challenges, like health challenges of their own or of the individual(s) they cared for or bereavement. We followed up with notes and phone calls to extend additional support as needed. If someone seemed quiet in a meeting, we followed up via phone or text to ask if it would be helpful to go over anything covered in the meeting. We received feedback that this was appreciated and helpful.

Finally we collected feedback via survey after each meeting to learn what worked well and what could be improved. For complicated matters, we reached out to members to understand the opportunities for improvement and implemented their suggestions when possible. We highlighted at the top of each meeting, the changes we made according to the Coalition's feedback.

Members regularly evaluated key outcome measures, including their sense of belonging, perceived impact, value, and communication.



Participants rated each session on a Likert scale (excellent to poor) and shared their thoughts on two critical questions: *'What should we keep doing / what worked / what did you enjoy?'* and *'What should we change / what didn't work / what was dissatisfying?'*

Every quarter, the Health Leads team paused to assess our processes through an equity lens, addressing diversity, inclusion, bias, and barriers to participation. This reflection allowed for ongoing process refinement and adjustments based on feedback. In addition, members completed a mid-way check-in survey to assess recruitment, onboarding, and operations, with results actively used to enhance effectiveness. This continuous cycle of feedback and adaptation was crucial for fostering a responsive and inclusive environment.

Recommendations and Next Steps

Future Opportunities for Caregiver Advocacy

The Caregiver Coalition successfully demonstrated the power of a diverse and large cohort to build a strong community and actively seek solutions for all caregivers. The development and testing of advocacy storylines led to a strong communications tool - a video for advocacy - that was well received at the [National Caregiver Summit](#) and has the potential to be a powerful tool for change with stakeholders across the caregiving spectrum.

Looking ahead, the Coalition aims to further refine the storylines and calls to action and create a discussion guide/training to raise awareness and advance advocacy efforts for caregiver financial sustainability. This could include a strategic communications campaign leveraging the resulting and fully produced video to pitch and secure meetings with key influential stakeholders, spark conversations and interviews with media, support the placement of op-eds, present at select conferences and place as a paid digital ad targeting core audiences. While the general population would benefit from this content, audiences of focus include employers, health systems, and managed care organizations.

To achieve this goal, securing funding is essential. Key activities would include:

- Recruiting a cohort of caregivers, care receivers, and organizational partners to incorporate remaining feedback into the prototypes and gather additional perspectives as needed.
- Creating and testing a discussion guide and calls to action to accompany the storylines.
- Partnering with key caregiver advocacy organizations to ensure calls to action are additive to existing efforts.
- Collaborating with a graphic designer, video producer and/or web designer to finalize the design of the tool and supporting promotional materials.
- Developing a full communications campaign around the video and supporting materials.

As we look to the future, we will continue to refine our approach, with a focus on deeper engagement, expanding resources, and enhancing support for family caregivers, care workers, and care receivers alike.

Acknowledgements

Caregiver financial sustainability is a critical and massive undertaking. It cannot be done solely by one individual or group. It requires all of us to come together and apply our collective power and expertise.

We extend our heartfelt gratitude to the [National Caregiver Coalition](#) for their unwavering commitment to this initiative. They have engaged both heart and mind in this endeavor, prioritizing the needs of fellow caregivers throughout the process. Many participants gained insights into caregiver roles they had not previously recognized, and these individuals became strong advocates for their peers. As anticipated, the group encompassed a wide range of viewpoints, yet they collaborated effectively and supported one another during this journey. We are profoundly thankful for their role in holding us accountable, highlighting our strengths, and consistently encouraging us to strive for inclusivity and equity.

We also express our sincere appreciation to the caregivers who played a pivotal role in organizing both the [inaugural Caregiver Summit](#) and the [2024 Summit](#). The vision of the Caregiver Coalition is a testament to their efforts, with many actively contributing to its realization—whether through providing feedback during the summit's design phase, assisting with recruitment, applying for Coalition membership, or shaping the 2024 Summit. Current members of the Summit design team also offered valuable insights on the communication tool developed by the Coalition. Thank you for your dedication, vision, and expertise!

We want to extend our heartfelt thanks to the Lucile Packard Foundation for Children's Health (LPFCH) for its generous support, which has been instrumental in advancing the Caregiver Coalition.

About Health Leads

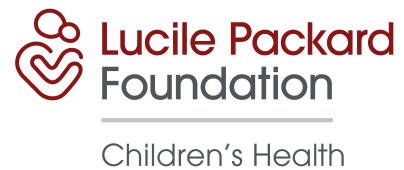
An innovator in community-led health equity initiatives and advocacy for over 25 years, [Health Leads](#) drives toward a vision of “health, well-being, and dignity, for every person, in every community.” We believe this vision must be driven by community leaders, especially caregivers, who know firsthand both the barriers to health and solutions for systemic change.



Health Leads has a proven track record of working collaboratively with local and national partners to unearth and address the root causes of some of the most pressing and complex health equity challenges of today. From maternal health to vaccine access, to housing and food security, our collaborative initiatives are focused on removing systemic barriers to health and building a future where communities have the essential resources they need to thrive.

About the Lucile Packard Foundation for Children’s Health

[The Lucile Packard Foundation for Children’s Health](#) is here to unlock philanthropy to transform health for all kids and moms, in Northern California and around the world. We are champions for children—driving extraordinary care for families today while fueling research, discovery, and change in our health care systems for a better tomorrow.



Our Foundation raises funds for child and maternal health at Lucile Packard Children’s Hospital and the Stanford School of Medicine. We also shape and support programs that make healthcare more accessible for children with complex medical needs.

Support for this work was provided by the Lucile Packard Foundation for Children’s Health, Palo Alto, California, [LPFCH.org/CYSHCN](#). The views presented here are those of the authors and not necessarily those of the Foundation or its directors, officers, or staff.



For more information about this initiative:
Tigee Hill , Executive Director, East
thill@healthleadsusa.org

Appendix A.

Community Agreements

- **Be Present & Accountable**
 - Feel no pressure to speak yet resist the temptation to stay silent
- **Be Brave, Be Inclusive**
 - Our values, cultural identities, and personal experiences matter. Recognize that conflict is always possible and conflict is OK
- **Take Space & Make Space**
 - Call attention to people's unheard voices, ensuring that all individuals have space to fully participate
- **Address Racially Biased Systems and Norms**
 - Call out power dynamics. Recognize personal biases and consider how they might impact actions. Avoid becoming defensive when Black, Brown, or Indigenous folks speak from lived experiences with racism
- **Don't Bring More Than We Can Carry**
 - Recognize that our work may bring up big emotions and trauma
 - Stay aware of our own needs
 - Take measures to care for ourselves
 - Ask for help when the need arises
 - Stay sensitive to the needs of others when possible and appropriate

Appendix B. Caregiver Definitions Created by Caregiver Coalition

Caregiver: Caregivers care for people who need some degree of ongoing assistance with daily tasks (including medical tasks) and/or skills on a regular basis. The recipients of care can live either in residential or institutional settings, range from children to older adults, and have chronic or acute illnesses, wounds or disabling conditions. These conditions can be physical and/or mental. While some caregivers are paid, many are not compensated for the care they provide.

Family / Informal Caregiver: A family caregiver is any family member, friend, or neighbor who provides any kind of support including: social and emotional support, transportation, errands, medical tasks, as well as, helping with organizing care, managing finances, and making health care decisions. Proximity of family caregivers can range from living with the care recipient to living nearby or in a different state or country. While some family caregivers are compensated for the care they provide, this role is often unpaid.

Formal Caregiver / Care Worker: A formal caregiver provides care and is usually associated with a formal service system. This support can be provided in the care recipients' home, community, or an institution. Formal caregivers often work closely with family caregivers to optimize care for the care recipient. Examples of formal caregivers include, but are not limited to home health aides, peer support specialists, community health workers, and doulas. Too often these roles do not provide a living wage.

Customized tool for aligning developing storylines with Coalition priorities

Morning 5A-12P

Narrative/Content/Feel	Perspective	Humor	Finance	Data	Moments	Mythbusters
Drugged & sleep-deprived, caregivers do not sleep well, can be awoken during the middle of the night, have a huge impact on caregivers throughout the day						
Medication or other assistive tech needs						
Caregivers wake up earlier for toileting, could use humor for how early caregivers have to get up, an important & stressful part of being a caregiver						
Caregivers have to be up early to coordinate what care receivers need and also what they can do in the morning						
Care receivers do not sleep well through the night (for various reasons, mental health needs), for caregivers & care receivers can be difficult to function during morning hrs						
Can add in other personal hygiene needs (shaving, dressing, etc.)						
Some families cannot participate or go to school or work						
Impact on safety & health, can have lifetime effects						
Totals:	0	0	0	0	0	0
Percent Represented:	0%	0%	0%	0%	0%	0%

Specific Examples	Perspective	Humor	Finance	Data	Moments	Mythbusters
Care receivers and caregivers who do not have a network of support vs. those who do (ex. Laura's network of caregivers) - showing a scene where this is depicted						
Lack of transportation in terms of not having the means for gas, car breaking down						
Care receivers have places to go & things to do which is often left out, they have value						
Scene: Someone's boss calling them because they are late/may not be able to make, care receiver may need to be able to go due to not having a caregiver						
Isolation means they can't build to social capital they need to ask for help						
A feeling that can be throughout the day: Isolation that care receivers often face because they rely on caregivers for independent living skills, can miss parties/etc						
Even if the care receiver has a caregiver, if the caregiver does not show, then the care receiver would not be able to go to work/school/etc						
Difficult for care receivers to have a job because they must rely on caregivers to get them up & get them to the job						
Burdens that care receivers feel (possible guilt), care receivers apologizing for their needs - it takes a lot for people to ask for help (Nanfi's story), possible scene?						
# of Times Represented:	0	0	0	0	0	0
Percent Represented:	0%	0%	0%	0%	0%	0%

Total Representations Morning (Narrative/Content/Feel + Examples)						
	Perspective	Humor	Finance	Data	Moments	Mythbusters
# of Times Represented:	0	0	0	0	0	0
Percent Represented:	0%	0%	0%	0%	0%	0%

Total Representations All Time Periods (Narrative/Content/Feel + Examples)						
	Perspective	Humor	Finance	Data	Moments	Mythbusters
# of Times Represented:	0	0	0	0	0	0
Percent Represented:	0%	0%	0%	0%	0%	0%

