



Reframing Caregiving

A Guide for
More Inclusive
and Effective
21st Century
Caregiving





*In collaboration with Amherst H. Wilder Foundation,
Minnesota Design Center (University of Minnesota, College of Design) and
The University of Minnesota Institute of Community Integration (ICI)*



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“What could the community’s lived experiences tell us about the current state of sandwich caregiving, and could then offer a different, more human-centered and equitable call to action?”



In 2019 a collaboration between the Citizens League, Amherst H. Wilder Foundation, Minnesota Design Center (University of Minnesota, College of Design) and The University of Minnesota Institute of Community Integration (ICI) launched a project to explore the “Sandwich Caregiving” experience. Funded by a Bush Foundation Community Innovation Grant, the effort aimed to better understand the challenges, hopes, fears and assets of those simultaneously caring for multiple generations, friends or families (typically children and aging adults). This report will outline project background, approach and objectives. It will also describe how the project evolved to respond to the 2020 COVID-19 pandemic, the racial reckoning and, finally, project outcomes and recommendations.

One of the most important insights to emerge from this work is that caregiving today, especially during a pandemic, is complex, dynamic and personal and simply admiring the challenge is not going to change that. Instead, our project partners spoke of the need for action and guidance to tackle the challenges where, how and when they exist – in families, communities and in the workplace. In response, our project findings have been organized in the form of a guide that can be used to promote action at the family, community, workplace and policy level (see “Equitable Caregiving Compass”).

This document is a guide that should be modified to fit each individual, family, community, and workplace’s unique needs while being respectful of cultural and community norms and traditions.



BACKGROUND

While more attention is being paid to caregiving in general, we still lack understanding of the increasing complexity of sandwich generation caregiving. According to a Pew survey, “Nearly half (47%) of adults in their 40s and 50s have a parent age 65 or older and are either raising a young child or financially supporting a grown child.” Most caregivers are ill-prepared for this role, but research shows that those living in lower socio-economic groups are especially susceptible to its challenges. At a 2018 Citizens League “Policy and a Pint” event focused on sandwich caregiving, audience members as well as panelists agreed that not only are there no easy answers, but we also don’t really understand the challenge itself. In short, we know very little about the lived experiences of sandwich generation caregiving, let alone what to do about it, especially at a socio-ecological system level. In this project, we sought to better understand the current caregiving ecosystem as it is experienced today, specifically by those most impacted by the challenges and with the most at stake in addressing them. The core objective of this effort was not to come up with a singular solution but ask, “What could the community’s lived experiences tell us about the current state of sandwich caregiving, and could then offer a different, more human-centered and equitable call to action?”



PURPOSE OF REPORT

Even with the best of intentions, an expert driven model, where the “usual suspects” drive the process, can often fail to realize the lived experiences and values of a community most impacted by a problem. We found value in an “outside-in” approach that ensures we are not only developing useful solutions, but even more importantly, we also are framing the challenges that matter most to the community. We have found in this project that while most experts talk about resources and programs, communities talk about meaning, purpose and agency, all of which are difficult to respond to if we are only focused on providing technical resources or programs. By starting with diverse and often overlooked communities, we have found unique insights that we could have never predicted, even with an unlimited number of resources and time. Starting from the “outside-in” is not only a source of new insights, but also a far more efficient way to work and test assumptions before spending significant resources and time developing solutions to problems that are not reflective of the communities dealing with them.

Who are caregivers today and how do their experiences, needs, values and challenges compare to that of previous generations? The reality is that caregiving is not static, and it certainly does not look like it did when most caregiving

policy and support infrastructures were built, especially given that the system was never built for many of the communities being disproportionately impacted by the challenges of caregiving today. The intention of this project raised the question, “How might we approach challenges differently when those most impacted help to create a call to action that is relevant and responsive to their specific concerns, perspectives, experiences and cultures?” This report is intended not only to yield guidance for how to better support sandwich caregivers and caregivers more broadly, but how to more directly engage, learn from, and co-design with communities that have not had opportunities to share their strengths and insights in the past.



APPROACH

Finding ways to better support caregivers, especially during a pandemic is difficult and complex. It is clear that the system (if it can be called a system) intended to support caregivers is siloed and outdated. COVID has only amplified that the system is not working for those being disproportionately impacted by the challenges of caregiving such as BIPOC (Black, Indigenous and People of Color) and disability communities. If we attempt to address these disparities in caregiving by simply tweaking existing infrastructure, we risk propping up a system that was never designed to support these communities in the first place. What we need is a way to reframe the challenges facing these caregivers that more accurately reflect the caregiver’s experiences, culture, values, hopes and fears. In short, we need an approach well suited for the guiding principles of Human Centered Design (HCD) (see **FIGURE 1 on page 6**).

FIGURE 1



HUMILITY

Top-down approaches tend to exclude those most impacted and with the most at stake in addressing problems from the design and decision-making process. In contrast, a citizen-design model formalizes opportunities for shared power and decision-making. This is especially important when working with marginalized communities where important relationships, institutions, systems, culture and history can be invisible to even the most thoughtful decision-makers.



RADICAL COLLABORATION

Collaboration is nothing new. Yet too often it involves the same people addressing the same problems in the same ways and expecting different outcomes. Radical collaboration suggests that diversity of ideas, experiences, cultures and socio-economic backgrounds is not only a good idea, it is fundamental to new ways of understanding and addressing old problems (creativity).



RAPID PROTOTYPING

The only safe way to navigate the unknown is to iteratively learn your way forward in small steps. Rather than fully deploying a few theory-only ideas, testing many rough assumptions and ideas in rapid iteration, or prototyping, aims to generate and test multiple alternative hypotheses, assumptions and divergent strategies before selecting the best available option(s) for further refinement.

ADAPTED FROM: Jess P. Roberts, Thomas R. Fisher, Matthew J. Trowbridge, Christine Bent, A design thinking framework for healthcare management and innovation, Healthcare, Volume 4, Issue 1, March 2016, Pages 11-14 h

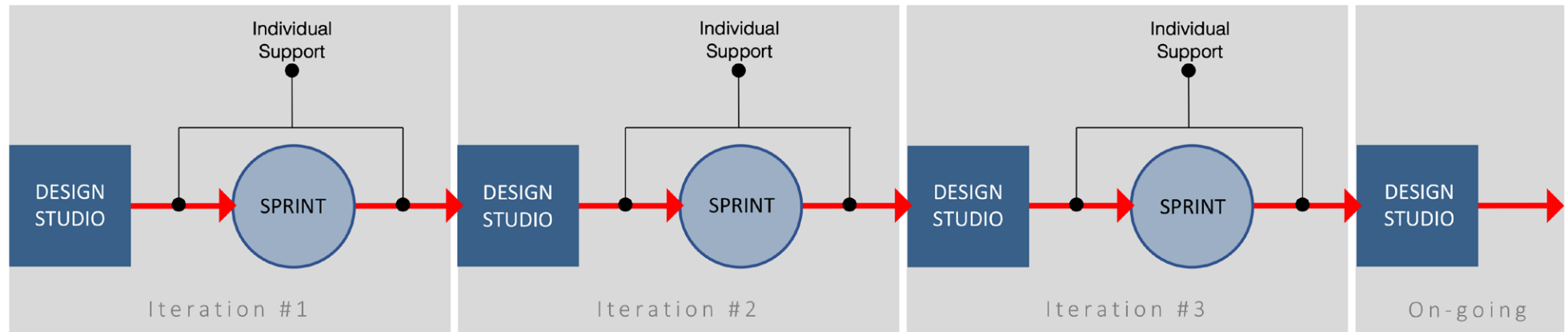
CULTURE OF HEALTH BY DESIGN

So how might we create authentic engagement and partnership opportunities? For our project, we drew from the principles of Human Centered Design (HCD), equitable civic engagement practices, and collective action. We explored a structure for co-design which is an iterative sequence of in-person (or virtual) “design studio” sessions where a diverse collection of community co-designers (who are all compensated as designers or researchers) come together and collectively interpret information and insights as well as co-develop and test promising challenges and concepts to explore/develop further (**see FIGURE 2 on page 8**).

Each collaborative studio session was followed by independent exploration sprints where co-designers could engage, collect insights, and develop ideas within their trusted networks (friends, families, neighbors, co-workers, etc.) and bring those ideas back to the next studio session. This allowed each co-designer to have trusted and in-depth explorations and conversations with community members (voices) that are often unreachable through other approaches such as advisory councils or listening sessions. Encouraging each co-designer to explore independently helps to avoid groupthink, tokenism, and group biases that can arise during program and policy development. The primary advantage of this structure is that it allows for longitudinal and in-depth engagement with community stakeholders. It allows for the emergence of insights that would be inaccessible otherwise - regardless of investment of resources or time.

FIGURE 2

CO-DESIGN APPROACH



DESIGN TEAMS

Design teams are a collection of co-designers that self-identify across a diversity of communities, values, cultures and lived experiences, especially those most difficult to reach in more traditional research and engagement efforts. Co-designers will draw on their trusted and intimate relationships with community members to offer deep insights and perspectives that would otherwise be inaccessible.

STUDIOS

Studios are the spaces/times for co-designers to come together and collectively interpret information, co-develop and test promising solution concepts, and to work with decision makers and community leaders to translate community vision into action. The studios are workshops for sharing what participants/teams have learned through the previous sprint and co-develop an approach for the next sprint.

SPRINTS

Sprints are where participants/teams explore the questions, ideas and community input that arise during the design studios. Sprints are the opportunity for co-designers to explore questions and test ideas within their trusted networks and generate insights and ideas to share at the next studio.

INDIVIDUAL SUPPORT

Design facilitators connect one-on-one with co-designers in each iteration to offer guidance and develop customized approaches and tools that are culturally appropriate and effective at better understanding community history, needs, and values.



COMMUNITY PERSPECTIVES AND EXPERIENCES

One of the greatest threats to working with community is that approaches can become too tightly managed, usually by the same organizations or individuals who have always had disproportionate decision-making power. We followed a rigorous and iterative process to ensure that our approach followed the lead of our community partners to avoid guiding them to predetermined ideas or starting with biased problem frames. Our approach started broadly, beginning with individual interviews of a large variety of stakeholders. The resulting information helped us identify a more specific set of stakeholder communities that should be involved in the next iteration of design studios. The findings from these sessions, along with the disproportionate impact of the COVID-19 pandemic, and racial unrest in the Twin Cities, informed the final, and most precise iteration of exploration design studios which included several individuals from BIPOC communities.

Individual Interviews

Over the first half of the project (approximately 1 year), we directly interviewed 48 individual stakeholders, including caregivers, social service providers, political leaders, business leaders, academic researchers and faith leaders (**see breakdown in TABLE 1 on page 10**). Each one-on-one interview was facilitated by phone or in-person, lasting between 30 and 60 minutes and covered a short list of exploratory questions (**see TABLE 2 on page 10**). We started with individual interviews because they, **1)** identified key areas for deeper exploration during the design studios, **2)** illustrated communities that might have unique and under-represented perspectives on caregiving and **3)** developed relationships with key leaders and community networks that could support the development and dissemination of this project.

Community Design Studios

Building off of the individual interviews, the project team recruited four different communities (**see TABLE 3 on page 10**) to engage in a co-design process (**see FIGURE 2**). The co-design agendas were developed from key insights and questions uncovered in the individual interviews but allowed each community to inform subsequent sessions. We facilitated 12 co-design sessions over the course of 8 months to **1)** deeply explore experiences, hopes, fears and perspectives that would not be accessible through surveys or one-off community meetings, **2)** access voices (co-designer friends, colleagues, neighbors, etc.) that are rarely captured in other approaches, and **3)** build trust over time with communities that is necessary to get beyond exploring transactional solutions.

TABLE 1

Primary Role (Self-Identified)	# Interviewed
Social Service Providers	24
Current Caregivers	10
Business Leaders	5
Academic Researchers	4
Political Leaders	2
Faith Leaders	2

TABLE 2

Individual Interview Questions

1. What do you think of when you hear “sandwich generation caregiving?” How would you define it?
2. What has been your sandwich caregiving experience (caring for multiple generations)?
 - What has been most difficult? Why?
 - What has been most rewarding? Why?
3. What people or resources have been most supportive to you through this experience?
4. What do you know now that you wish you would have known before this experience (caregiving experience)?
5. Who else would you recommend we talk to and would you be willing to offer a “warm handoff?”
6. Are you willing to be contacted about opportunities to contribute to this project in the future?

TABLE 3

Community Co-Design Studios (in order of engagement)	# Interviewed
Nurses and Social Workers	10 participants (3 sessions)
East African Community	Elders (men): 10 participants (1 session) Women: 11 participants (1 session) Youth: 12 participants (1 session)
Sibling Caregivers	7 participants (3 sessions)
Liberian Community	Community PCAs: 5 participants (1 session) Youth: 15 participants (1 session) Multi-generational: 4 participants (1 session)



EARLY INSIGHTS

At the midpoint of this co-design effort, after completing 12 co-design studios across four different communities, we outlined key insights that would guide co-design studios and collaborations for the second half of the project. Generally, we found that **1)** almost no one was identifying themselves as a caregiver, and **2)** almost no one was actually talking about navigating the system. Our participants shared their long-standing belief that the system was not designed for them and reported that they intentionally avoided it and the associated level of power and privilege needed to access/leverage it. More specifically:

Identifying as Caregiver

The vast majority of community participants do not use the term “caregiver” and some even find it disrespectful; Instead, they see their efforts as something family or community simply do for one another. This insight suggests that most individuals do not self-identify as “caregiver,” and thus the way health systems, nonprofits, and policy makers talk about, and support, the work of caregiving needs to better reflect that caring for each other is a consistent part of daily life for most communities.

Caregiving Economy

Most community participants did not identify a need for technical resources or services, instead they noted that the opportunity to directly provide the most appropriate care for their loved ones was most needed. This insight suggests a need for more flexible and supportive employment opportunities, environments and formal caregiving employment opportunities (such as in-home caregivers) that provide meaningful benefits and living wages.

Caregiving Units

Many participants discussed that caregiving occurs in family/friend groups or units of care, rarely in isolation. However, most noted that resources and services are targeted at the individual level. This insight suggests the need to develop policies and resources that respond to the family and community-scale of caregiving. For example, social stigma and its resulting isolation was mentioned across communities, especially among family/friend groups providing long-term care.

At the point that we were compiling these insights (winter 2020), the COVID-19 pandemic emerged and shortly

thereafter, the murder of George Floyd launched a racial reckoning unlike anything this country has seen since the 1960s. What was being highlighted in our early work, that the caregiving support system was not well aligned to the way BIPOC communities experience and prioritize care, was only amplified in both focus and urgency. The challenges facing these communities felt so overwhelming that we pivoted to focus on the disparities in caregiving and find ways that people could engage and act on the system rather than feel removed from it.

When sharing our early findings, we often heard things like, “the problem is so big, what can we do?” Given the scale and dynamic nature of the caregiving ecosystem, we recognized that most well-meaning policy makers, organizations, and concerned citizens were asking the wrong question. The way forward was not a singular solution or intervention, instead it would require a way to strategically navigate and unleash the rich assets across the region to creatively support caregivers just as we were seeing across communities as they responded to the COVID-19 pandemic. To develop this report, we would look once again to our community partners who could leverage their lived experiences to, **1)** help synthesize the information collected through our extensive community co-design process and, **2)** inform an actionable output to empower and guide those working at the forefront of sandwich caregiving. Our community co-designers included:

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Georgean

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ACTION GUIDE

One of the key challenges facing those navigating the complex and dynamic system of caregiving (policy makers, service providers, employers and communities/families) is that “solutions” tend to be technical and overly specific - they only solve certain issues for certain communities, usually at the expense of BIPOC communities. The reality is that caregiving occurs in an ecosystem and is constantly evolving along with other economic, technological, and demographic shifts. While stakeholders might be looking for silver bullet solutions, the reality is that they need something less prescriptive to effectively navigate the caregiving landscape of today and tomorrow.

The following guide does not outline specific or prescriptive solutions. Instead, it is intended to act as a compass for those navigating caregiving challenges in the 21st Century at the individual, local, and regional scale. While many will argue it is important to tackle caregiving at the systems level, it is far too big and abstract to tackle the full system of disparate challenges caregiving communities. The guidance outlined here is to help act on the most impactful system levels within the caregiving ecosystem – what we have found to be the most promising six (6) system levers or “reframes” in our research.

Each of the six **system reframes** outlined in this guide is organized to offer context and guidance in the form of specific guiding principles and actionable exploratory questions for policy makers and service providers, organizational leaders (employers), and communities or family members. Each of the system reframes are distinct but related and if you are able to deliver in one area, you are likely to see positive outcomes in the others - the definition of a system. This guidance is intended to act as a **wayfinder** to adapt to the conditions and unique opportunities and leverage the existing assets of your region, organization, or community/family. While one reframe might be most relevant to your community, organization, or personal situation, we suggest reviewing all of the sections together as they may lend insights and guidance that isn’t available focusing on only one. Most importantly, the guide should not be used as a checklist of tasks, but as conversation-starters with other leaders and stakeholders. It should be part of an on-going conversation and response to the long-term challenges of equitable and effective caregiving support, which then has real opportunity to spur creativity and innovation in caregiving similar to that we have seen in other sectors.

Key System Reframes

1. **From** Caregivers as Receivers of Policy **to** Caregivers (and Care Recipients) as Participants in Policy
2. **From** Transactional and Static Support **to** Adaptive and Dynamic Support
3. **From** Caregiving to Meet System **to** Systems to Meet Caregiving (Systemic Individualism)
4. **From** Caregivers as Gap Fillers **to** Caregivers as “Bridgers”
5. **From** Individuals as Caregivers **to** Units (Friends and Families) as Caregivers
6. Women as Primary Caregivers (**unchanged**)

1 From Caregivers as Receivers of Policy to Caregivers (and Care Recipients) as Participants in Policy
Many co-designers noted a need for supportive policies, workplaces and resources that are reflective of their day-to-day realities of caregiving. Co-designers identified the challenges of decisions being made in isolation by individuals that cannot understand the lived experiences of those intended to benefit from them. They noted community engagement burnout because research, policy and programming felt “done to” not “with” community. No amount of engagement will remedy this without direct and meaningful involvement (including shared decision making) with those most impacted and with those most at stake in addressing the issue(s). Caregivers and care recipients should be leading voices in the co-design process of caregiving systems, to ensure that they reflect the actual lived experiences of those they intend to serve.

When Julia hears people talk about “common language” in the care system, it is almost always about “regular people” needing to learn medical terms. She wonders what it might look like if health systems and service providers worked with communities to craft more appropriate ways of talking about things like pain, fear, caregiving, etc. within various cultural contexts (i.e. rather than communities learning about how to communicate with service providers, what about service providers learning to communicate directly with community members in the ways they understand, receive, and act on information/resources)?

Q: How might governments and organizations create formal opportunities for power-sharing in the design and decision-making process to develop responsive and innovative caregiving policies and practices?

Wayfinding

Policy Makers + Service Providers

- Who stands to be most positively impacted by this policy/service? Who stands to be most negatively impacted by this policy/service?
- How are community stakeholders and those most impacted by these policies being engaged as equal partners in the development and design of these policies? Will the impact be positive for all stakeholders or will there be inequities?
- How are community stakeholders helping to prioritize this policy/service? Whose voices are missing and why? How do you know?
- Who is defining whether a policy is equitable and accessible? How are you measuring whether a policy is or is not meeting that definition of equity and accessibility?
- How might this policy/service shift from managing inequities to eliminating them? On whose timeline?
- How might this policy/service contribute (or detract) from community trust?
- How might policymakers and service providers revisit and refresh policies/services on an ongoing basis with community centeredness and co-designing at the core?

Employers

- What is the status of the organization's existing caregiving services/policies? Which services/policies are not being fully utilized (or not used at all) and is this a trend with certain segments of the workforce? Is fear of disciplinary action or guilt a likely factor?
- How might employees have a more direct role in co-developing and implementing caregiving services/policies? How will the organization ensure a diversity of employee collaboration opportunities (diversity of employee perspectives and engagement formats)?
- To what level is the organization willing to invest in co-developed services and policies?
- How might the organization reward open and honest communications about caregiving experiences?
- How might the organization build trust and safety across the organization so employees do not feel guilty when they need to access caregiving services/policies? How might the organization identify what these often-unspoken pain points are?

- How might the policies developed actually include challenges/needs from BIPOC or disability communities when their members are not yet well represented among employees? How might this work improve recruitment and retention by considering caregiving from the perspectives of future employees from under-represented communities?
- How might the organization revisit and refresh policies on an ongoing basis with employer centeredness and co-design at the core?

Communities/Families

- What would you want your policy makers to know about the challenges of caregiving/supporting others? Why?
- What would you want your employer to know about the challenges of caregiving/supporting others? Why? Who/what might you need to share these insights with your policy makers?
- How might you share your experiences, both challenges and success, to others in your community? What would you like to learn about the caregiving/supporting experiences of others in your community?
- How might your community come together to share your collective caregiving lived experiences? How might you involve existing organizations that support your community?
- Which member's voices in your communities are still missing in discussions about caregiving? How can you bring these community members to participate? What barriers might they face and how can you eliminate these barriers? Are care receivers included in discussions about caregiving?

2 From Transactional and Static Support to Adaptive and Dynamic Support

Most caregivers were not interested in traditional resources as they often required additional time, effort and know-how to navigate (which they did not have) and rarely have these resources met their specific cultural or familial needs. Many saw accessing caregiving resources as a luxury they simply did not have. What they were asking for was more time, permission and space to provide the most appropriate, trusted and cost-effective care for the person they were caring for, and time and space for self-care as caregivers. Co-designers universally described caregiving as iterative, not linear; each day brought unique challenges and opportunities, both of which require on-the-fly adaptation. What families are looking for is a compass, not a map.

When Sahra's father was being discharged from the hospital, she received a printout of resources that might help her care for her father at home. After 3 hours on the phone, she felt that most of the resources did not align to her cultural beliefs or required her to find whether or not she/her father would qualify; in short, they felt like they were not the "right" set of resources for their specific family needs and expectations. To further illustrate this, when a friend suggested that she drop her father off at a respite care site, she said, "if I don't trust the people caring for my father, my time away from him will be more traumatic than restful."

Q: How might policies, workplaces and support resources enable and support the often unpredictable and iterative nature of caregiving over long periods of time?

Wayfinding

Policy Makers & Service Providers

- How will this policy support those providing short term (acute illness) and long term (lifelong or forever) caregiving situations?
- How might useful policy or service in one area negatively affect the other?
- How will you ensure the ability of this policy/service to adapt and change as needs change? Such as, to meet advancements in medicine (certain cancers have become long-term chronic conditions, many 'long-haulers' with chronic care needs post-COVID infection, and how more caregiving responsibilities are falling to younger adults)?

- How might this policy discriminate against cultural norms in caregiving (in some cultures, family caregiving falls to the eldest daughter, others to the eldest son, or to the youngest daughter, etc.)?
- How might policies/services respond to changing health status of those being cared for (become more complex as someone's condition deteriorates or the care system becomes more clinically and technologically advanced)?
- How might policies lead to proactively addressing possible future caregiving challenges?
- How might policymakers and service providers revisit and refresh policies/services on an ongoing basis with community centeredness and co-designing at the core?

Employers

- Instead of a focus on generic services/policies, how will the organization create opportunities for employees that are flexible and adaptable to provide the care that is most needed and valued? What has navigating COVID-19 taught the organization about flexibility?
- How will these services/policies alleviate or improve tensions inherent to caregiving (if I reduce my hours at work to care for family, will it jeopardize my retirement plan, promotion opportunities, or ability to keep my job)?
- How might services/policies support caregivers who don't have predictable caregiving responsibilities (short-term needs that emerge all year that would not be covered during a 2-week paid leave)? How might you build in flexibility to allow for customized strategies to achieve work/home balance?
- How might the organization revisit and refresh policies on an ongoing basis with employer centeredness and co-design at the core?

Communities/Families

- What has been the most rewarding part of caregiving? What person, place or resource have you relied on most to support your role of caregiving/supporting others? How has this changed over time?
- What do you feel is the greatest need for caregivers now? How prepared do you/your community feel to address these needs? What assets do you or your community have to address these needs?
- What do you feel will be the greatest needs for caregivers in 5 years? How prepared do you/your community feel to address these needs? What assets do you or your community have to address these needs?
- What are care receivers experiencing in your family or community that works and what do they wish they had more of?

3 From Caregiving to Meet System to Systems to Meet Caregiving (Systemic Individualism)

Many co-designers felt that the caregiver support system was not designed for them or their circumstances and even alienated them at times. While direct caregiving required skill and time, some co-designers found that attempting to navigate care systems and resources was like having another job or “learning another language.” For example, the notion of “health literacy” which assumes that communities must experience, understand and learn health in the same way that the healthcare system understands health. If a person cannot or doesn’t wish to do this, the health system will not work for them. Co-designers asked for systems to instead become more literate to the actual people they seek to support and who come from a wide variety of lived experiences (cultural, educational, economical, racial, ethnic, etc.). No one community experiences caregiving in a uniform way, and no one member within a community shares the same perspectives or experiences necessarily, so policy makers need to employ deep listening and a setting aside of assumptions about any community or family. Seeking and including an array of members from across the community and/or family, including those receiving care, is critical so that the co-design process is flexible and adaptable.

Imagine your partner or your parent has just received a stage two cancer diagnosis. You are immediately thrust into a lengthy process of additional testing, appointments with specialists, and are asked to make care and treatment decisions. You are both confused, upset and not able to focus on organizing the necessary steps outlined to you by the health professional. You feel the burden. There is an assumption by the service providers that you will accomplish the necessary tasks. The urgency of action is highlighted to you, and you are put on notice of potential negative impacts if there is a delay.

Instead of handing off an exhaustive list of responsibilities to the one person who carries the responsibility of relaying information and managing emotions, what if you were allowed to instead be a part of the care team to support communication, cultural specific preferences, health goals, and person-centered care. What would that look like?

Q: How might policies, workplaces and support resources respond to common challenges facing caregivers and care receivers while allowing for a level of personalization and flexibility that meet complex cultural, familial and personal dynamics?

Wayfinding

Policy Makers & Service Providers

- How might policies/services respond to and serve those that do not see themselves as traditional “caregivers” (Not everyone providing care, considers themselves a caregiver and must be inclusive of cultural norms and relationships)?
- How might policies/services be inaccessible to certain communities (will it require certain knowledge, skillsets or cultural norms that may exclude certain caregivers)?
- How might this policy promote addressing disparities in access to resources and services? How will success be measured, and by whom?
- How will policies/services allow for autonomy by those accessing them (having choice)?
- How might this policy have unintended consequences, such as added burden (paperwork or navigation) for caregivers?
- How might policymakers and service providers revisit and refresh policies/services on an ongoing basis with community centeredness and co-designing at the core?

Employers

- How might the organization reach individuals that do not see themselves as traditional “caregivers” (cover a broad definition of “care”)?
- What options are available to offer flexibility with saving plans, including employer matches to support employee’s caregiving costs, and reduce the fear of not having a financial safety net?
- How might services/policies not require employees to divulge that they are caregiving and share their personal information (how will the resources feel safe and readily accessible for all)?
- How might the work environment positively support everyone to “show up” at their best (at work and home)? How might caregiving services/policies become an effective and powerful recruitment/retention tool?
- How might the organization revisit and refresh policies on an ongoing basis with employer centeredness and co-design at the core?

Communities/Families

- What are the work-arounds (the tricks or shortcuts) you have discovered to make caregiving easier or more effective? How did you learn about these? How might you share these with other family/community members?
- What are some of the practical supports (that don't require special requirements, qualifications or complex navigation) you have found to support you (as a caregiver) or those you are caring for? How did you find these? How might you share these with other family/community members)?
- How have you been able to make the health system, care agencies, government agencies and/or employers work for you (best support you as a caregiver)? What do you look for, or what do you avoid when looking for supportive resources/services? How might you find more supportive resources/services and avoid less supportive ones in the future?
- Based on what is working now, how might the community build the capacity for future generations to provide care?

4 From Caregivers as Gap Fillers to Caregivers as “Bridgers”

Many caregiving resources and services offer gap filling for essential caregiving services like food security, therapy, respite care or financial aid. While these are essential, co-designers, specifically those who were young and whose families are recent immigrants, found that caregiving required them to “bridge” significant complexity and generational changes. Significant burden is being placed on a new and more diverse generation of caregivers where in addition to providing direct care (filling gaps) they are also needing to interpret, advocate, translate and educate across generations and contexts.

Sandra’s dad became ill suddenly and because his cultural norms were different Sandra felt like she had to fill a specific role to interpret and step in for him. The doctors and care team recognized Sandra as a crucial part of her father’s care team and went to her right away to develop a culturally-relevant care plan for her father. Sandra was able to speak with her father about his needs and effectively communicate those things to the care team and feel included in his plan not only to bridge the cultural differences but to ensure that he had a voice in his own care.

Q: How might policies, workplaces and support resources adapt to a caregiving identity that requires bridging across culture, geography, education and economic status?

Wayfinding

Policy Makers & Service Providers

- How might this policy/service address geographical challenges to caregiving (caregivers living significant distances from those receiving care)?
- How might this policy/service support caregivers as the most trusted point of service (how might services be delivered through caregivers instead of untrusted systems)?
- How might this policy/service support the relationships between caregivers and those receiving care?
- How might this policy/service disrupt or enhance the perceived value of providing care, a tradition that has withstood generations?

- How might this policy/service support multiple generations simultaneously (children, parents, grandparents for example)?
- How might policymakers and service providers revisit and refresh policies/services on an ongoing basis with community centeredness and co-designing at the core?

Employers

- How might services/policies provide “back-ups” for caregivers that currently do not have any?
- How does the service/policy avoid attempting to “fix” a perceived problem and instead seek to offer culturally appropriate support?
- How might services/policies support flexibility in work schedules and formats? How might services/policies include flexibility for employees to serve in multiple roles: caregiver, interpreter, educator, advocate?
- How might services/policies support employees with unexpected caregiving responsibilities (short-term needs that emerge throughout the year that would not be covered during a 2-week paid leave)?
- How might the organization tangibly demonstrate a culture that values the caregiving roles many employees are balancing?
- How might the organization revisit and refresh policies on an ongoing basis with employee centeredness and co-design at the core?

Communities/Families

- What role would you play in supporting your family and/or friends? How would you describe this role of caring and supporting people outside of your family?
- What do you feel is missing most in traditional “caregiver” support/resources? How might you look outside those traditional sources to find supports that are better suited for your needs as a “bridger” caregiver?
- Have you found others serving a similar “bridger” caregiving role as yourself? If so, how might/do you support one another? If not, how might you find others who can share your experiences?
- What assets do you feel your community has for “bridger” caregivers? What would you ask of your community to better support you and those you care for?
- Caregiving is a journey; how might you find ways to feel accomplished everyday (feel like you are making progress toward goals)?

5 From Individuals as Caregivers to Units (Friends and Families) as Caregivers

Almost every co-designer noted that caregiving occurs in groups or units of care, making many resources and services (which are targeted to individuals) difficult to access/qualify for. This “unit-scale” caregiving includes immediate family, extended family and even community-wide efforts (as was often the case in non-white communities). An increasing number of families live in multi-generational homes to better support caregiving units. Given the increasing complexity and duration of caregiving, most noted that it is no longer feasible for one person to tackle all of the needs and concerns of those receiving care given the necessary time, resources and knowledge.

When Monica’s 89 year old mom fell and broke her hip, Monica quickly transitioned from being one of four daughters to becoming her mom’s “family caregiver”. Monica’s mom had moved in with her 3 years prior, and was mostly able to manage during the day when Monica was working. Monica worked two part time jobs to allow for time between jobs to check in on her mom. She didn’t have much in savings, so she needed both jobs to make ends meet. Monica’s siblings live more than an hour away, including one sister who lives in another country. Based on proximity alone, Monica was tasked with coordinating appointments, managing documents, picking up supplies and being present to encourage and support her Mom through this unexpected health crisis. Monica is faced with quitting one of her jobs just to manage the extra responsibilities. Gloria, Monica’s Mom, has a host of friends and family that want to support her and likewise they are eager to be involved in Gloria’s care. Monica’s sisters are all working part-time to full-time jobs, with a variety of family caregiving responsibilities. They want to support Monica and their mom, but in order to do that Monica needs to coordinate consent forms, schedules and allow them to have access to medical, financial and insurance information.

Q: How might policies, workplaces and support resources concurrently meet the needs of those serving in caregiving units (caregiver teams/families over multiple generations)?

Wayfinding

Policy Makers & Service Providers

- How might this policy/service impact (negatively or positively) caregiving units (all those involved in supporting caregivers and care receivers)?
- How might this policy/service support a broad definition of care teams to include individuals providing various levels of care, and allow for interchangeable care team members?
- How might this policy/service support multiple generations simultaneously (children, parents, grandparents for example)?
- How might this policy/service impact (negatively or positively) those living in multigenerational homes (might they make it more difficult to access resources because of “household income” limits)?
- How might this policy/service impact the next three generations of caregivers?
- How might policymakers and service providers revisit and refresh policies/services on an ongoing basis with community centeredness and co-designing at the core?

Employers

- How might services/policies support or discriminate against cultural norms in caregiving? In some cultures, family caregiving falls to the eldest daughter, others to the eldest son, some to all children.
- How might services/policies support family-centered needs simultaneously (bundled services such as elder care, child care, food assistance, etc.)?
- How might services/policies support a balanced work-life balance, including work environments/schedules that are flexible to unpredictability of care needs across generations?
- How might the organization create flexible opportunities to support caregivers as well as offer flexible employment opportunities to post-retiree communities?
- How might the organization revisit and refresh policies on an ongoing basis with employer centeredness and co-design at the core?

Communities/Families

- How do you support others in your community/family and how do they support you? How might your family/ community collaborate to provide the best support to those needing it?
- How might “best practices” for culturally appropriate caregiving be reliably passed on to future generations?
- How might you include those receiving care to participate in the decisions about their care?
- How might the community alleviate fear of those in isolation or in fear of being ill or dying alone in their home?
- How might the community/family support those dealing with anxiety, grief, isolation, fear, guilt and anger (especially in response to COVID-19)?
- How might the community/family discuss and respond to cultural changes (Americanization/enculturation) over the generations and how it impacts caregiving?

6 Women as Primary Caregivers (unchanged)

The co-design process identified one key aspect of caregiving that has not changed — challenges and responsibilities of caregiving are being disproportionately carried by women, especially BIPOC and immigrant women. While we made significant efforts to include an equal number of men in this research, professional, cultural and familial roles still disproportionately placed women in the primary caregiver role in the communities we engaged with. Data from the Department of Labor shows that the pandemic has only amplified this disparity with record numbers of women leaving the workforce to take on primary sandwich caregiving responsibilities. While gender dynamics have been slowly shifting, the pandemic and a growing lack of accessible and affordable support services such as daycare and elder care have created a persistent and potentially generational setback to women in the workforce, women's pay and regional economic growth.

Cynthia had been working half time for a cleaning service company so that she could drop off and pick up her children from school and spend evenings (after her partner came home from work) with her mother who had early stage dementia, but still lived by herself. When COVID-19 hit and her children had to stay home for school, she had to leave her job to homeschool full time. Additionally, her mother's dementia had progressed to the point that she moved in with Cynthia. Even though her children returned to school, her mother's needs were too severe to leave her for long periods of time and the cleaning agency was unable to provide the flexibility she required.

Q: How might policies, workplaces and support resources look to better support women caregivers, especially those balancing career and caregiving now and for the next generation?

Wayfinding

Policy Makers and Service Providers

- How might policies/services support women in the workforce?
- How might policymakers change the narrative from one of individual burden to one of shared community or a collective challenge?

- How might policies/services address the generational impact of COVID-19 on women in the workforce, including lower pay, lower retirement savings, lower lifetime earnings and lower social security potential?
- How might policies/services impact (negatively or positively) fair and equal opportunities for women and girls today and in the future?
- How might you include the lived experiences of working women in the development of policies/services?
- How might policies ensure that men will be willing and able to take on more of the caregiving duties women do now?
- How might policymakers and service providers revisit and refresh policies/services on an ongoing basis, and whom might they prepare now to include in those revisits as co-designers?

Employers

- How might services/policies support women employees, especially those in caregiving roles?
- How might services/policies create a safe culture to discuss caregiver needs in the workplace? How might they create safe channels for women caregivers to explore flexible options that support their caregiving needs?
- How might services/policies create career flexibility for women caregivers?
- How might services/policies address pay gaps resulting from caregiving leaves, which have been exaggerated during COVID-19?
- How might the organization value and directly incorporate the perspectives of women with caregiving lived experiences?
- How might the organization revisit and refresh policies on an ongoing basis with employer centeredness and co-design at the core?

Communities/Families

- How might your family/community support women caregivers?
- How might your family/community create systems of care that do not burnout or overburden women and girls while still maintaining cultural norms and expectations?
- How is the role of women caregivers in your family/community changing? How might they be supported so that they can choose the caregiving role they play?

- How might your family/community create safe and trusted opportunities for women caregivers to share their experiences and struggles?
- How might families/communities see new approaches to ensure men will be willing and able to take on more of the caregiving duties that women do now?
- How might your family/community create “fall back” supports for women caregivers (so they do not feel solely responsible)?



CONCLUSION AND NEXT STEPS

Caregiving and the needs of caregivers have changed dramatically over the past 50 years and are likely to continue to evolve as we experience unprecedented demographic, economic and technological shifts. The reality is that as a society, we have failed to keep pace with these changes and have placed a disproportionate burden on BIPOC communities and women. The intention of this project and subsequent guide is to better equip frontline caregivers and their supporters to manage the changes taking place and to do so in a far more equitable manner. Our sincere hope is that this isn't seen as a report, but rather a call to action with real and practical ways for all of us to shift to more inclusive and effective 21st Century Caregiving.

This is a living document, and we look to collectively learn with you. Please use the contact information below to let us know how you are using and adapting this guide. Let us know what is working, what has been most difficult and what has surprised you along the way. Additionally, we are always looking for ways to collaborate directly with communities, organizations and policymakers to advance effective and equitable caregiving support and advocacy.

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