

Embodying Care Event
Laura Mauldin
She/her

Opening remarks:

I want to first thank the panel organizers for inviting me to be a part of this wonderful event and conversation. I want to especially acknowledge the fore fronting of access for this event with regard to captions, description of visual materials, and the later posting of the video and transcripts. Thank you. I am Laura Mauldin and I am an Associate Professor at the University of Connecticut with appointments in Women's Gender and Sexuality Studies, Human Development and Family Sciences, and Sociology. For those who need a visual description, I'm a middle-aged white woman with dark curly hair, wearing a black shirt and green cardigan.

My work on care is primarily focused on unpaid caregiving. My book project, which is supported by the Social Science Research Council, is based on fieldwork with spousal or partner caregivers specifically, and when possible, their partners. I want to note that this book project is focused *solely* on spousal or partner caregivers (SCs) for a few reasons. [Studies](#) (put out by the National Alliance for Caregiving and AARP) show that compared to other kinds of unpaid caregivers, spouses 1) assist with more activities of daily living, 2) perform more medical or nursing tasks, 3) are almost always the sole caregiver, and 4) are far more likely to be doing "high intensity" caregiving. Over the last year, I interviewed more than 50 people across the U.S. about unpaid caregiving, including 43 caregivers (ages 29-87) in 21 states. And I interviewed all of them twice. I recently published some my initial findings with respect to Covid19 for the [Caring Across Generations](#) blog, but I will summarize them for you now:

1. During the pandemic, like many of us, SCs have been full of anxiety and fear. The vulnerability of their spouses to the virus was the key concern. As many told me, if their spouse got COVID, they would certainly die. Those of working age with lower paying jobs, especially in rural areas where residents may not be taking COVID seriously, were especially anxious and

stressed. Those of retirement age largely did not leave the house out of fear that any small mistake could be fatal for their partner; the thought of leaving the house caused panic.

2. Like many of us, SCs are isolated. Their loneliness came through in so many of my interviews. SCs talked about the lack of social interaction and the detrimental effects this was having on their lives, from the emotional toll of no longer being able to get support in their caregiver support groups to not seeing friends, and especially missing the lives of their grandchildren.

3. Support systems, including hospitals, were in freefall, leaving SCs to do both more caregiving and more medical care on their own. An enormous problem was the loss of home health aides, primarily because agencies that employ them were not providing testing and there was no policy mandating that they do so. Furthermore, the ER was no longer an option and many SCs were treating their spouses themselves for urgent care needs at the instruction of doctors, including gruesome wound care, monitoring for infection, giving infusions and so on.

4. SCs reported that their ill and disabled partners were deteriorating. Without socialization with their friends or family, they withdrew. Without access to routine PT or OT, they were rapidly losing strength and flexibility. They all worried about the drastic effects both mentally and physically.

*

Certainly there is much we could discuss here in terms of how the pandemic has strained our already inadequate and crumbling systems for long term care and home and community-based services in the US. Part of what I want to do here is to think through how looking at the struggles of caregivers points not towards the “tragedy” of disability or illness, but to problems in our systems. What I don’t want the above list to do is to be interpreted as a series of types of

individual “caregiver burdens.” Because for me, that phrase “caregiver burden” over-individualizes. Instead, I want to emphasize that caregiver burdens, both during COVID19 and beyond, are often structural. Their burden is the result of bearing the weight of being largely structurally abandoned. That is, our care infrastructure in the US is so poor that SCs *are* our care infrastructure and they are largely holding it up alone.

And this is a central argument I will talk about in my book: that caregivers (and we could include paid care workers here to as well) are dangerously abandoned because, quite simply, we devalue ill and disabled people. If we do not value disabled people, then why would we value the people who care for them? We need only to recall the moments in the pandemic that exposed our raw ableism: Disabled people are disposable, older folks should “sacrifice” themselves for the economy—more than one government official stated ideas like these in media interviews. In my view, the lives of caregivers and the lives of ill/disabled people overlap and are yoked together; their predicaments are *shared*, both are products of ableist ideologies. To understand why we devalue caregiving then not only requires understanding sexism and racism, but also how ableism, or bias against disability or bodies deemed “unproductive,” plays a role. Ableism is an ideology that devalues non-normative bodies and any kind of “dependence” or care. Ableism is at the heart of American ideals that equate “independence” with worth. Ableism profoundly shapes how our care systems are structured and funded (or not) in the first place. Ableism tells us that some people are worthy of collective care and concern and others are not. Ableism denies that disability and illness are normal parts of life. Ableism is not seeing that disabled people contribute to the world. Ableism is rooted in eugenics and racism and clearly reflected in US neoliberal policies related to a lack of universal healthcare and home care supports.

Thus, in my view, our care scholarship and advocacy must engage with disability and confront ableism. And I use disability broadly here, to capture the heterogeneous category of disabled, chronically ill and elderly people – all of which are affected by the same structures and systems of care (though they experience these systems in different ways depending upon what other social locations they may occupy). The good news is that framing care as a disability issue opens up new possibilities for cross-movement mobilization between caregiving organizations and disability communities and organizations, both of which have long advocated for more long-term care and home and community-based services. And there is so much work being done on the ground by disability justice advocates. These are the folks that have been out there all pandemic, but also prior to it, shouting that our systems were failing and creating new care relations based on mutual aid and collective care.

So I want to connect all this with care, to put out there that caregivers are backed into perilous circumstances (during COVID19 and always), without support, not just because we think so little not of caregiving, but of the people they care for. This devaluation leaves millions of families to face seemingly insurmountable obstacles when simply trying to ensure folks can live a good life in the face of the entirely expectable and human experience of disability and illness.