







# CARING FOR THOSE WHO CARE

## What we learned from four years of caregiving collaboration in Santa Barbara County

### Final Report on the Community Caregiving Initiative 2016 to 2020

SANTA BARBARA FOUNDATION

EVALUATION SPECIALISTS

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# LETTER FROM THE FOUNDING DIRECTOR OF THE COMMUNITY CAREGIVING INITIATIVE

I remember the day the pieces suddenly fell into place. I had been pondering aging issues, and the challenges kept rolling around in my mind. There was the huge demographic shift to an older population fueled by the aging Baby Boomers. Projections indicated that the needs for this group would far exceed existing resources. Older people want to age in place—how would our community honor this desire? Who would invest in older people when children are "the future?" The moment of clarity came while reading a statistic from the Journal of the American Medical Association: **87% of the Americans who need long-term care receive it from unpaid family caregivers.**[1] OF COURSE!! Why hadn't I seen it before? The issues and needs related to aging went well beyond specific demographics and a singular focus—caring was an individual issue, a family issue, a community issue, as well as a state and national issue.

My realization brought new questions, new learning, and new awareness. How could Santa Barbara County support and sustain care within its communities, especially when most care was provided by unpaid family caregivers who never called themselves caregivers? They called themselves husbands or wives, sons or daughters, friends or neighbors, and the like. Social systems were built on the dual assumptions that family caregiving was obligatory and freely given. These assumptions failed to acknowledge the staggering personal cost of caring borne by these caregivers themselves.[2] Yet, there they were—struggling to navigate fragmented social and healthcare systems to find resources and advocate for their friends and family members as best they could. No wonder, I had not seen it—family caregivers had been rendered invisible by systemic assumptions and cultural norms! The situation was now clear! Caring under these conditions was already quite challenging. With the increasing need for care and fewer family caregivers to provide it,[3] caregiving would be impossible to sustain in the future.

And, the questions kept coming. What could we do to prepare for the future that was unfolding? Could individual organizations and programs become partners in supporting family and friend caregivers? Would these partnerships lead to a network that was easy for caregivers to navigate? What services and programs needed bolstering? Were the services culturally relevant? Would family and friend caregivers feel stronger and more able to provide care if they were able to access the support and given the tools they needed? Would a community-based approach for caregivers offer better care to the care recipients? And finally, how would we find the answers to these questions?

Thus began the Community Caregiving Initiative of Santa Barbara County—an inclusive, connected community learning together how to strengthen the care given by family and friends. By coming together as partners representing organizations and listening to caregivers in our community, we thoughtfully and deliberately decided what kind of change we would strive for and how we would measure it. It was a disciplined, collaborative approach that found partners in expected and unexpected places, including hospitals, social service agencies, a fire department, and the employer community. As the data was gathered over the years, we learned and became better partners and a more caring community emerged.

This report details the powerful impact that a strategic, coordinated effort can have on caregivers, those they care for and the community's care network. It is the result of the collaboration, experimentation, creativity, patience, and yes, CARE, as well as the commitment of the Santa Barbara Foundation to bring this work to fruition. I hope you will find the results presented here stimulating, thought provoking, encouraging, and inspiring, and that you will begin to see how your community, and any community committed to supporting caregiving, can come together to grow and sustain the ability to care for its members.



Phylene Wiggins, (former) Sr. Director of Community Investments and Founding Director of the Community Caregiving Initiative, Santa Barbara Foundation

1 Source: Kaiser Family Foundation (http://www.kff.org) analysis. Original data and detailed source information are available at http://facts.kff.org/JAMA_082813

2 P. Wiggins, M. Gibson, G. Gonzales, "Worn Out and Invisible: Family Caregivers of Santa Barbara County," Santa Barbara Foundation and Area Agency on Aging – San Luis Obispo and Santa Barbara Counties, Santa Barbara, CA, August 2018, https://www.sbfoundation.org/what-we-do/community-caregiving-initiative/

3 D. Redfoot, L. Feinberg, A. Houser, "The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers," AARP Public Policy Institute, Washington, DC, August 2013, https://www.aarp.org/home-family/caregiving/info-08-2013/the-aging-of-the-baby-boom-and-the-growing-care-gap-AARP-ppi-ltc.html

# ABOUT THE SANTA BARBARA COUNTY COMMUNITY CAREGIVING INITIATIVE

The Santa Barbara Foundation (SBF) believes that aging with dignity should be a shared community value. Caring is the foundation of our humanity. At the same time, caring for others can be demanding and even draining. When a society depends on family members to care for elders, the needs of those providing such care must also be seen and addressed. For these reasons, SBF envisioned and provided leadership and support for the Santa Barbara County Community Caregiving Initiative (CCI).

In Santa Barbara County and across the country, most long-term care is provided by unpaid family caregivers. In Santa Barbara County alone, an estimated 99,000 people (approximately 29 percent of the population) are unpaid family caregivers. While caregiving provides rewards, it also exacts a toll. Caregivers are at significant risk for serious stress and diminished health outcomes.

With the understanding that families are the backbone of long-term caring, SBF supported the CCI to develop a system that was better prepared to address the needs of caregivers and those they care for. The vision was to improve services to family caregivers, including helping people identify with and value the caregiving role, and develop more integrated and inclusive health and social systems, that would allow caregivers to access support more easily in culturally aware, respectful, and appropriate ways. This support would in turn improve quality of life for caregivers themselves and the friends and family members they care for.

To do this, CCI leadership and partners based their work on four strategies:

- Strengthening caregivers individually
- Connecting community organizations and agencies to ensure caregivers can easily access supportive services
- Creating new knowledge that will benefit caregivers
- Raising awareness about caregiving and policy solutions that support caregiving

Since its inception, more than 28 organizations and entities, representing a broad range of service providers throughout Santa Barbara County, have participated in the CCI as partners and stakeholders. A complete list appears in Appendix A. The list includes only organizations that participated in the Partner survey one or more times. Additional organizations, not listed here, also contributed to this work. SBF owes each of these organizations and their staff a debt of gratitude for their contributions.

To evaluate the impacts of these investments and efforts, SBF contracted Evaluation Specialists (ES) to design and conduct an external, mixed-methods evaluation of the CCI.[1] The purposes of this evaluation were to:

- Develop a Theory of Change for the CCI (shown in Appendix B)
- Provide timely, ongoing information to Initiative partners to guide program improvement
- Assess how effective the CCI was in meeting its key goals
- Characterize how agencies across Santa Barbara County were working together to better support caregivers, specifically how they communicate and collaborate with one another to improve caregiver services and referrals
- Identify successful practices as well as barriers to program delivery and opportunities for program improvement
- Develop actionable recommendations for Initiative enhancement and sustainability

In 2016 ES engaged SBF and CCI partners in an interactive process to identify collective goals of the community and develop shared definitions of varying levels of success. In this process the group established criteria to transparently evaluate ten Initiative goals as well as the overall Initiative.

ES collected and analyzed data four times, in Spring 2017, Fall 2017, Fall 2018, and Fall 2019. At each timepoint, they reviewed findings from four sources: a caregiver survey, a partner survey, caregiver interviews, and CCI Partner interviews. Each time they collected data they analyzed it to characterize the level of success achieved in each of the goal areas.

Overarching findings from this evaluation are summarized in the CCI Performance Dashboards on the next page. This third and final evaluation report summarizes key impacts and learnings from four years of CCI efforts.

**COVID-19 Organizational Impacts and Needs**

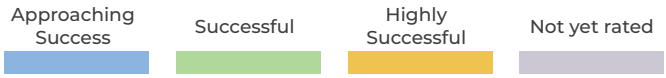
Early in the pandemic in March 2020, Evaluation Specialists assessed COVID-19's impact on 23 CCI partners, asking about its effects on their services and organizations, and about what they saw as caregivers' and care recipients' areas of greatest need. Please see Appendix F for the findings from this assessment.

**About Santa Barbara Foundation:** The Santa Barbara Foundation, located on the south-central coast of California, was established in 1928 by Max Fleischmann and a forward-thinking group of individuals who wanted to enrich the lives of people from Santa Maria to Carpinteria. For more than eight decades, the Santa Barbara Foundation has been at the center of civic activity, a vibrant expression of its engaged citizenry, a solver of problems, a partner in philanthropy, and a critical supporter of community organizations and efforts.

1. In 2017, AARP provided support for the evaluation efforts of the CCI in order to identify promising practices and lessons learned and inform its national priority of family caregiving.

## CCI Performance Dashboard

These tables summarize the current level of success for each CCI impact area and its associated sub-goals, as of December 2020. Detailed descriptions of each level of success for each goal component were collaboratively developed by CCI partners and can be found in Appendix C.




### CCI has positively impacted caregivers' ability to meet their own needs and well-being.

| Goal Components | Level of Success 2017 | Level of Success 2018 | Level of Success 2019 |
|---|---|---|---|
| Improve caregiver appreciation of their role. | Approaching Success | Approaching Success | Successful |
| Improve caregiver access to information needed to care for themselves. | Approaching Success | Approaching Success | Approaching Success |
| Improve caregiver skills and capacity to care for themselves. | Successful | Approaching Success | Successful |
| Improve the well-being of caregivers. | Approaching Success | Approaching Success | Approaching Success |

### CCI has positively impacted caregivers' ability to provide (and ensure provision of) the best possible care for those they provide care for.

| Goal Components | Level of Success 2017 | Level of Success 2018 | Level of Success 2019 |
|---|---|---|---|
| Improve caregiver access to information needed to care for their care recipient(s). | Successful | Approaching Success | Approaching Success |
| Improve caregiver skills and capacity to care for their care recipient(s). | Approaching Success | Approaching Success | Approaching Success |
| Caregivers are able to provide (and ensure provision of) the best possible care for their care recipients. | Approaching Success | Successful | Successful |

### The CCI has succeeded in creating systems that support effective communication, collaboration, and referrals across partner organizations.

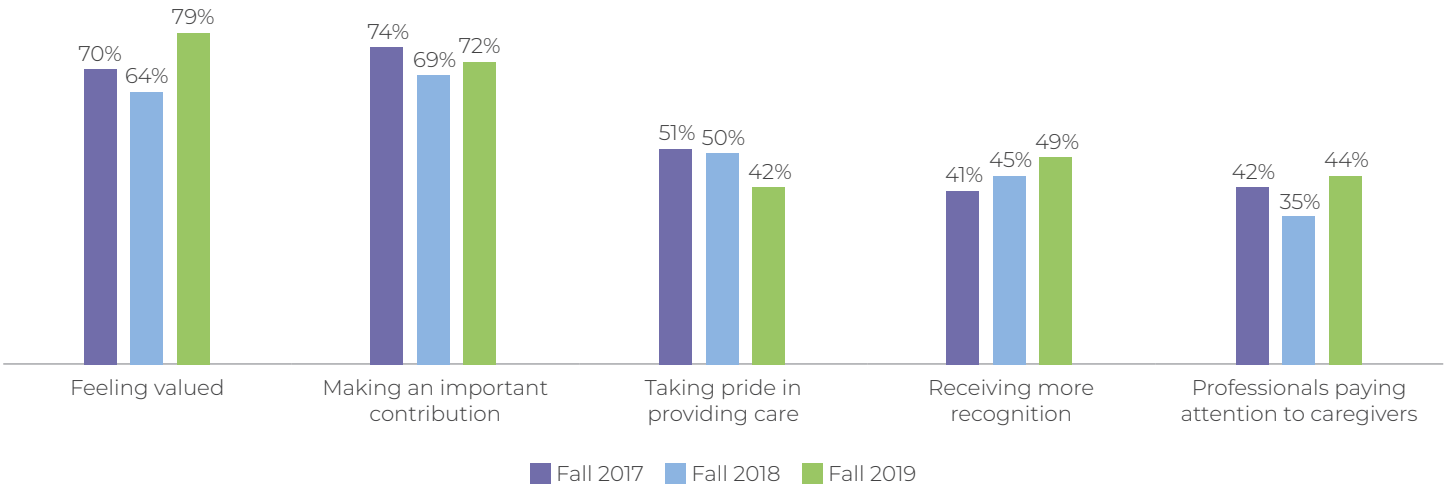
| Goal Components | Level of Success 2017 | Level of Success 2018 | Level of Success 2019 |
|---|---|---|---|
| Generate partner organization commitment/buy-in to CCI as a mechanism to improve system of care for caregivers. | Highly Successful | Approaching Success | Highly Successful |
| Create systems that support effective communication, collaboration, and referrals across Partner organizations to develop a system of care for caregivers. | Successful | Successful | Successful |
| Develop a sustainable system of care to support caregivers in their work. | Not yet rated | Approaching Success | Successful |

# IMPACTS ON CAREGIVERS

## Evaluation Question 1: How has the CCI contributed to improvements in caregivers' awareness of the important role they play in the health care system?

**Answer: When caregivers used services and interacted with staff it improved their perceptions about the importance and value of being a caregiver.** Two-thirds to three-quarters (between 64% and 79%) of caregivers reported that services improved their feeling of being a valued part of their care recipients' health care, and that as caregivers they were making an important contribution to the overall health care system. About half (between 41% and 51%) reported that their service experiences increased their pride about providing care and the recognition they received in their community, and that professionals paid attention to their needs as caregivers (Figure 1). CCI partner responses (not shown) support these findings. **Almost all CCI partners agreed or strongly agreed that their organizational practices increase awareness and appreciation of caregiver contributions** (90% in Fall 2017, 93% in Fall 2019, and 100% in Fall 2019).

**Figure 1:** Caregivers agreed that services improved their perceptions of the important role they play in the health care system, including...




**What we learned: Many caregivers do not recognize the critical role they play as part of the larger health care system**, even though they realize they provide important care to their care recipient. Medical providers may lack this awareness as well, often taking caregiver efforts and their important role for granted. As one caregiver shared, "The general population doesn't realize that being a caregiver is a 24/7 job. You don't learn this until you are thrown into the role."[3] This lack of awareness and recognition of the critical role caregivers play reduces their likelihood of seeking and receiving the support they need.

**Caregiving comes with both joys and challenges.** People we talked with cited pride, love, reciprocity, dignity, and intimacy as some of the best parts of being caregivers. One caregiver shared, "I cared for my mom, with Alzheimer's, for 15 years, and the best part about caring for her was I really felt like I was honoring her and giving her the weight and space of being able to keep her dignity." Caregivers also described anxiety, fatigue, and feeling overwhelmed. "She's my mom. So, I can't just go 'Okay, I'm done.' I can't walk out the door and say, 'Okay, I put my hours in. Someone else's turn.'"

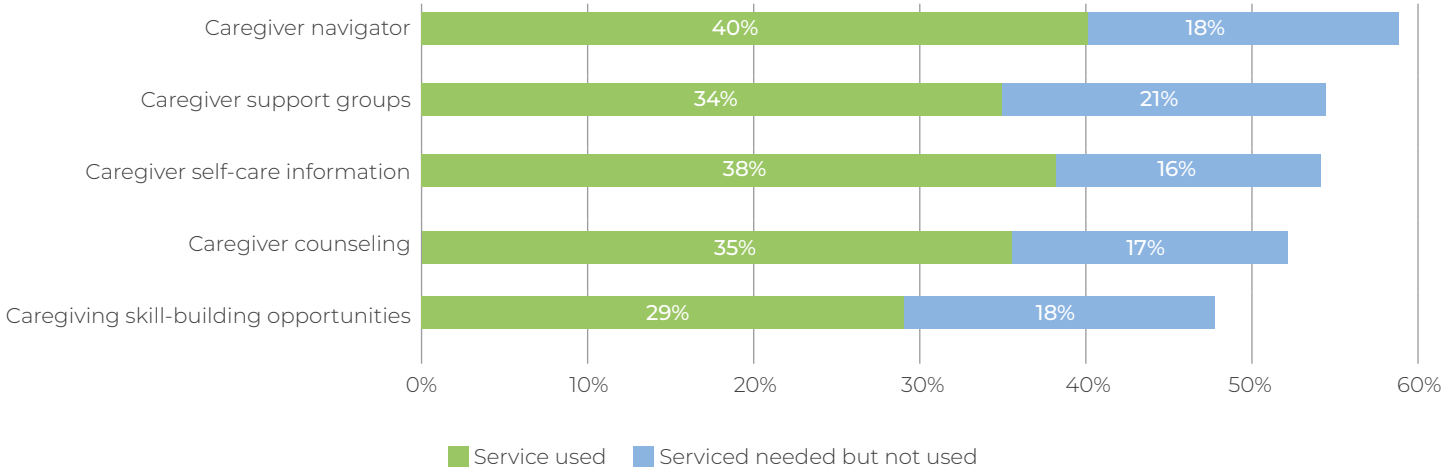
3. Illustrative quotes in this report are drawn from qualitative data we collected in interviews with caregivers and key informants.

## Evaluation Question 2: How has the CCI contributed to improvements in caregivers' access to information and services to care for themselves?

**Answer: Only about half of caregivers received all the information they needed on self-care topics, suggesting the CCI did not measurably impact caregivers' access to information.**[4]
This finding (which ranged between 40% and 61%) remained consistent across all four surveys.

**Caregivers' need for services exceeded their use.** About a third more caregivers reported needing services (between 16% and 21%) than reported using them (between 29% and 40%) (Figure 2). Caregivers reported using and needing caregiver navigator services most, and caregiving skill-building opportunities least. Lack of awareness of available services may have contributed to the difference between use and need. Between 31% and 38% of caregivers said they were unaware that some services were available.[5] CCI partner responses support these findings. **Almost all partners think the CCI contributed a moderate amount or a lot to caregivers' ability to receive needed support for themselves** (90% in Fall 2017, 81% in Fall 2018, and 100% in Fall 2019).

**Figure 2:** Caregivers' need for services exceeded their use (Average percent from Spring 2017 through Fall 2019)



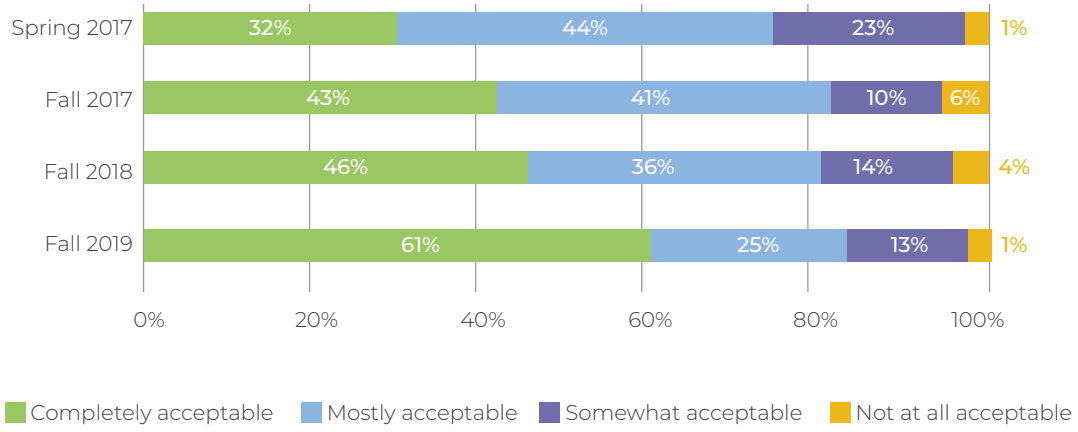

**Caregivers' ratings of the acceptability of any services they received to support them as a caregiver in the previous six months (in terms of language, culture, religion, sexual orientation, and age) improved substantially over time.**
The percent of caregivers reporting that services they or their care recipients received in the previous six months that were completely acceptable in these ways almost doubled from Spring 2017 to Fall 2019 (Figure 3). This provides an overall sense of how well services are working for caregivers and care recipients in this important regard.



4. Self-care information included: 1) community resources available for caregivers, 2) common stressors associated with caregiving, 3) Importance of self-care, 4) How to take care of yourself, and 5) how family dynamics change with caregiving.
5. Available caregiver services included: 1) skill-building opportunities, 2) caregiver navigator (a person that provides caregivers with options counseling and resource referral services), 3) counseling, 4) support groups, and 5) self-care information.

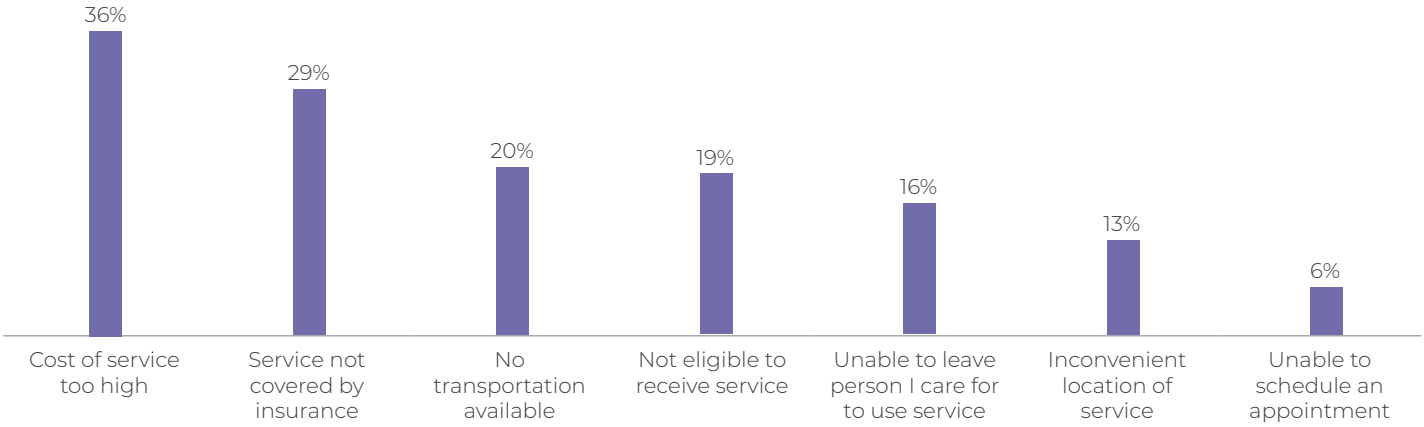
While there is still much work to be done in this area, this finding is consistent with the CCI focus on improving the acceptability of services for all caregivers in Santa Barbara County.

**Figure 3:** Caregivers' ratings of the acceptability of services they or their care recipients received in the previous six months improved substantially




**The most common challenges to using needed services were related to a lack of resources.** The most common reasons were high cost and lack of insurance coverage, followed by lack of transportation and ineligibility to receive the service. Less common challenges included being unable to leave their care recipient, inconvenient service locations, and inability to schedule appointments (Figure 4).

**Figure 4:** Caregivers faced several challenges to using services in the previous months, including...

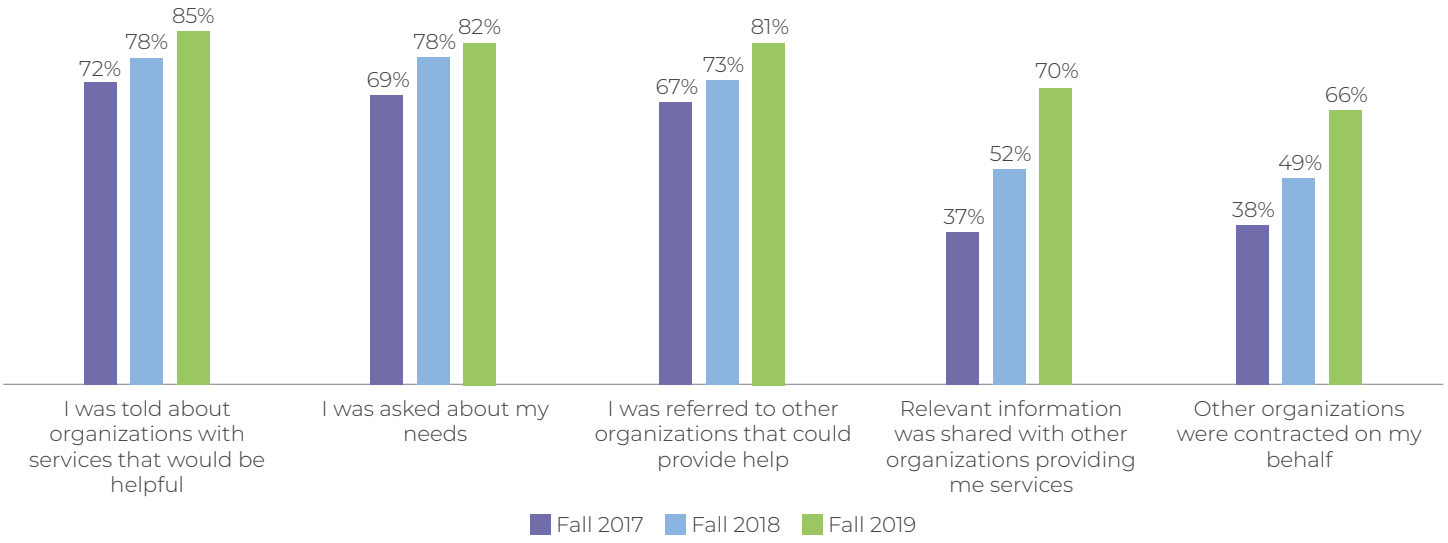



**What we learned: Caregivers often don't know where to begin to seek help**, saying things like "in the very beginning, you don't even know what you need." Several partners noted that "there are community resources and information that can help overcome some of these challenges, but some folks aren't able to tap them. There are practical barriers – like how much time caregivers have to actually request assistance."

## Evaluation Question 3: How has the CCI improved caregivers' ability to care for themselves?

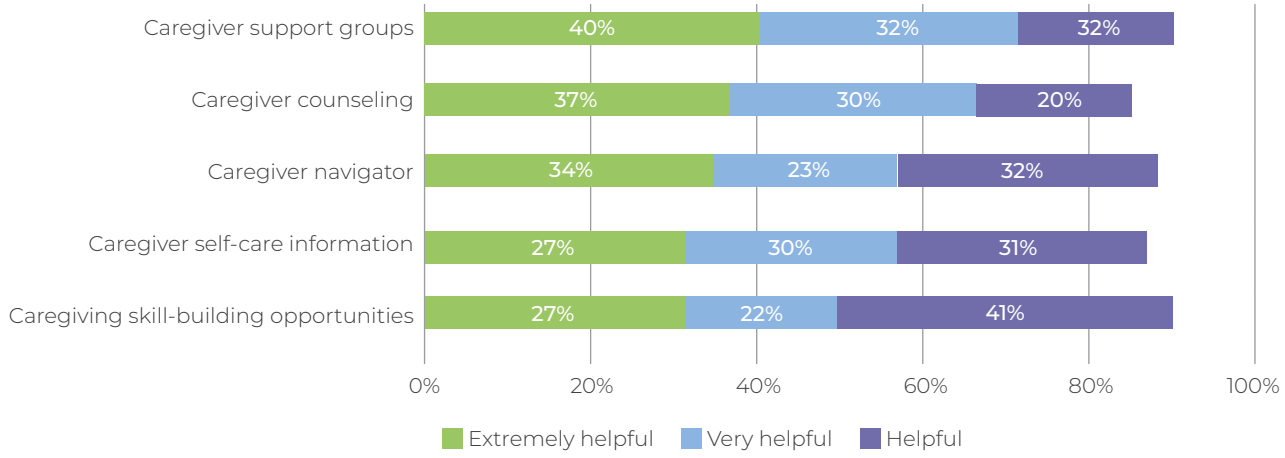
**Answer: At the start of the CCI, partners committed to prioritize implementation of five practices that support caregivers – all five practices increased over time.** From Fall 2017 to Fall 2019, a larger percentage of caregivers agreed or strongly agreed with the statement reflecting each practice (Figure 5).[6] CCI partner responses support these findings. **Three-quarters or more of partners think the CCI contributed a moderate amount or a lot to caregivers' ability to take care of themselves and meet their own needs** (80% in Fall 2017, 75% in Fall 2018, and 93% in Fall 2019).

**Figure 5:** Caregivers reported that agency practices intended to support them increased over time.
(% of caregivers that agree or strongly agree)




**Caregivers found the services they used helpful, and half or more found them very or extremely helpful.** While all the services were found to be helpful, caregivers found support groups to be the most helpful, followed by counseling and caregiver navigators, caregiver self-care information, and skill building opportunities (Figure 6).

**Figure 6:** Almost all caregivers found the services they received helpful, and half or more found them very or extremely helpful (Average percent from Spring 2017 through Fall 2019)




6. These questions were not asked in Spring 2017.

**What we learned: Seeking support can feel overwhelming to caregivers who are already overwhelmed.** Their many day-to-day responsibilities can make caregivers feel unable to allot time to getting support for themselves. And some feel it's "just part of what you signed up for" as a family member. They wanted service providers to understand that sometimes in the beginning, they didn't know exactly what they needed, what services were available or might be useful to them, who to talk to, or what to ask for. Just getting started was a major step.

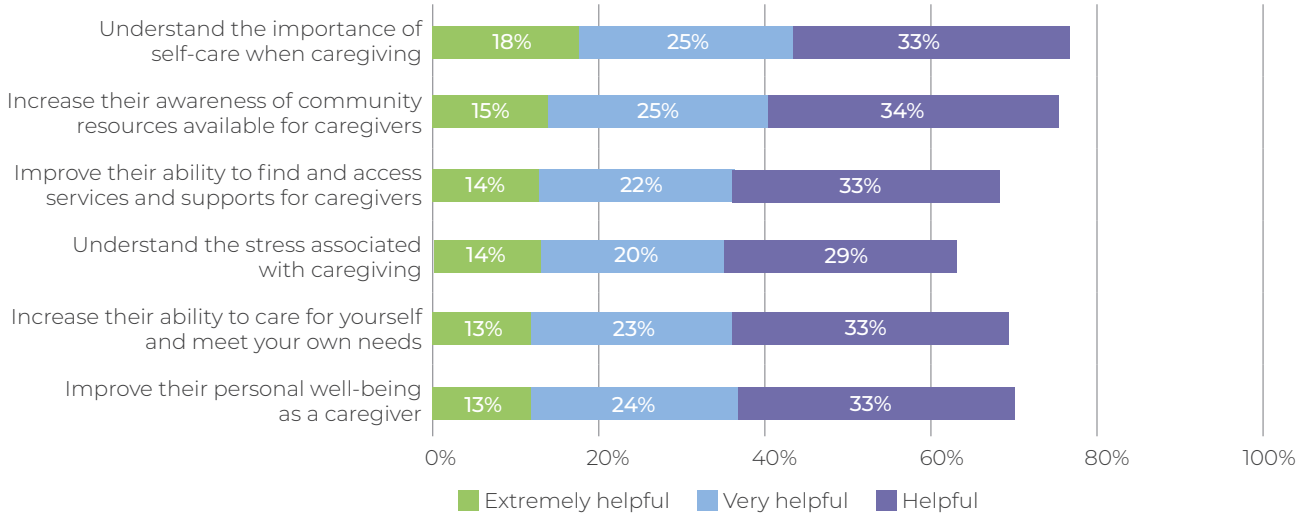
**Many caregivers need to be encouraged to prioritize self-care and get support.** However, service providers making personal contact with caregivers and reducing barriers to getting support can help. One caregiver summed it up by saying, "I think that one of the best ways people can get informed is through someone else." Another said, "There are people who, not all of them, but some, who need to be guided and grabbed by the hand. If not, they don't do anything." Caregivers also said personal contact from a service provider gives them "a lot of support. They know where the services are, and can facilitate the process for me, because they provide me phone numbers or brochures, so it's easier for me to get access to what I need."

**Address the barriers that stand in the way of caregivers getting support.** Language is a serious barrier to accessibility that takes many different forms. The use of automated responses, impersonal and/or poor customer service, or requiring a caregiver to repeat their situation multiple times are also barriers. Many caregivers find it difficult to leave their care recipient to get services for themselves. Common challenges like these can result in caregivers falling through the cracks.

## Evaluation Question 4: How has the CCI improved the well-being of caregivers?

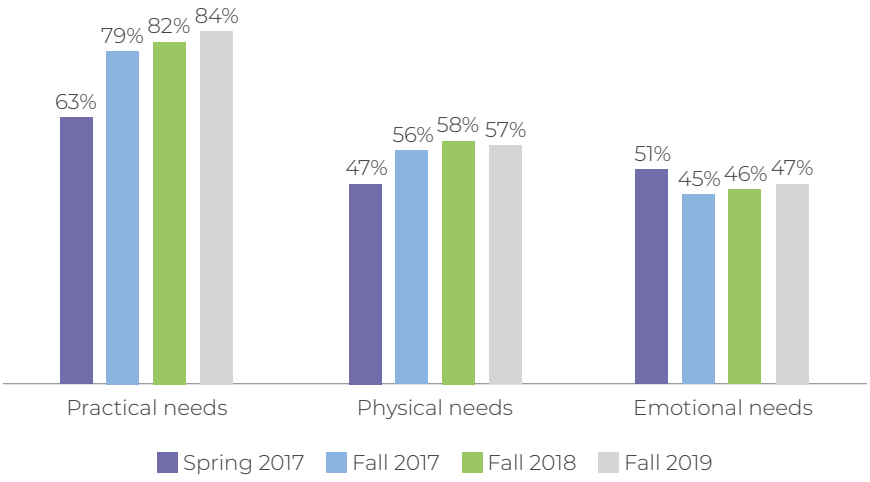
**Answer: Services helped caregivers' improve their personal well-being in several ways.** Caregivers said the services they or their care recipients received helped them understand the importance of self care when caregiving, increased their awareness of community resources, and their ability to find and access services. Services also helped them understand the stress associated with caregiving, increase their ability to care for themselves and meet their own needs, and improve their personal well-being as a caregiver (Figure 7). CCI partner responses support these findings. **A majority of partners think the CCI contributed a moderate amount or a lot to caregivers' personal well-being** (80% in Fall 2017, 69% in Fall 2018, and 86% in Fall 2019).

**Figure 7:** Caregivers reported that services they or their care recipient received helped them…
(Average percent from Fall 2017 through Fall 2019)



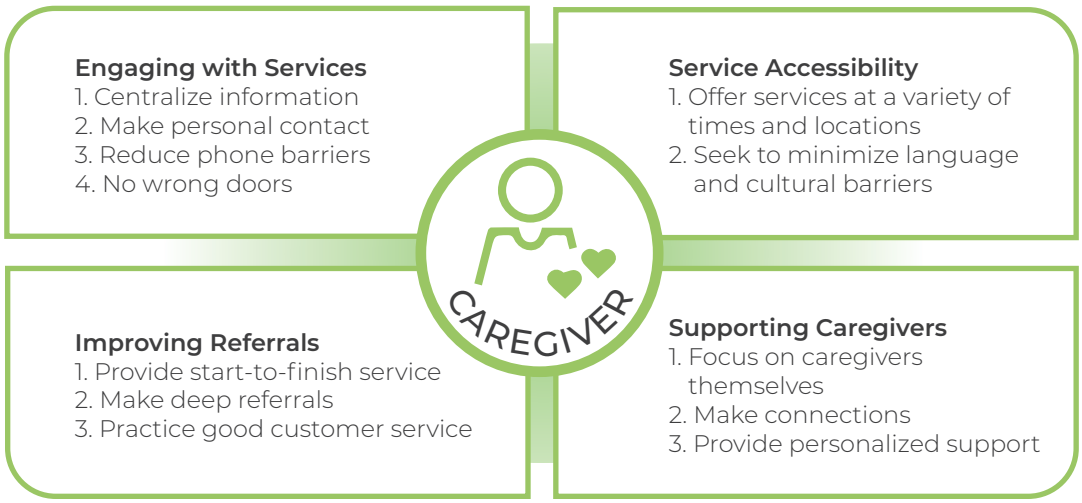
**Caregivers were more likely to meet their practical needs (for example, shelter and finances) than their physical needs (for example, diet and sleep) or emotional needs (for example, coping with stress).** The proportion that met their physical and practical needs increased over time (Figure 8). Caregivers were least likely to meet their emotional needs, and their ability to do so changed little over time. There were also opportunities for health care and social service providers to better attend to the needs of caregivers. Less than half of caregivers (between 35% and 44%) reported that such professionals paid attention to caregivers' needs.

**Figure 8:** Over time, more caregivers were able to often or always meet their physical and practical needs, but their ability to meet their emotional needs stayed about the same.




**What we learned: Provide caregivers multiple points of entry into the system of care:** We conducted in-depth interviews with both CCI partners and English and Spanish speaking caregivers to gather their recommendations for improving service access and delivery. CCI partners emphasized the importance of caregivers gaining access to needed supports regardless of where they first accessed services. "We used to use the term 'no wrong door' – however a caregiver enters, whatever door, that they are seen as someone the community wants to support and they are whisked into this world and know there is a system there to support them." From the caregiver interviews we identified four areas in which caregivers could be better supported, each with specific recommendations (see Figure 9).

**Figure 9:** Put caregiver needs at the center of intake, referral, and follow-up systems[7]



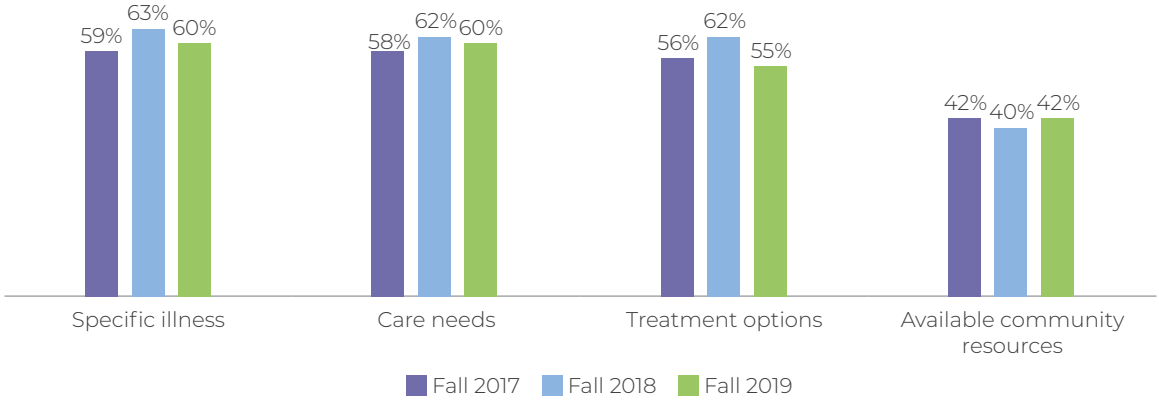

7. These recommendations were identified from in-depth interviews with English and Spanish speaking caregivers.

# IMPACTS ON CARE RECIPIENTS

## Evaluation Question 5: How has the CCI contributed to improvements in caregivers' access to information and services they need to care for their care recipients?

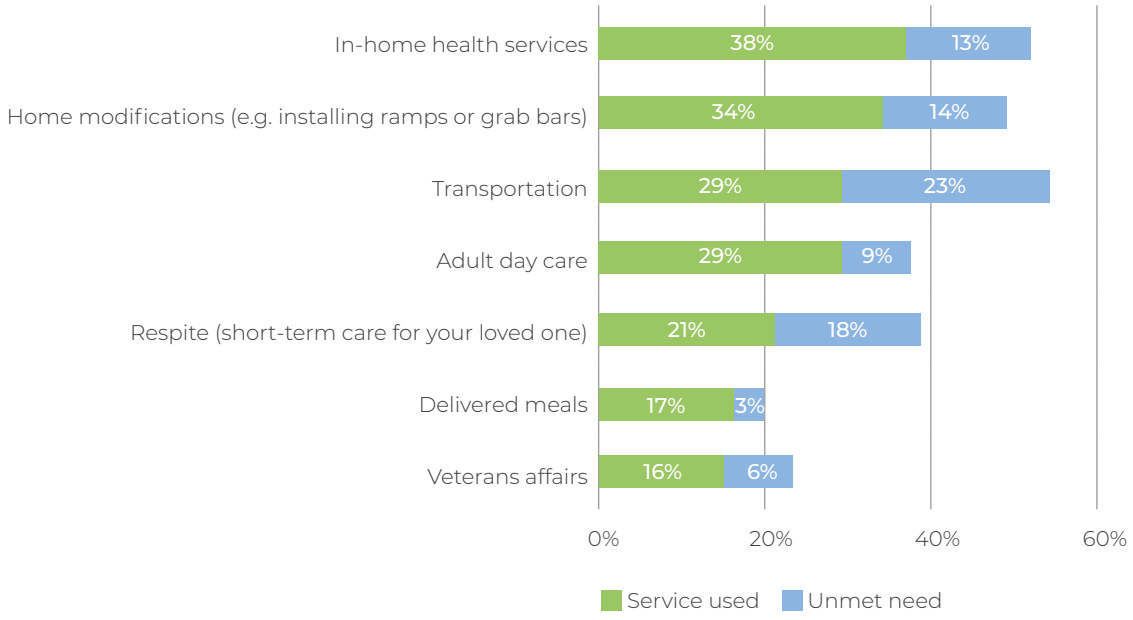
**Answer: A majority of caregivers reported receiving all the information they needed about topics related to their care recipient,** including information about their specific illness and care needs, and their treatment options, while less than half (about 41%) received as much information as they needed about community resources available for their care recipient (Figure 10). Importantly, when care recipients receive services, their caregivers' awareness of available community resources increases. Two-thirds of caregivers (about 67%) reported when their care recipient received services it helped increase their awareness of other available community resources. CCI partner responses provide support for these findings. **More than three-quarters of partners think the CCI contributed a moderate amount or a lot to caregivers' ability to advocate for appropriate care for their care recipients** (75% in Fall 2017, 75% in Fall 2018, and 93% in Fall 2019).

**Figure 10:** A majority of caregivers received needed information about their care recipient's specific illness, care needs, and treatment options, while a minority received needed information about available community resources



**Care recipients' need for services also exceeded their use.** The services most used were in-home health services and home modifications. Least used were delivered meals and Veterans affairs. Lack of awareness of available services may have contributed to the difference between use and need here as well. Not all caregivers were aware that the services they were asked about were available. Awareness of all available services ranged from 76% to 81%. The greatest area of unmet need (caregivers that said they needed, or were unsure if they needed, but did not use a service) was in transportation (23%), followed by respite (18%). The area with the least unmet need was delivered meals (3%).

**Figure 11:** Care recipients' need for for services exceeded their use
(Average percent from Spring 2017 through Fall 2019)




**What we learned: Each interaction with a provider or agency creates an opportunity to provide information and connect caregivers and their care recipients with the supports they need.** Caregivers need relevant information and access to supportive services in order to provide the best care for their care recipients.

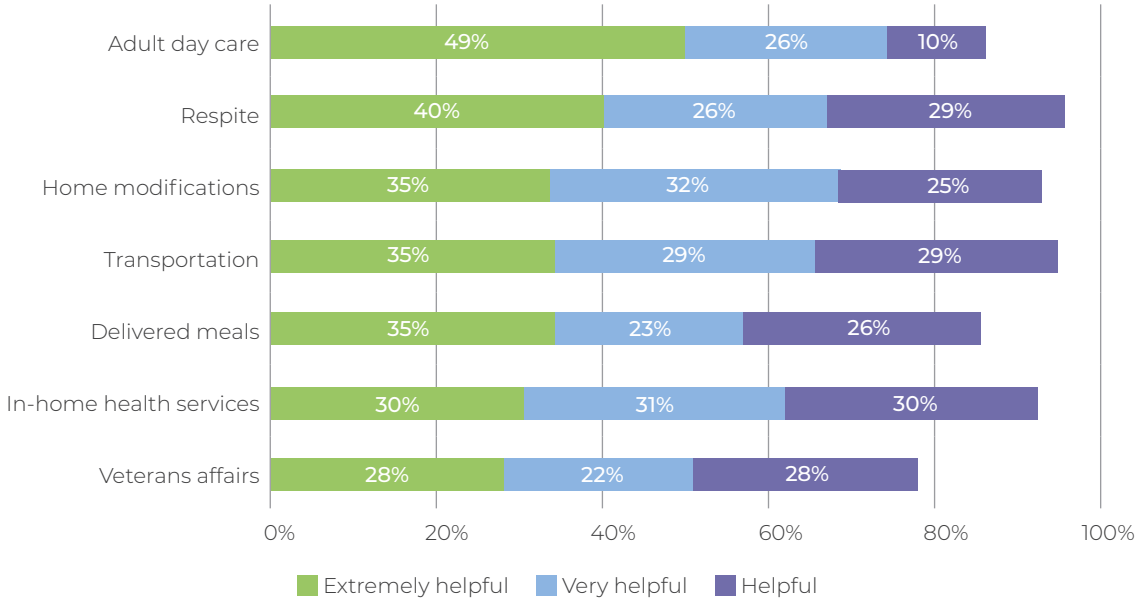


## Evaluation Question 6: How has the CCI contributed to improving caregivers' ability to care for their care recipients?

**Answer: The percentage of caregivers that reported using all the services their care recipients needed increased,** from 49% in Fall 2017 to 60% in Fall 2019. However, a substantial minority (40% in Fall 2019) are still not using all the services their care recipients need. CCI partner responses suggest one reason for these findings. **Additionally, more than half of partners think the CCI contributed a moderate amount or a lot to caregivers' ability to navigate the health care system** (75% in Fall 2017, 56% in Fall 2018, and 57% in Fall 2019).

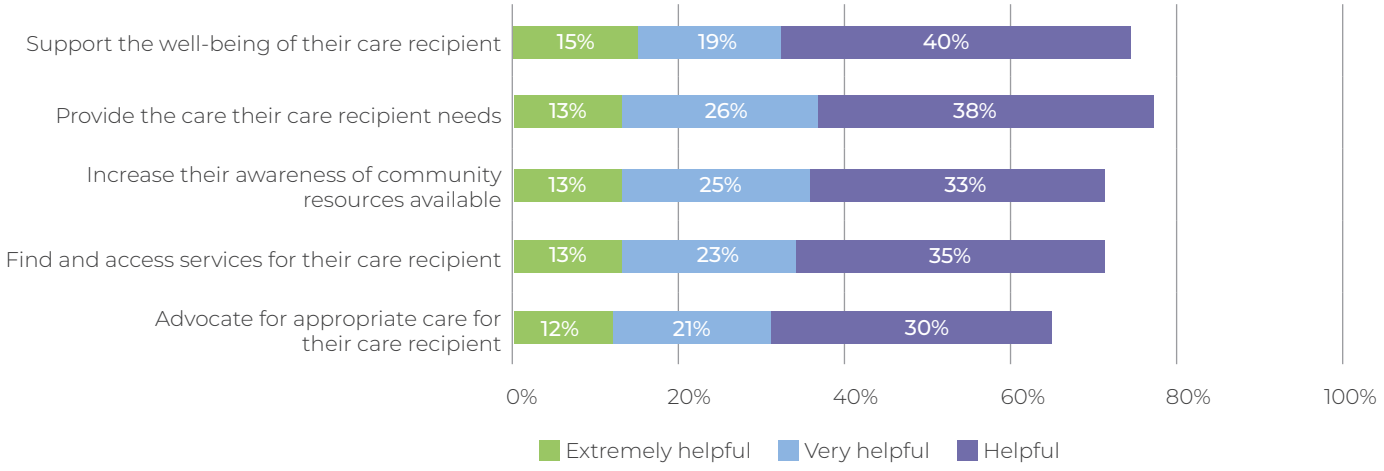
**Caregivers found the services their care recipient received to be helpful.** For every service we asked about, half or more of caregivers said it was very or extremely helpful. Caregivers found adult day care to be the most helpful, with 49% saying it was extremely helpful, followed by respite, home modifications, transportation and delivered meals, in-home health services, and Veterans affairs (Figure 12).

**Figure 12:** Most caregivers found the services their care recipient received to be helpful… (Average percent from Fall 2017 through Fall 2019)



**Caregivers also reported that services improved their ability to care for their care recipient in several ways** (Figure 13). Consistent with the caregiver findings, **a majority of CCI Partners think the Initiative contributed a moderate amount or a lot to caregivers' ability to provide the best possible care for their care recipient** (85% in Fall 2017, 81% in Fall 2018, and 79% in Fall 2019).

**Figure 13:** Caregivers reported that services they or their care recipient received helped them…
(Average percent from Fall 2017 through Fall 2019)




**What we learned: While caregivers differ in their level and type of service use, those that report higher use of services report being able to provide better care to their care recipients.** We learned this by conducting Latent Class Analysis to identify groups of caregivers who use services very differently.[8] The four groups we identified were: High service users, moderate to high service users, moderate service users, and very low service users.

Caregivers in Santa Barbara County used between 3 and 4, on average, of the 12 types of services available over the past six months. Most caregivers in all four groups were caring for parents. But people in the High Service User group (who use between 7 and 8 on average) were twice as likely as those in other groups to be solo caregivers, and a little more likely to be caring for spouses.

Across all four groups, caregiver reports of self-care and well-being were similar. All caregivers reported feeling stressed sometimes to often because of their caregiving responsibilities. However, a key finding was that caregivers in the High Service User group were more likely to report being able to provide better care to their care recipients in some areas (to a statistically significant level). Specifically, they were more likely to be able to figure out where to get services, make sure their care recipient received the services they need, work with their medical providers, and be actively involved in their care decisions.

8. Detailed LCA findings can be reviewed in Appendix E.

## Evaluation Question 7: How has the CCI contributed to improvements in the wellbeing of care recipients?

**Answer: Most care recipients had a variety of indirect, direct, and complex care needs.** Nearly all caregivers reported their care recipient required indirect support (for example, finding needed services and working with medical providers) and direct care (for example, helping with daily activities and managing medications). Many also needed complex care (for example, giving injections or managing use of medical devices).

**Thus, caregivers often need to provide a range of indirect support, direct care, and complex types of care for their care recipient.** We asked about twelve types of care and grouped them into three categories: indirect support, direct care, and complex care. Between 80% and 96% of caregivers provided the types of indirect care we asked about (Figure 14). Direct care, which typically involves more interaction with the care recipient, was provided by 60% to 90% of caregivers (Figure 15), while complex care, which requires specialized knowledge or training, was provided by 11% to 58% of caregivers (Figure 16).

**Figure 14:** Types of indirect support provided by caregivers to their care recipients ...
(Average percent from Fall 2017 through Fall 2019)

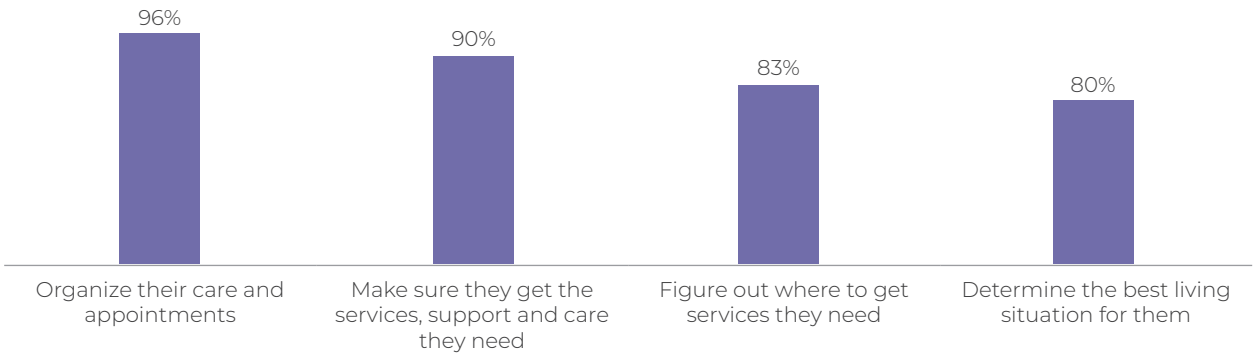



**Figure 15:** Types of direct care provided by caregivers to their care recipients...
(Average percent from Fall 2017 through Fall 2019)

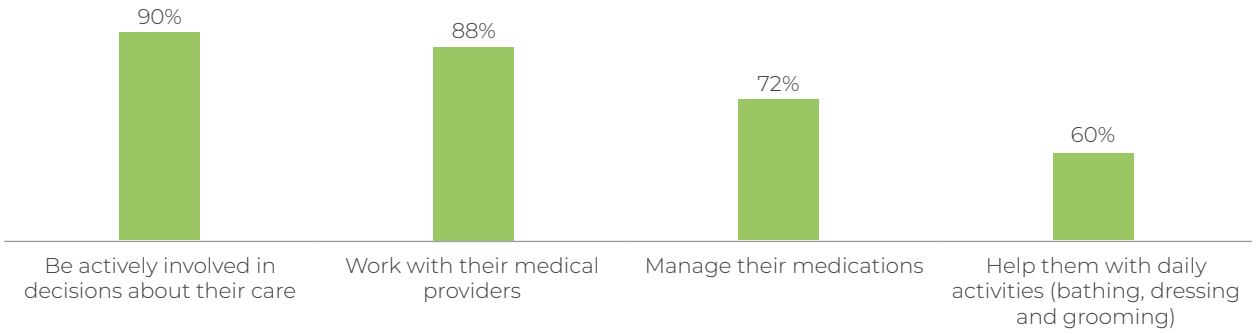
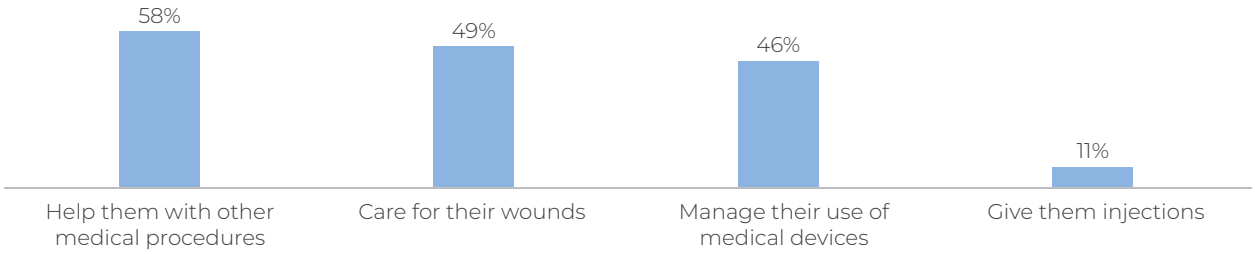
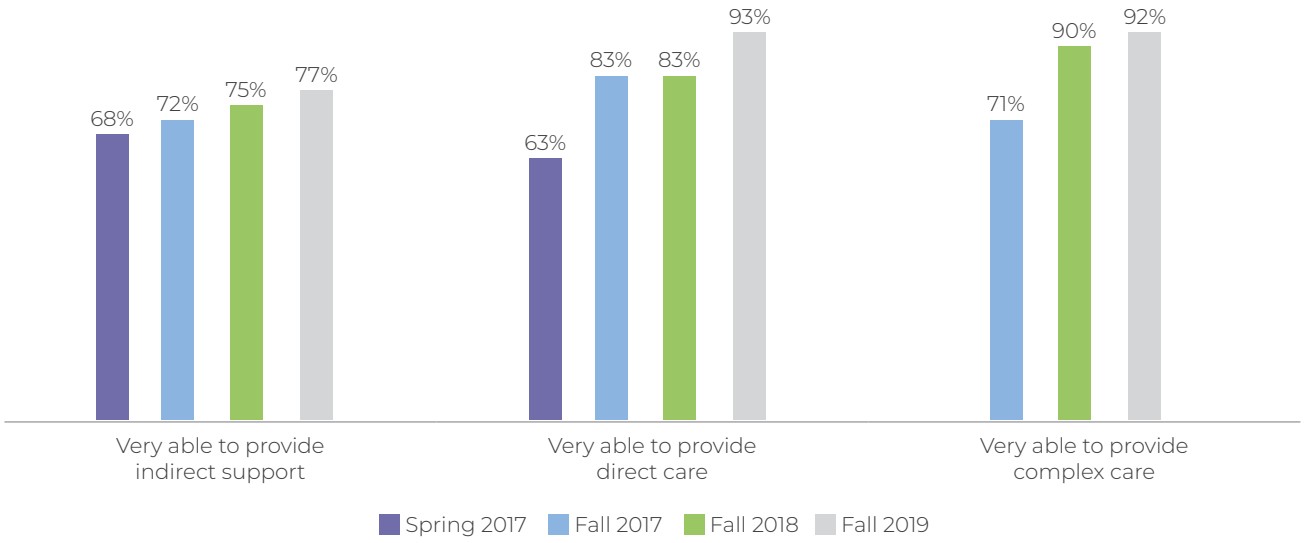


**Figure 16:** Types of complex care provided by caregivers to their care recipients…
(Average percent from Fall 2017 through Fall 2019)




**Over time, more caregivers reported being very able to provide the indirect, direct, and complex care their care recipients needed.**[9] By Spring 2019, the majority of caregivers (77% to 93%) felt very able to provide the care needed by their care recipient (Figure 17). Findings from CCI partners concur with caregiver findings. Over time, about 80% of partners reported they believed CCI improved caregivers' ability to provide the best possible care and improved the well-being of care recipients. Consistent with the caregiver findings, **about three-quarters of CCI partners think the Initiative contributed a moderate amount or a lot to caregivers' ability to improve the well-being of their care recipient** (85% in Fall 2017, 88% in Fall 2018, and 71% in Fall 2019).

**Figure 17:** Over time, more caregivers felt very able to provide the types of care needed by their care recipient




**What we learned: Providing education to key audiences can improve services.** Caregivers benefit from education about the importance of their role, stressors associated with it, and available resources. Medical professionals, employers, and the general public benefit from education about the important role caregivers play in the health care system, and what they can do to better support them.

**Navigators help caregivers use the "system of care" (a spectrum of effective, community-based services and supports) to better support their care recipients.** One caregiver described the navigator as, "someone in the system that can help me…and values the contribution that I'm bringing."

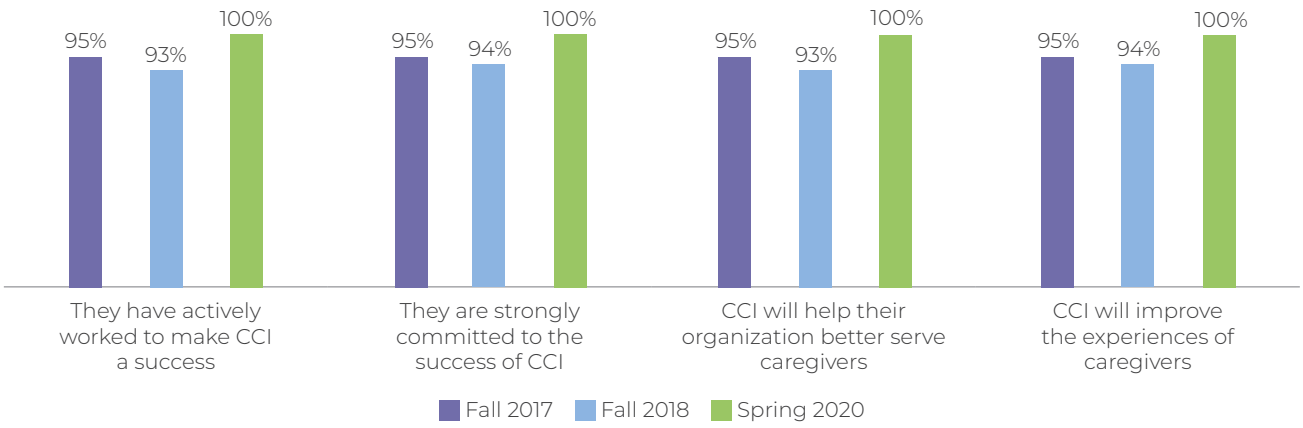
9. We did not ask about complex care in Spring 2017

# IMPACTS ON THE SYSTEM OF CARE

## Evaluation Question 8: To what extent are CCI partner organizations committed to the goals of the CCI?

**Answer: Partners strongly believe in the CCI as a mechanism for change and are committed to working together to improve the well-being of caregivers and their care recipients.**[10] Almost all partners actively worked to make the CCI a success and were strongly committed to this goal. Similarly, almost all partners believe the CCI will help their organization better serve caregivers and improve their experiences (Figure 18).

**Figure 18:** Almost all partners agree or strongly agree...




**What we learned: It helps to have a champion to take the lead.** In the case of the CCI, this was Phylene Wiggins, Senior Director of Community Investments at Santa Barbara Foundation. Partners described her as "[the person] making these linkages happen," "excellent in her communication style and keeping everyone informed," and "a force of nature... amazing in her ability to connect people and ideas." Another responsibility of the champion is to make clear that "partners are striving for the same things and feel part of developing a shared vision."

**Both financial and other types of support need to be provided.** Partners described the critical importance of both funding and other types of support to network development. One partner noted "without their support we couldn't do this. They [SBF] are the backbone of the project... not just funding but offering education and resources... offering layer upon layer that helps us be better at what we do." Another said, "SBF didn't just write us checks. They stayed with us throughout the process and listened to our feedback about how they could help... and then followed through with it."

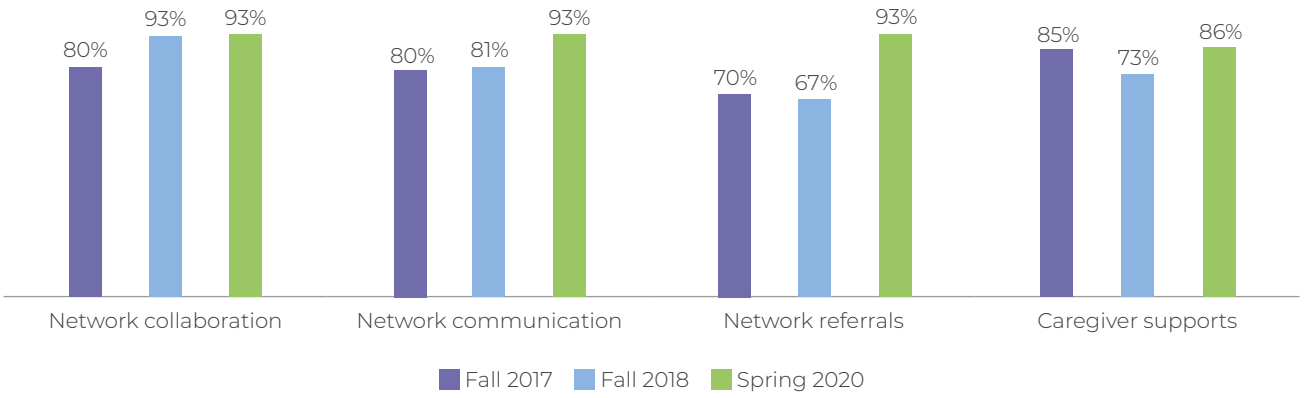
**Individual and organizational connections are the foundation of this work.** As one partner stated, "Success depends on working together!" Participation in the CCI was open to all organizations and service providers working with caregivers throughout Santa Barbara county. SBF intentionally fostered connections and relationships by hosting a mixture of in-person convenings, interactive webinars, and teleconferences. One partner commented, "Our communication with other partners is invaluable. Meeting face to face, emails, etc., keep us all in the loop, connected, fresh and supportive. Because of this connection and frequent communication, we all are better equipped to serve our clients and community." Another said, "We partner directly and through collaborations with many of the CCI partners." As a result of these connections, one partner commented that their "referrals have increased over the past two-three years."

10. Partner survey findings may differ slightly from previous reports. This is because one partner that had participated said they did not feel they could adequately respond to the questions, so their data was removed from all three data sets.

## Evaluation Question 9: How effective has the CCI been in creating a systemic network of partner organizations?

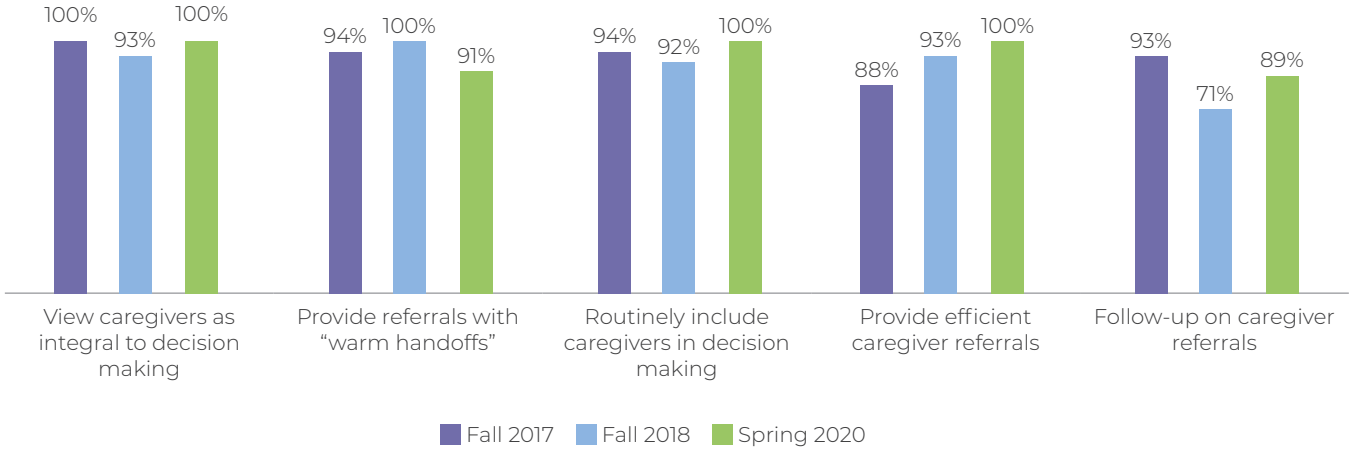
**Answer: The CCI has created a network of partner organizations that regularly communicates, collaborates, and make referrals to one another.** A majority of partners in the network reported that the CCI improved the effectiveness of critical network components including collaboration, communication, referrals, and caregiver supports (Figure 19).[11] These lines of contact remained stable even as CCI incorporated new partners into the network and weathered changes in Initiative leadership at Santa Barbara Foundation.

**Figure 19:** Partners reported the CCI improved the effectiveness of critical network components a moderate amount or a lot, including...




**CCI partners share a strong commitment to engaging in practices they have found, through their collective experience, are important to supporting caregivers.** These included viewing caregivers as integral to decision making and routinely including them in it, providing efficient referrals with "warm handoffs," and following up on those referrals to make sure a caregiver did not fall through the cracks. Almost all partners agreed that staff at their organizations embraced and implemented these practices (Figure 20).

**Figure 20:** CCI partners consistently agree or strongly agree their staff engage in practices that are important to supporting caregivers, including...




11. Collaboration means working together to make decisions, set goals, share resources, or work together on projects. Communication can include email, phone calls, instant messaging, meeting together, or any other ways of exchanging information.

**What we learned: Complex systems change efforts benefit from a large number of independent organizations working towards a shared outcome.** John Holland calls this "emergence" – a process by which individual entities interact and work to address a constantly evolving set of challenges. The results are more sophisticated than what could have been created by an individual entity. Evidence of rich interaction among partners and shared problem solving, or emergence, was apparent at every network gathering.

**Partners need clarity regarding goals, responsibilities, and roles.** "In the beginning [the challenge was] understanding how we would work together. Roles and what our agencies were expecting of us, in addition to what SBF was expecting with the grant."

**Partners wanted and benefitted from in-person gatherings and opportunities to make connections and develop relationships.** Time and again partners said how important it was to have network gatherings. It allowed them to put a face to a name, and to meet the people at other partner organizations they made referrals to. These relationships were critical in helping partners respond and adapt to the COVID-19 pandemic.

**Plan for abundant time to do the work.** One partner said it this way: "Take what you think it's going to take in terms of time – and triple it."

**Streamline data collection and reporting processes.** CCI partner support for data collection activities was strong, despite the time required to recruit caregivers to take surveys, complete partner surveys and participate in key-informant interviews. We began collecting data more frequently in the beginning, but after the first year we reduced the frequency of data collection to reduce the burden on partners.

**Promote collective interpretation and use of data.** Evaluation findings were provided annually to partners for their interpretation and use. One partner said, "the data was really important, you know, making sure that we had appropriate data to work with and we were working with real numbers and real people." We experimented with several approaches to engage partners with the data, including hosting in-person "data parties" where partners were asked to work together to interpret the data, providing interim reports, providing individualized reports to each partner, and hosting webinars to review and discuss findings.

## Evaluation Question 10: How effective has the CCI been in creating a network of care that is sustainable and able to evolve as needed?

**Answer: The CCI has created a network of partners who are committed to sustaining the relationships and the caregiver support system they've developed.** Compared to other working groups, the CCI functioned better: "I do feel like all of these things are in place, the communication, the collaboration… that there's a familiarity that we haven't had before, that I don't have with some of the other groups… we're all coming together to collaborate towards this single goal. […] we're all coming together as this united front." The CCI network was also continuing to grow, with every year bringing in: "more and more people, you know? Different individuals. We started out with this first group that had so many of us… and as time has gone by, we've brought more people in."

**The CCI has developed a culture that encourages and supports collaboration.** This is the bedrock on which the rest of its work rests: "The reason it's successful is because we have a really strong collaborative. The foundation was built very well from the beginning and created the collaboration between all of the partners, and actually doing the work -- not just planning the work but doing the work -- and having responsive partners, too." Another partner agreed: "The relationships themselves are very strong, and the communication is very strong. And I see that continuing beyond the life of the grant, and I'm really happy to see that." Not surprisingly, several partners noted that CCI relationships and collaborations tended to be stronger regionally. "It's been very effective, particularly in Mid- and North County. I know that there are some challenges still that exist in South County. But even still, I met folks at convenings and sessions in South County that I probably wouldn't have met and worked with otherwise."

**The COVID-19 pandemic has illustrated the value of this collaboration.** "I think the current crisis has sort of proved the point that we've been highly successful at this because we put it into practice during this crisis." Having these relationships in place supported effective responses during difficult times: "I think that the other thing that it's done is it has helped us to work with each other more quickly, more successfully during this pandemic that we've had. We had established relationships with folks."

**The CCI has developed relationships among partners that remain strong.** Partners believe these relationships will sustain their networks: "One lasting effect is a stronger collaborative network across the county and particularly within each region. It's given us a lot of time to develop these really strong friendships, partnerships, colleagueships."

**The CCI has created a necessary and important focus on the needs of caregivers.** Multiple partners agreed, saying things like "It's important to introduce the concept of family caregivers and what their specific needs are… the role of a caregiver and how it impacts so many aspects of the community," And "I think definitely one of our primary goals was to increase that awareness and sensitivity towards caregivers and I think that's just been really elevated." Other partners were awakened to the importance of caregivers' role through their CCI participation: "It brought this issue to the table as a priority for my organization…So it definitely broadened our network and then helped bring the issue area into our focus as an organization." This focus even led to some policy-related work: "Our program influenced their work in developing a policy position on insurance coverage for caregivers, and certainly awareness across the country on the issues associated with informal caregiving. That was huge!"

**Partners were optimistic that the CCI could continue to evolve to meet the needs of caregivers.** "I think that all these agencies have really been able to change the way they do their work and adapt to the changes. And I feel like that's a good sign for the future." At this moment the path forward for the CCI isn't totally clear. "I think that we're still figuring that out… I think it can be done without Santa Barbara Foundation Funding. But I think as partner organizations we're not aware of how that's going to happen yet. […] So, it's definitely an important moment for us, for the CCI, to ensure longevity and make sure that the transition happens." But the majority of partners interviewed expressed optimism with statements like "do I think the networks will evolve as needed? I really do."

**Some partners expressed concern over the future of the CCI, given anticipated funding and leadership changes.** Expressions of concern included: "I do not think that the CCI collaborative of funded projects is organized well enough to be sustainable and independent without additional funding around that ultimate objective" and "When you have a group that's kind of been in charge of pulling everyone together, and now that is dissolved, or they're asked to step back […] people start to fall off. And when people start to fall off, the momentum starts to fall off." Other partners, however, expressed hope: "I do think that there might be partners that might not be able to continue without the funding. But I think for the most part, because that relationship is so strong, I think the work will continue. It may not look exactly the same, but I do think that the work will continue."

# MEET TRACI–REGRESSION ANALYSES HELP US SEE SUBTYPES OF CAREGIVERS

## Caregivers' characteristics can help us understand areas where they might need more or less support

We wanted to learn whether caregivers with certain characteristics (for example, those who were older, or were women, or who worked full time) reported better caregiving experiences, as well as which characteristics were associated with more challenges in caregiving.

Read on for the whole story, but in brief:

- Caregivers who were unemployed needed more caregiver-related services and were less often able to meet their own practical and physical needs.
- Male caregivers, on average, reported a higher ability to meet their own emotional needs than female caregivers.
- Younger male caregivers who are caring for a non-parent family member reported being less able to meet the needs of the person they cared for.

Tuning in to how those with particular characteristics may need different support, while avoiding stereotyping any group of caregivers, can help organizations meet caregivers where they are.



**Meet Traci**



We wanted to look at ways that who caregivers are might affect their caregiving experiences. Let's be very clear that there's not only one kind of caregiver. All caregiving experiences are unique and important.

For this inquiry, we picked characteristics based on preliminary analyses showing that they were the most common, or typical, in our caregiver group. This let us tell the story of a person who represented the most common caregiver characteristics in our sample. We named this person Typical Traci, and we'll follow Traci's journey throughout this section of the report. Traci is a caregiver who is:

- Aged 60 to 69
- Female
- White
- Employed full-time
- Caring for a parent

If you're a person who likes statistics, Traci's characteristics are what's technically known as the "reference categories" for the dummy variables we used in our multivariate regressions. And if you're a person who really likes statistics, please check out Appendix D for details on our methods and a table of regression results.

Looking at the data this way lets us compare Traci to caregivers with different characteristics, to see which ones may have better or worse caregiving experiences, and need different kinds of support. Examples include caregivers of different age groups, male caregivers, Latinx caregivers, those who were unemployed or retired, or those who were caring for a spouse instead of a parent.

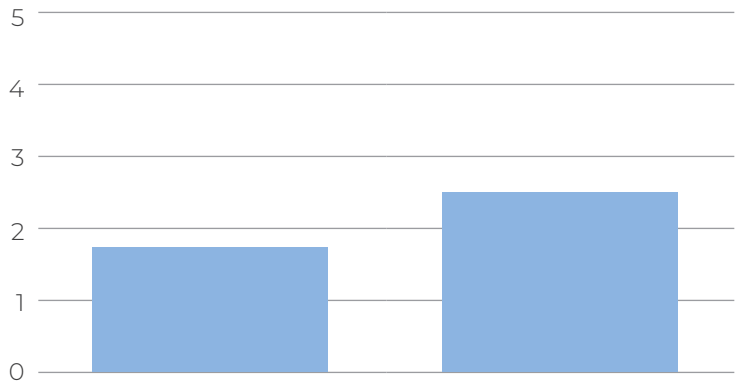
### Traci's Caregiving Experiences

The details of our results suggest situations in which certain caregivers may be more resilient or more vulnerable than the most typical caregiver, Traci. They let us see how a person's characteristics may combine to make their caregiving experiences better or worse.

***Need for caregiver services***

Caregivers who are unemployed need more caregiver-related services on average.





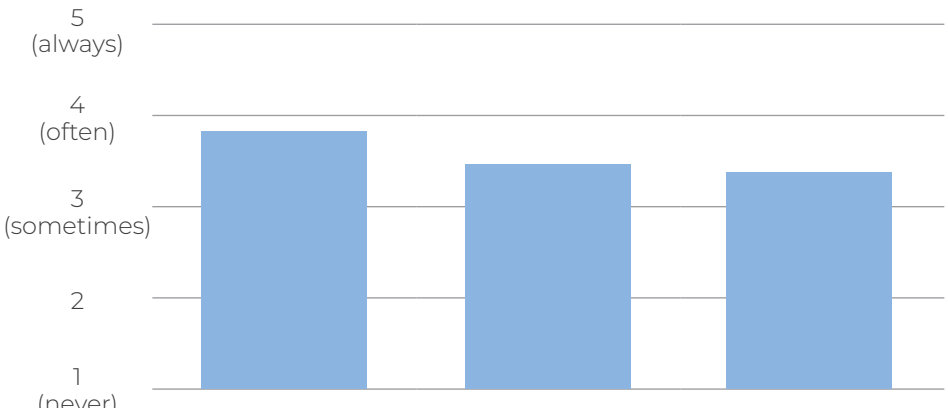

On average, Traci needs **1.7** caregiver-related services of 5 that are available.

If Traci was **not employed,** she would need nearly one more additional service (+0.6) on average.

***Caregiving stress***

On average, younger caregivers who are Latino report feeling stress less often.






Traci reports feeling caregiving stress "often" (an average score of **3.8**)

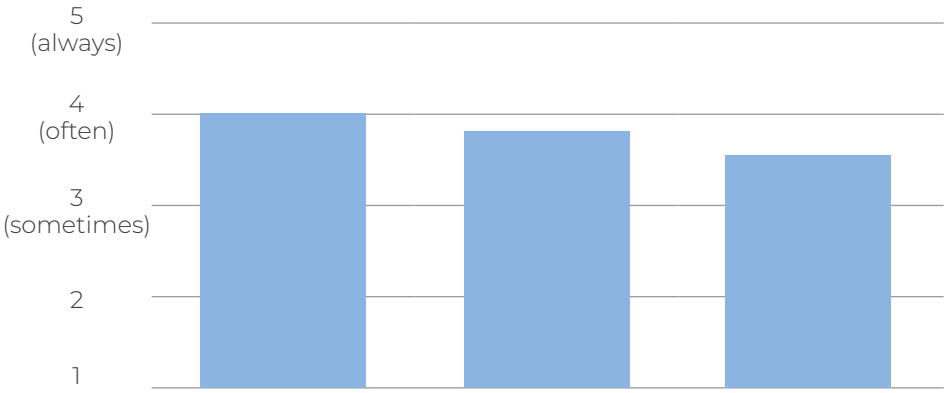
If Traci were **under age 49** her average would be **0.5 lower**, equivalent to feeling caregiving stress only "sometimes."

And if she was under 49 AND described herself as **Latina**, her average stress score would be another **0.2 lower**.

***Ability to meet own practical and physical needs***

Overall, caregivers do well at meeting these needs. Younger caregivers (though not the youngest) who are unemployed report being able to meet their practical and physical needs less often on average.






Traci tells us she can "often" meet these needs (an average score of **4.0**)

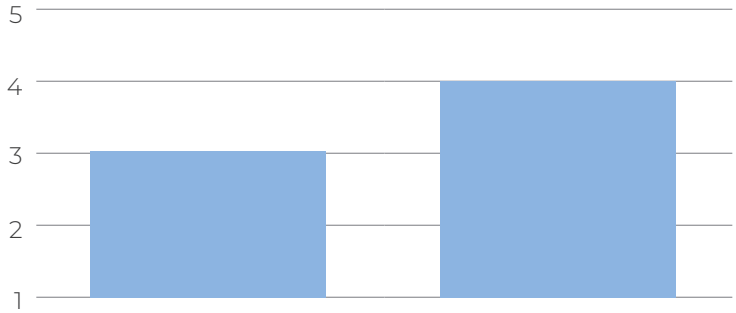
If Traci were **between 40 and 59,** her average would be **0.2 lower**, but she would still be meeting these needs "often".

But if she was this age AND **unemployed**, her average score would be another **0.23 lower**, only meeting these needs "sometimes".

***Ability to meet own emotional needs***

Caregivers overall do less well at meeting emotional needs. Male caregivers, on average, report a slightly higher ability to meet their own emotional needs than female caregivers.



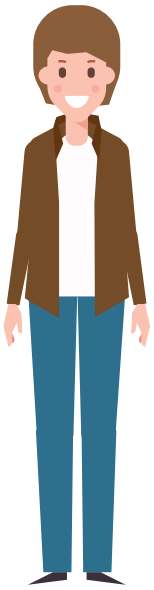


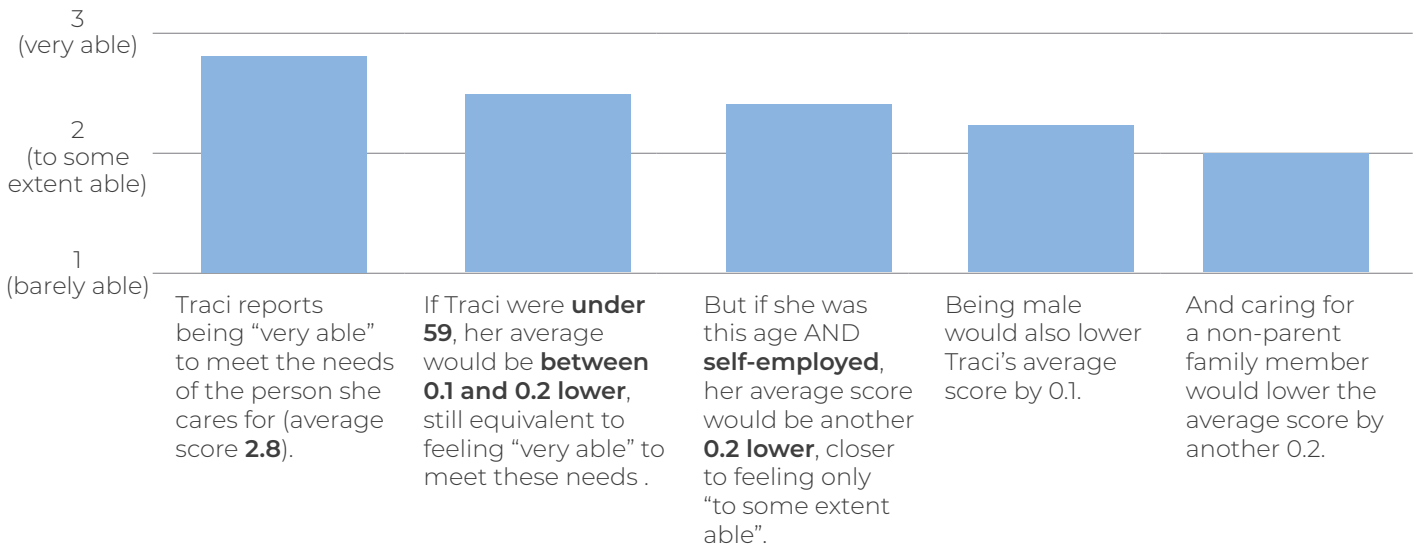

Traci reports that she can meet her own emotional needs "sometimes" (an average score of **3.4**).

If Traci was **a man**, her score would be **0.21** higher on average, equivalent to meeting these needs "often".

***Ability to meet needs of person receiving care***

On average, caregivers who are younger than Traci, who are male, who are self-employed, and who are caring for a non-parent family member report being slightly less able to meet the needs of the person they care for.






Traci reports being "very able" to meet the needs of the person she cares for (average score **2.8**).

If Traci were **under 59**, her average would be **between 0.1 and 0.2 lower**, still equivalent to feeling "very able" to meet these needs .

But if she was this age AND **self-employed**, her average score would be another **0.2 lower**, closer to feeling only "to some extent able".

Being male would also lower Traci's average score by 0.1.

And caring for a non-parent family member would lower the average score by another 0.2.

# EVALUATION METHODS

The Santa Barbara Foundation contracted with us (Evaluation Specialists, ES) to design and implement a comprehensive, mixed-method, external evaluation of the Santa Barbara Foundation Community Caregiving Initiative. The purposes of this evaluation were to:

- Provide timely, ongoing information to Initiative partners to guide program improvement
- Assess how effective the CCI was in meeting its key goals
- Characterize how agencies across Santa Barbara County were working together to better support caregivers, specifically in relation to how they communicate and collaborate with one another to improve caregiver services and referrals
- Identify successful practices as well as barriers to program delivery and opportunities for program improvement; and
- Develop actionable recommendations for Initiative enhancement and sustainability.

To establish common goals for the CCI, we engaged the partners in an interactive process to identify collective goals and shared definitions of success. From this process, we developed data collection tools and an evaluative rubric. The purpose of the evaluative rubric was to use predetermined criteria to transparently evaluate: 1) each goal with predetermined criteria against data collected to determine Initiative attainment of each stated goal; and 2) the overall Initiative. We systematically applied data collected in Fall 2017, Fall 2018, and Fall 2019 through Summer 2020 to the CCI evaluative rubric to characterize the level of success achieved in each goal and subgoal area.

## DATA SOURCES

**Caregiver survey:** Different groups of caregivers were recruited to take the online survey in Spring 2017, Fall 2017, Fall 2018 and Fall 2019. This cross-sectional design provides snapshots over time of caregiver needs and experiences. We designed the survey to monitor caregiver needs and evaluate the combined efforts of partners participating in the Community Caregiving Initiative. Specific information collected included awareness and use of types of information, services and support, receipt of this information, and the perceived helpfulness of these services. Caregivers across Santa Barbara County who had received services from partner agencies in the previous six months were eligible to participate in the survey. Staff at CCI partner agencies invited caregivers to take the survey.

**Partner Organization Survey:** ES invited CCI Partners to participate in an online survey in Spring 2017, Fall 2017, Fall 2018, and Spring 2020. The purpose of the partner survey was to understand how partner organizations across Santa Barbara County are working together to better support caregivers. Specifically, we wanted to characterize how partner organizations communicated and collaborated with one another to improve caregiver services and referrals. The survey included social network (SN) questions in which each partner reported on how much they had communicated with, collaborated with, and made referrals to each other CCI partner. SN questions also asked whether the partner desired less, the same, or more communication, collaboration, and referral-making with others in the future. The other type of questions involved the partner assessing their own organizational practices as well as attitudes about the CCI.

**Key Informant Interviews:** To gather input from CCI stakeholders, ES invited partners and other key informants to participate in web-based interviews. In Fall 2017, ES conducted 17 interviews with 26 CCI partners (some of whom were interviewed together at their request). ES conducted interviews again in Fall 2018. This time 17 interviews were conducted with 22 partners. Our final round of interviews was conducted in Summer 2020 with 13 partners. We invited representatives from each of the funded CCI grantee organizations, one representative from each of the funded collaborative partners of these grantees, and members of the SBF leadership team and CCI Advisory Council to participate as key informants. In cases where SBF staff believed additional interviews would add important perspectives, we included more than one person per organization. We audio recorded these interviews.

**Caregiver Interviews:** To better understand how caregivers experienced referrals for needed services and supports, and to explore from their perspective how the system for referrals could be improved upon, we conducted fourteen in-person interviews with family caregivers in Santa Barbara County in April 2018. Interviewees represented a mix of English and Spanish speakers living in the North and South regions of Santa Barbara County. We conducted interviews in the preferred language of each caregiver. All interviews were recorded, transcribed, and, if needed, translated from Spanish to English

## DATA ANALYSIS

We analyzed the caregiver survey, as well as the partner survey's questions about organizational practice/attitudes, using descriptive analysis (i.e., means and frequencies) in SPSS. We conducted social network analysis using UCINET and Netdraw. Application of Data to Evaluative Rubric: After we analyzed data from the caregiver survey, partner survey, and key informant interviews, we used the evaluative rubric to determine the success of CCI in meeting each of its goals. We assigned one of four levels to each goal: not successful, approaching success, successful, and highly successful. To do this, we first identified which CCI goals were addressed by each finding from the key informant interviews and the caregiver and partner surveys. Then we reviewed the findings relevant to each goal and determined the level of success. In cases where findings from different sources scored at different levels of success, we gave the data from caregivers more weight in the final decision. This process resulted in the rubric dashboard. This dashboard summarizes current CCI success on all stated goals.



## ACKNOWLEDGMENTS

The CCI Advisory Committee and staff members of the Santa Barbara Foundation (SBF) desired a rigorous evaluation of the CCI. Evaluation Specialists worked with them to actualize their vision, and to develop an evaluation plan, rubric, and associated measures. The critical thinking of the foundation and the community partners was paramount in developing the rubric and metrics for the work of the CCI and describing its impact. Deep gratitude goes out to the family caregivers in Santa Barbara County who participated in the caregiver survey. Additionally, staff at the many community organizations throughout Santa Barbara County who devoted time and energy to completing surveys for their own organizations and assisted in the distribution and gathering of the caregiver survey, deserve special recognition for making this work successful. The Community Caregiving Initiative and the development of a robust evaluation efforts were made possible by the donors of the Santa Barbara Foundation. Among them is AARP and we are grateful for their willingness to learn with the Santa Barbara County Community Caregiving Initiative about how to better serve family caregivers in a local context.

Please cite this report as follows: Vanslyke, J., Mathies, A., Masters, N.T., Beadnell, B., (2021, February). Santa Barbara County Community Caregiving Initiative (CCI): Impacts and Learnings from 2017 to 2020 available at www.sbfoundation.org and www. evaluationspecialists.com.

For additional information please contact Rubayi Estes, Vice President, Programs, Santa Barbara Foundation, at restes@sbfoundation.org, or call Santa Barbara Foundation at (805) 963-1873.

More information on the Community Caregiving Initiative can be found at www. sbfoundation.org. Santa Barbara Foundation, South County Headquarters 1111 Chapala Street, Suite 200 Santa Barbara, CA 93101

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