



Santa Barbara Foundation Community Caregiving Initiative (CCI)

Interim Report Fall 2017



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THE SANTA BARBARA FOUNDATION COMMUNITY CAREGIVING INITIATIVE STORY

The Santa Barbara Foundation (SBF) envisioned and provides leadership and support for the Santa Barbara County Community Caregiving Initiative (CCI). The foundation believes that living and aging with dignity should be a shared community value. That is why it is committed to innovative solutions supporting people who need care and the people who care for them.

As demographics shift to an increasingly older population, the CCI acknowledges that caregiving is critical to addressing the needs and hopes of elders. The CCI is a groundbreaking, county-wide, collaborative effort focused on the backbone of the long-term care system—family caregiving. By building cross-sector partnerships, particularly in the healthcare and social services sectors, SBF is addressing the needs of caregivers and those they care for.

Currently, over 80% of long-term care is provided by unpaid family caregivers—people who often don't self-identify as caregivers. In Santa Barbara County, an estimated 60,000 to 70,000 unpaid family caregivers provide care valued at \$624 million annually. While caregiving provides certain rewards, it also exacts a toll on those providing it. Caregivers are at significant risk for diminished health outcomes. Providing support and services to family caregivers, including helping people identify with their roles in caregiving, and developing more integrated and inclusive health and social systems, will allow caregivers to more easily access support and improve the quality of life for both themselves and the friends and family members they care for.

The CCI is working to increase awareness and advance support for family caregivers in Santa Barbara County through four inter-connected strategies: 1) strengthening caregivers individually; 2) connecting community organizations and agencies to ensure caregivers can easily access supportive services; 3) creating new knowledge that will benefit caregivers; 4) raising awareness about caregiving and policy solutions that support caregiving. Additionally, the CCI embraces and supports multi-cultural competency to ensure that all caregivers can find the information and services necessary to care for their friends and family members.

Through its local partners, the CCI is supporting caregivers and connecting community organizations in the following ways:

- Encouraging Self-Identification and Engagement
- Integrating the Caregiver as a Medical Team Member
- Broadening Access to Therapy for Caregivers
- Increasing the Effectiveness of Lay Latino Health Workers
- Connecting and Educating Families of Patients Diagnosed with Alzheimer's
- Enhancing Support for Caregivers of Medically Fragile Patients and those with Dementia



“Caregivers have repeatedly declared that they would not be able to continue caring for their loved ones at home if it weren't for the support provided by our services. They also indicate they are able to care at home longer – up to 3 years longer than they would be able to care at home should these services not be available.”

Additionally, the CCI represents a broad range of service providers throughout Santa Barbara County. SBF is proud to list the following organizations and entities as CCI partners and stakeholders:

- Alzheimer's Association - California Central Chapter
- Antioch University
- Area Agency on Aging
- Atlas of Caregiving
- Atterdag Village of Solvang/Atterdag at Home
- Coast Caregiver Resource Center
- Community Action Commission
- Community Partners in Caring
- Cottage Rehabilitation Hospital
- Family Service Agency
- Friendship Center
- Goleta Valley Cottage Hospital
- Life Steps Foundation - Santa Maria Wisdom Center
- Lompoc Valley Community Healthcare Organization
- Lompoc Valley Medical Center/Lompoc Family Caregiver Support Center
- Marian Regional Medical Center
- Partners in Caring Foundation
- Sansum Clinic
- Santa Barbara County Adult Protection Services
- Santa Barbara County Coalition in Support of Promotores de Salud
- Santa Barbara Cottage Hospital
- Santa Barbara County Adult and Aging Network
- Valley Haven
- Visiting Nurse & Hospice

To evaluate effectiveness and the impacts of these investments and efforts, SBF commissioned Evaluation Specialists to design and conduct an external, mixed methods evaluation of the CCI. 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.

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.



CCI PERFORMANCE: SETTING AND MEETING OUR GOALS



Community Caregiving Initiative (CCI) partners have worked collaboratively with the Santa Barbara Foundation (SBF) and Evaluation Specialists (ES) over the past two years to identify collectively shared goals and performance criteria for evaluating Initiative success. This process has required genuine commitment on the part of all – including the caregivers who made time in their already busy lives to complete our caregiver survey so that we could assess how CCI efforts are working for them and their loved ones. Data collection and evaluation activities described in this report began in 2016 and will continue throughout 2018. In our final report, we will describe how CCI outcomes have changed over time since the data were first collected and how successful the CCI was at meeting its stated goals.

We are pleased to share the interim results of the SBF CCI in this evaluation report. In this section, CCI PERFORMANCE, we describe our process for setting and evaluating our goals, provide a snapshot of our current level of success across these goals, and share key findings. Detailed findings for each of the three goals are shared in the three CCI IMPACTS sections of the report. Partner identified next steps for furthering the Initiative goals, based on the review of the data presented here, are shared in the CCI OPPORTUNITIES section. Additional findings about caregivers in Santa Barbara County, including a description of caregivers that participated in the survey in fall 2017 and their care recipients, are shared in the WHAT WE'VE LEARNED ABOUT CAREGIVERS section. Lastly, details about the evaluative approach, data collection methods, and data analyses are described in the EVALUATION METHODS section.

SETTING OUR GOALS

In the summer of 2016 ES facilitated a process with CCI partners and SBF staff to identify key Initiative goals, and define what success would look like for each. CCI goals fall within three areas: 1) CCI IMPACTS ON THE DEVELOPMENT OF A CAREGIVER SUPPORT SYSTEM IN SANTA BARBARA COUNTY, 2) CCI IMPACTS ON CAREGIVERS, and 3) CCI IMPACTS ON CAREGIVING AND CARE RECIPIENTS. The product from this meeting created the foundation for the development of the CCI Theory of Change (Appendix A) and evaluative rubrics (Appendix B). The evaluative rubrics informed the development of the data collection tools, including the caregiver survey, partner survey, and formative stakeholder interviews.

The CCI Theory of Change provides a high-level snapshot of the activities and contextual factors theorized to create desired changes in the short, medium and long-term Initiative goals. With partner and stakeholder input, ES created the CCI caregiver and partner surveys and key informant interview guide to support internal learning, program improvement, and the evaluation of the Initiative. We included measures from more than one data source for each sub-goal, where possible, to validate findings and identify areas of agreement and disagreement from different sources (e.g. caregivers and partners).

The CCI evaluative rubrics define what different levels success look like for each sub-goal within each goal. Questions from the data collection tools are mapped to each sub-goal, and thresholds were established for varying levels of success. CCI thresholds for success were either determined or informed by partners after reviewing the baseline data (collected in spring 2017) during our first “data party”. The purpose of the “data party” was to collaboratively define thresholds for Initiative success using a transparent and stakeholder informed process.

MEETING OUR GOALS

To determine current levels of success in the three CCI goal areas, ES applied the data from the caregiver survey, partner survey, and stakeholder interviews to the evaluative rubrics. Using the established thresholds for each measure we determined the current level of success of each sub-goal. By looking at the level of success across sub-goals, we determined an overall level of success for each goal area.

The CCI is currently performing at the following level of success in each goal area:

Goal 1 – CCI IMPACTS ON THE DEVELOPMENT OF A CAREGIVER SUPPORT SYSTEM IN SANTA BARBARA COUNTY – **Successful**

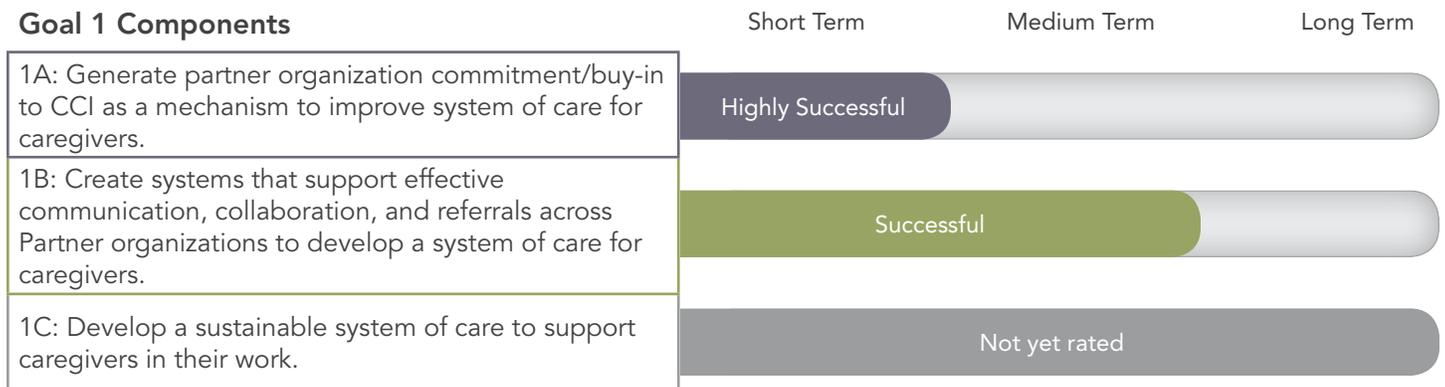
Goal 2 – CCI IMPACTS ON CAREGIVERS – **Approaching Success**

Goal 3 – CCI IMPACTS ON CAREGIVING AND CARE RECIPIENTS – **Approaching Success**

The three CCI Performance Dashboards below show the current level of success for each sub-goal, and whether that goal is short, medium or long-term.

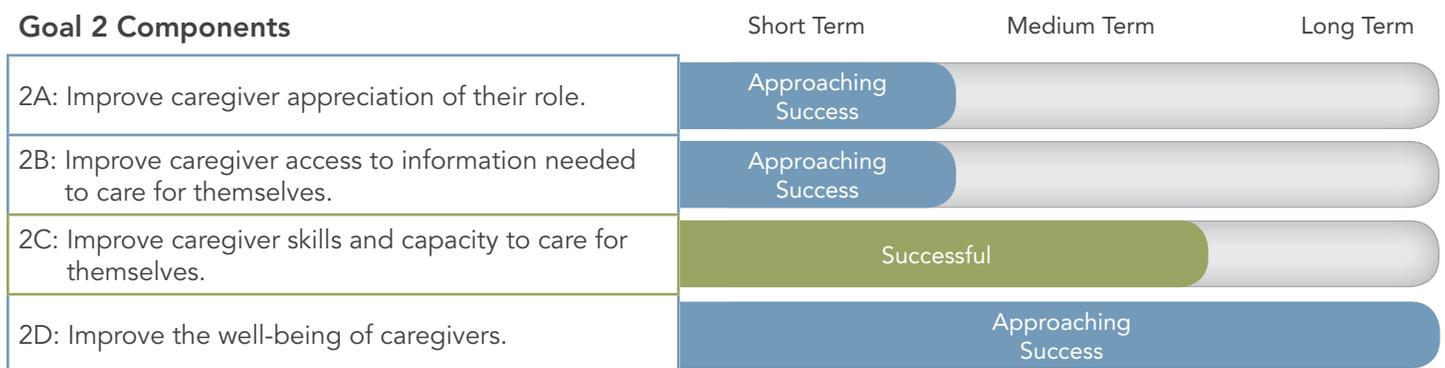
CCI Performance Dashboard - Goal 1

CCI IMPACTS ON THE DEVELOPMENT OF A CAREGIVER SUPPORT SYSTEM IN SANTA BARBARA COUNTY



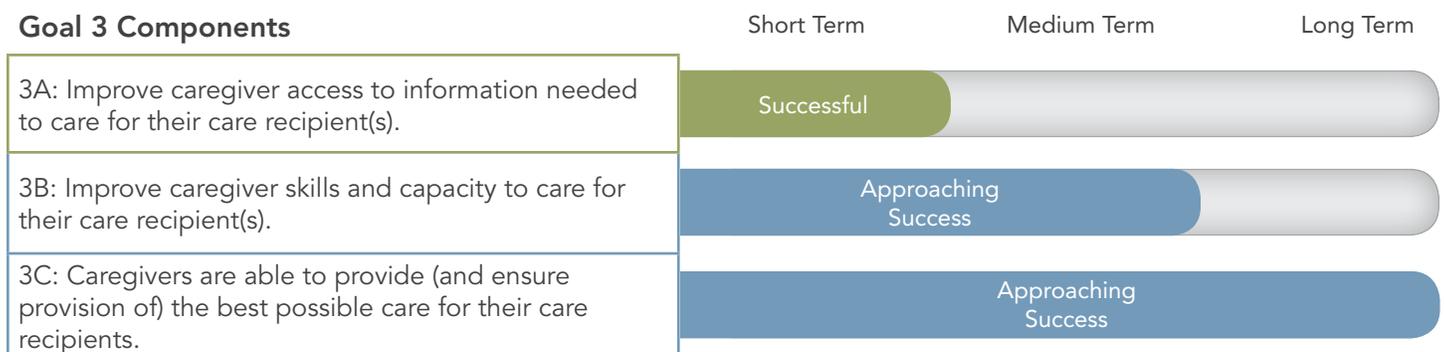
CCI Performance Dashboard - Goal 2

CCI IMPACTS ON CAREGIVERS



CCI Performance Dashboard - Goal 3

CCI IMPACTS ON CAREGIVING AND CARE RECIPIENTS



KEY LEARNINGS

One of our overarching key learnings is that, for many measures, partners perceive the CCI to be having a greater impact on caregivers than caregivers themselves report experiencing. This has important implications for interpreting these findings and identifying opportunities for Initiative improvement.

Another key learning is that caregivers differ in their level and type of service use. We identified four groups of caregivers (using Latent Class Analysis) who reported using services very differently. The group of caregivers that reported using the most services for themselves and their care recipients were more than twice as likely to report being able to provide better care (this finding was statistically significant). Specifically, they were more likely to be able to figure out where to get services for their care recipient, make sure they received the services they need, work with their medical providers, and be actively involved in their care decisions. Below we list our key learnings for our three goals and the sub-goals within each. We invite you to explore these findings in greater detail in the detailed findings section of this report.

CCI IMPACTS ON THE DEVELOPMENT OF A CAREGIVER SUPPORT SYSTEM IN SANTA BARBARA COUNTY

Goal 1A: Generate partner organization commitment/buy-in to CCI as a mechanism to improve system of care for caregivers.

Partners shared their clear and strong commitment to both improving care for caregivers and the goals of the CCI. This buy-in is not just a passive attitude – partners report putting effort into tasks that are part of the CCI goals. Many partners demonstrated their commitment to the CCI with highly supportive statements.

Specifically, partners showed clear understanding of caregivers' multiple needs, and worked to address them. They agree the CCI has the potential to help them better serve caregivers. And that the Initiative will improve the experiences of caregivers in the County. Partners have made efforts -- and expressed commitment -- to making the CCI a success.

Goal 1B: Create systems that support effective communication, collaboration, and referrals across partner organizations to develop a system of care for caregivers.

CCI partners are developing into a healthy and vibrant network with an impressive amount of both communication and collaboration. There is also strong agreement across partners that staff are using good referral practices. However, these practices have not yet translated into caregiver experiences as evidenced by their reports about referrals.

Two areas have room for future improvement. First, partners indicated a desire for a bit more communication and collaboration, and a majority desired to make and receive more referrals. Second, it would be worthwhile to explore why caregivers do not seem to be experiencing these positive referral practices.

Stakeholders emphasized the CCI's success in creating a healthy network. They believed funding and other types of support were key to network development. From their perspective, the CCI is fostering new connections among agency partners, with national funders like the AARP, and with businesses.

All partners reported communicating with others, and almost all reported working to enhance communication with other agencies. Similarly, all partners reported collaborating with others. Of note, twenty-one report the highest possible amount of collaboration with one or more others. Partners differed in their level of activities to foster collaboration. Two thirds or more shared training opportunities and developed interagency agreements. A little less than half supported development of a data management and referral system.

Yet, many partners wanted to see increased referrals. Almost all partners agreed or strongly agreed their staff are knowledgeable about and used positive referral practices. Of note, two thirds of partners wanted to make more and three quarters wanted to receive more referrals. Caregivers, however, were less positive about partner referral practices. On average, they neither agreed nor disagreed that they experienced such practices.

CCI IMPACTS ON CAREGIVERS

Goal 2A: Improve caregiver appreciation of their role.

CCI partners strongly believed their practices benefited caregivers by enhancing their awareness of their own contributions. This was supported by caregiver reports. A majority of caregivers reported that the services received helped them feel a valued part of their loved ones' care. Similarly, many caregivers stated their service experiences led to a stronger belief in themselves as contributors to the health care system, and increased pride in caring for their loved one. Recognition of the important role of caregivers in the local community remains a weaker link. While some reported that service experiences led them to perceive greater local recognition as caregivers, most did not.

Many stakeholder impressions reflected these findings. Some saw awareness of the value of the caregiving role as high among caregivers themselves, but low elsewhere. For example, they expressed that medical providers were not aware of caregivers' important role in the health care system, often taking their efforts for granted. They felt this was also true of people in general. Other stakeholders believed that caregivers' valuing of their role was far from universal. For example, one stated that caregiving was "just part of what you signed up for" as a family member, particularly as a woman. Along with this, these stakeholders believed that even when caregivers recognized they were critical to their loved ones' wellbeing, they did not necessarily recognize themselves as part of the larger health care system.

Goal 2B: Improve caregiver access to information needed to care for themselves.

Gaps exist in terms of caregivers feeling they have information about their own self-care. While many did report receiving such information, a noticeable portion (typically a third or more) reported needing more. More than half did not perceive any changes in the past six months but found the information they received to be helpful.

Goal 2C: Improve caregiver skills and capacity to care for their themselves.

Partners perceived the CCI as having positive effects in supporting caregivers' self-care. Nevertheless, these efforts have not yet fully affected all caregivers. While about half of caregivers said that they received all the services they needed to assist themselves, the rest did not. In fact, a noticeable portion reported receiving less than half of what they needed.

Goal 2D: Improve the well-being of caregivers.

Understandably, many caregivers reported feeling stressed due to their caregiving responsibilities. It is also not surprising that caregivers are only sometimes or often able to regularly ensure their own practical, physical, and emotional needs are met.

In terms of action to address this, all partners believed that the CCI had improved caregivers' ability to engage in self-care. Caregiver reports corroborated that view. Many caregivers also reported that services had been helpful in reducing their stress and improving their well-being. However, there is room for improvement in the level of attention given to caregivers' needs by professionals. Only a minority of caregivers believed that improvements had occurred in this area.

CCI IMPACTS ON CAREGIVING AND CARE RECIPIENTS

Goal 3A: Improve caregiver access to information needed to care for their care recipient(s).

Caregiver awareness of resources overall was high: three-quarters stated they were aware of the services that they needed to provide care. Many said that the services they received were helpful in achieving this awareness. While many caregivers also report having received all the information they need, gaps remain for others. Some continuing need for information exists: while over half received information that helped them care for their loved one, a substantial amount expressed a need for more.

Goal 3B: Improve caregiver skills and capacity to care for their care recipient(s).

Partners all believed that the CCI had contributed, at least a small amount, to caregiver capacity to provide care. Indeed, half or more of caregivers typically said they got the services they needed to provide specific types of care. However, gaps exist. A clear segment reported they did not receive all of the services they needed and that they were not able to provide specific types of care.

Goal 3C: Caregivers are able to provide (and ensure provision of) the best possible care for their care recipients.

All partners believed that the CCI helped to improve caregivers' abilities to ensure quality care for their loved ones. Caregivers agreed. Most saw services as being anywhere from a little to extremely helpful. Of concern is that about half of caregivers reported being unable to complete all of the tasks they needed to care for their loved one. Of particular relevance to the CCI, caregivers were least likely to report being very able to find where to go to get services they need and making sure their care recipients were getting the care they needed.

CAREGIVERS DIFFER IN THEIR LEVEL AND TYPE OF SERVICE USE

Caregiver use of 12 services (such as respite care and delivered meals) for themselves and their care recipients differed greatly. We used Latent Class Analysis (LCA) to identify distinct groups among caregivers. Detailed LCA findings can be reviewed in Appendix D. Here's what we learned.

We identified four groups of caregivers who use services very differently: High Service Users, Moderate to High Service Users, Moderate Service Users, and Very Low Service Users. Caregivers in Santa Barbara County over the past six months, on average, used between 3 and 4 of the 12 types of services available. Most caregivers in all four groups are caring for parents. But people in the High Service User group are 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. And all caregivers reported feeling stressed "sometimes" to "often" because of their caregiving responsibilities. However, **a key finding is that the High Service User Group was 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.

Questions raised by these subgroup findings include:

1. How can people move along the continuum from being Very Low Service Users to higher levels of service use?
2. Do caregivers in High and Moderate to High Service Use groups start by using more caregiver-focused services? Or do they begin using these services for themselves later in their caregiving journey?
3. Does being in the High Service Use group translate into better self-care and increased well-being over time, although it did not in this analysis?

To gather formative input from Community Caregiving Initiative (CCI) stakeholders, Evaluation Specialists conducted 17 interviews (with 26 CCI partners and stakeholders, some of whom were interviewed together at their request) in the late summer of 2017. Here we share what we learned from partners and stakeholders about (1) caregivers' experiences and perceptions and (2) stakeholder experiences with the CCI so far. Findings from these **STAKEHOLDERS** reflect common themes shared across multiple interviewees.

Findings shown in this report were shared with **PARTNERS** at the second CCI "data party" in December 2017. During this day-long event, partners were asked to work in small groups to discuss the findings and identify possible next steps to move the Initiative closer to its' goals. Here we also share those identified next steps.

STAKEHOLDER INSIGHTS ABOUT CAREGIVERS

People we talked to during formative key-informant interviews expressed differing opinions about caregivers' awareness of the important role they play in the health care system.

- Some saw awareness as **low**, stating that caregivers did not self-identify in the role. Rather, caregiving was "just part of what you signed up for" as a family member, particularly as a woman. Even when caregivers recognized they were critical to their loved ones' being cared for, they did not recognize themselves as part of the larger health care system.
- Others saw awareness as **high** among caregivers themselves, but low elsewhere. They expressed that medical providers were not aware of caregivers' important role in the health care system, often taking their efforts for granted. They felt this was also true of people in general "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."

Stakeholders also identified several barriers to caregivers accessing needed services for themselves and their care recipients.

- A major caregiver barrier mentioned by nearly all interviewees was **being overwhelmed** and not knowing where to begin. Caregivers have so many day-to-day responsibilities that they often feel unable to allot time to seeking help: "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."

Other barriers mentioned included:

- The **user-UN-friendliness of the health care and service system**, with accounts of caregivers "having to tell your story to 10 different people" and "getting the run-around."
- **Medical professionals'** need to improve, including their unawareness of caregivers' important role, and their lack of cultural awareness and language proficiency.



One of the CCI's aims is to "elevate the work of caregiving [so that caregivers are] recognized as a vital piece of the safety net... shine a light on issues of people that are vital to the overall health of the community."

SUGGESTED MECHANISMS TO SUPPORT CAREGIVERS AND THEIR CARE RECIPIENTS

Several mechanisms for addressing existing barriers for caregivers were offered by interviewees:

- Creating **multiple points of access** to the system of care was mentioned as an ideal mechanism to help by several interviewees: *“What we’re hoping will happen through this – 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.”*
- **Caregiver navigators** were a mechanism that many people thought was very helpful to caregivers: *“[The navigator is] someone in the system that can help me... and values the contribution that I’m bringing.”* Offering more navigation services, and offering them at more locations – *“all the places people access care”* – was urged.
- Stakeholders emphasized that **adding more resources** to existing services could make great improvements: Navigators at more sites, more points of access, more funding and staffing to decrease waits for an appointment.
- **Increasing connections** – both among agencies and between medical professionals and agencies – was another suggested way to improve services.
- **Providing education** for different audiences was key to improving services. Caregivers themselves could be educated about the importance of their role, stressors associated with it, and available resources. Medical professionals, employers, and the general public were also seen as needing to understand caregiving better in order to support service improvement.

After reviewing the findings in this report, partners offered several possible next steps they could take to move CCI goals forward in these areas:

- **Do more promotion of and expand the network** and have leadership work to keep existing efforts alive – encourage enthusiasm and candor.
- **Identify gaps** in network communication, collaboration and referrals.
- Focus on a **standard referral procedure** for a full circle process.
- Increase **awareness of available services** in the geographic area of caregivers.
- **Continue outreach and education** and **provide useful gifts** to family caregivers to demonstrate their value.
- **Expand access** to caregiver resources and information via telemedicine, telephone/internet classes, and by sharing You Tube resources.
- Promote the **Senior Resource Directory and 2-1-1**.
- Communities need to **have all options available**, and **increase in-home access** for services and supports. Focus on caregiver **respite**, make **peer support** more acceptable.
- **Engage Primary Care Providers**, and work with the **medical community** to promote family caregiver self-care.
- Change CCI partner **human resource/employee practices and policies** to better support family caregivers.
- Look at how information is being conveyed and services are being provided; ensure they are **culturally appropriate**; provide resources in **Spanish**.

STAKEHOLDER INSIGHTS ABOUT THE CCI



Interviewees overall had a clear sense of the CCI's purpose and were excited about it: "What the initiative is trying to achieve on a macro level is so exciting – it can permeate into so many areas and is so needed."

Generally, people we talked with emphasized the CCI's **success in creating a healthy network**, saying things like: *"[The initiative] allows us to be a part of a larger, organized, focused effort in regard to caregiving... So many large societal changes need to happen – the initiative lets us be a part of these larger changes."* They felt that the CCI's authentic interest and the activities they organized were helping communication and collaboration happen. They detailed success in two main areas.

- **Providing financial and other support.** People described the critical importance of both funding and other types of support to network development. Many clearly felt what one stated when they said the initiative was "the glue that binds the network."

"Without their support, we couldn't do this. They 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."

- **Enabling new connections.** People talked about two types of new connections being established. Within SBC, new collaborations were developing among agency partners as a result of participating in the CCI. Partners also mentioned connecting with national funders like the AARP and with businesses. For example, one said: *"[The CCI] helped us get in front of business community and employer groups. Let them know we are a support system to them and their employees – helped us to open quite a few doors."* Both kinds of outside connections were seen as potentially bringing visibility to the work and driving policy change.

Other successes were also mentioned:

- Some stakeholders were pleased that SBF acknowledged the importance of **Latino communities** and elders; one said *"CCI is starting to shed light on this population and the people that are taking care of them."*
- Finally, many interviewees mentioned the importance of SBF's **Phylene Wiggins, the CCI Director**, in the Initiative's successes, describing her as: *"making these linkages happen," "excellent in her communication style and keeping everybody informed,"* and *"a force of nature... amazing in her ability to connect people and ideas."*

People were also frank about challenges they had experienced as the CCI network began to form.

- Most prominent among these was a strongly felt **shortage of time** and other resources: *"When we signed up for this we didn't fully know what we were signing up for... I understand why it's happening but it's still saturating. There's a lot more that's expected of the players and that can feel saturating for non-profits when we have so many other things we do."*
- Another area for improvement stakeholders mentioned was **clarity about responsibilities and roles**, and the need to be explicit about expectations: *"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."*
- However, several interviewees stated that they expected challenges since **improving systems is inherently challenging work**: *"System change is not something an individual agency can do. It requires a champion... to take the lead. CCI is doing this."*

SUGGESTED MECHANISMS TO STRENGTHEN THE CCI

People expressed their commitment to the CCI's work with statements like *"There is a significant burden of responsibility, being part of this. It's not a short-term thing. We need to be committed to the long-haul because it will take time."* They also had suggestions for improving the CCI.

One area mentioned was to **improve evaluation activities** at partner agency sites.

- Several interviewees urged grantees to be more strategic about goals and measurement so that they first figured out what they wanted to learn, then created and deployed data collection tools, saying that *"articulating bigger goals that could be measured... would be a really good way to start."*
- One also stated that if evaluation was important to the foundation, grantees might need additional training and assistance to carry it out effectively.

Stakeholders also offered concrete suggestions to **improve network activities**, such as:

- Building in time at meetings to let people check their phones and email,
- Locating meetings somewhere more convenient for all partners (particularly North County), rather than in Santa Barbara only,
- Using a mixture of in-person meetings and interactive webinars or teleconferences to lessen the travel burden,
- Creating communication tools, such as newsletters, to share trends, updates, and what is changing on a regular basis while also reducing meetings, and
- Adding more communication about each of the projects so that grantees and partners can keep up other projects' work, accomplishments, and challenges.

After reviewing the findings in this report, partners also offered possible next steps SBF and CCI could take to move the Initiative goals forward:

- Assist and facilitate the **County-wide process**; share results about what we've learned in **communities**; map **geographic availability of services**.
- Continue to work to **engage key service providers** in the CCI.
- Engage all staff in partner organizations in the **evaluation** process.
- Serve as a liaison to **share best practices** related to what other partners are doing.
- Promote and get the **Care Map** out to the public; for example, have MDs pass it out during patient visits.
- Engage the **Chamber of Commerce and employers** to develop policies and practices that support family caregivers
- **Advocate with funders** to support family caregiver needs.
- Distribute and **promote Resource Directories**; include a link to the Senior Resource Directory and Lompoc Resource Directory on the SBF website.
- **Keep doing what you're already doing. We need to share this connection and success!**

SUSTAINABILITY

SBF and CCI partners recognize and are invested in developing a sustainable network of service providers that will continue to support caregivers and their loved ones into the future. The CCI evaluation will include an examination of factors related to Initiative sustainability in 2018. Interviewees, however, offered several recommendations to support CCI sustainability:

- A need for **ongoing financial support** was the sustainability topic raised by a majority of interviewees, who emphasized its importance to them in statements like:

“Ongoing funding, even if minimal, would help us feel sustained and supported.”

“I hope the foundation can continue in some capacity to support caregiving. They have put a substantial amount of funding into the community, and other agencies can’t possibly absorb what they’ve done. I understand their hope is that agencies will be self-supporting, but any time you remove money there are ripple effects on other funders.”

“It would be nice to have a long-term commitment from SBF/CCI – to move from 1-year funding to 5-year funding so agencies know they can move forward.”

Some offered very concrete suggestions about improving the CCI’s sustainability financially. The most important of these, emphasized by many stakeholders, was:

- **Extending SBF’s funding cycle from one year to 2 or even 5 years** would allow grantees to plan better.
- Another mentioned **anchoring the Initiative within a large medical system** where resources were likely to continue.

People we talked with had other sustainability advice for the CCI’s work, which included:

- Adhering to **good universal practices** like being patient, flexible, and ready to compromise to move forward.
- **Allotting abundant time to do the work:** *“Take what you think it’s going to take in terms of time – and triple it.”*
- **Using existing research** by *“having someone identify state and local best practices literature. [Caregiving is] not a new issue. Use the research that’s already been done.”*
- **Connecting with clarity** so that *“partners are striving for same things and feel a part of developing shared vision,”* people have the same expectations, and strong relationships are nurtured that support collaboration even when it is challenging.



CCI IMPACTS ON THE DEVELOPMENT OF A
CAREGIVER SUPPORT SYSTEM IN
SANTA BARBARA COUNTY

GOAL 1A SUMMARY

Generate partner organization commitment/buy-in to CCI as a mechanism to improve system of care for caregivers.

Definition of Highly Successful: Each CCI partner organization believes in the initiative as a mechanism for change, is committed to working together to improve the well-being of caregivers and their care recipients, and is actively thinking about ways to improve the collaborative and sustain their work together. Staff understand and creatively work to address the full range of caregiver needs.



Partners shared their clear and strong commitment to both improving care for caregivers and the goals of the CCI. This buy-in is not just a passive attitude – partners report putting effort into tasks that are part of the CCI goals. Many partners demonstrated their commitment to the CCI with highly supportive statements.



“Without their support, we couldn’t do this. They 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.”

GOAL 1A FINDINGS

PARTNER COMMITMENT TO AND WORK TOWARD CCI GOALS

- 1 Partners showed clear understanding of caregivers' multiple needs, and worked to address them.
- 2 They agree the CCI has the potential to help them better serve caregivers. And that the Initiative will improve the experiences of caregivers in the county.
- 3 They made efforts -- and expressed commitment -- to making the CCI a success.

Almost all **PARTNERS** agreed or strongly agreed that their staff...

Understand that caregivers often need a range of social, medical, legal and financial supports.



Work to address a range of caregiver needs, including social, medical, legal and financial supports.



Similarly, almost all partners agreed or strongly agreed they...

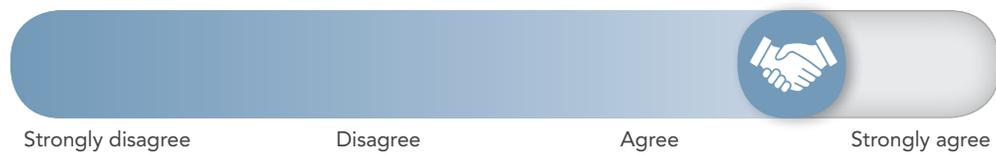
Believe the CCI, if successful, will help our organization better serve caregivers.



Believe the CCI, if successful, will improve the experiences of caregivers in Santa Barbara County.



Are strongly committed to the success of the CCI.



Have actively worked to make the CCI a success, to the extent possible given our available resources.



“Santa Barbara Foundation 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.”

GOAL 1B SUMMARY

Create systems that support effective communication, collaboration, and referrals across partner organizations to develop a system of care for caregivers.

Definition of Successful: An effective and practical system of communication, collaboration, and referrals has been developed across the network.



The data show the CCI partners are developing into a healthy and vibrant network with an impressive amount of both communication and collaboration. There is also strong agreement across partners that staff are using good referral practices. However, these practices have not yet translated into caregiver experiences as evidenced by their reports about referrals.

Two areas have room for future improvement. First, partners indicated a desire for a bit more communication and collaboration, and a majority desired to make and receive more referrals. Second, it would be worthwhile to explore why caregivers do not seem to be experiencing these positive referral practices.



“The CCI allows us to be a part of a larger, organized, focused effort in regard to caregiving. So many large societal changes need to happen – the initiative lets us be a part of these larger changes.”

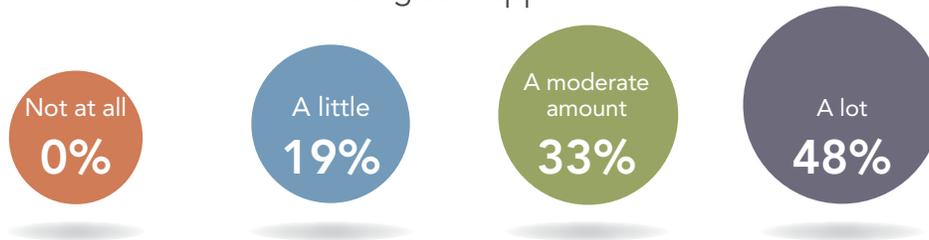
GOAL 1B FINDINGS

PERCEPTIONS OF CCI EFFECTIVENESS

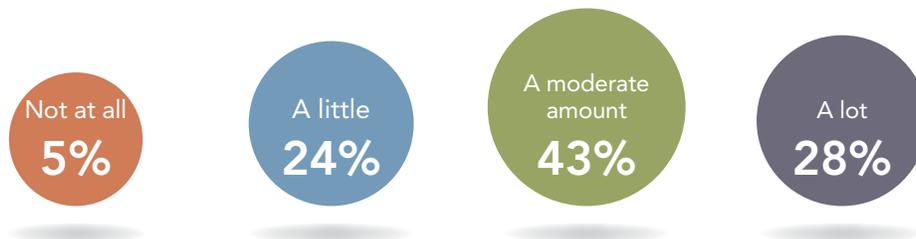
- 4** About three quarters of partners believed that CCI's efforts led to a moderate or a lot of improvement in all three areas of network interactions: communication, collaboration and referrals.
- 5** All partners believed that CCI's efforts led to improvement in communication and collaboration. Of note, 43% reported a lot of improvement in both areas.
- 6** The vast majority believed improvements occurred in referrals.

PARTNERS reported how much they think the CCI has improved the effectiveness of...

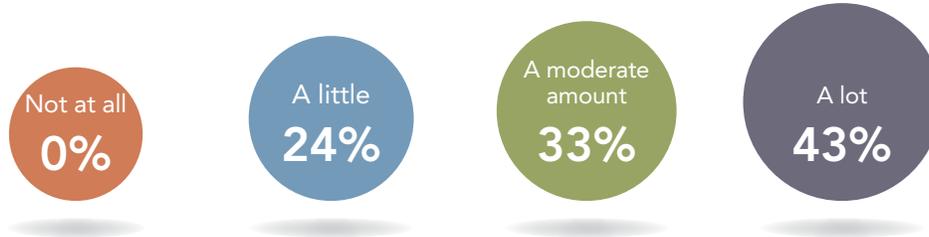
...caregiver supports?



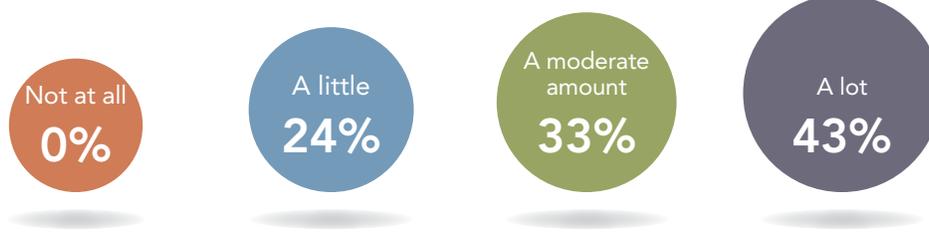
...referrals among network partners?



...network communication?



...network collaboration?



GOAL 1B FINDINGS

PARTNER AND CAREGIVER DESCRIPTIONS OF REFERRALS

7 Almost all partners agreed or strongly agreed their staff were knowledgeable about and used positive referral practices.

8 Caregivers were less positive about partner referral practices. On average, they neither agreed nor disagreed that they experienced such practices.

Almost all **PARTNERS** reported that staff in the previous six months...

Were knowledgeable about caregiver services and supports available at other organizations.



Knew the appropriate way to make caregiver referrals to other organizations serving caregivers.



Provided caregivers with warm referrals to other organizations serving caregivers.



Provided caregivers with efficient referrals to other organizations serving caregivers.



Followed-up on caregiver referrals to other organizations to make sure services have been received.



(Note: Appendix C shows findings for each partner's current referral activities and desires in the future.)

GOAL 1B FINDINGS

YET CAREGIVERS REPORTED A SOMEWHAT DIFFERENT EXPERIENCE...

61% agreed or strongly agreed that organizations asked about their and their care recipients' needs.

42% agreed services received increased their belief that professionals serving the person they cared for paid attention to their needs.

On average, caregivers agreed they were told about organizations with services that would be helpful.

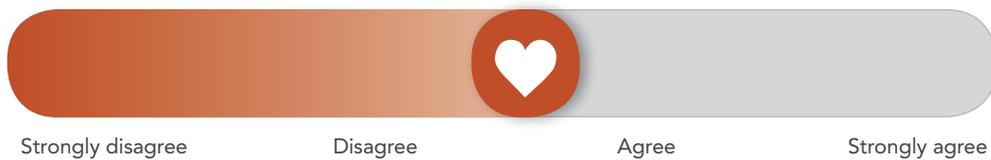


...but, on average, neither agreed or disagreed they...

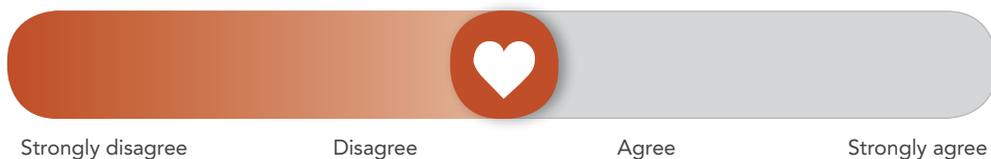
Were referred to other organizations that could provide help.



Had their information shared with other organizations providing them services.



Had other organizations contacted on their behalf.



GOAL 1B FINDINGS

PARTNERS DESCRIPTIONS OF THEIR ACTIVITIES

- 9 Almost all partners reported working to enhance communication with other agencies.
- 10 However, they differed in their level of activities to foster collaboration. Two thirds or more shared training opportunities and developed interagency agreements. Less than half supported development of a data management and referral system.

For the previous six months **PARTNERS** reported on staff communication...

90% of partners worked to increase their awareness of new caregiver supports offered by other organizations.

89% worked to make systems for across organization communication more effective.

and...staff collaboration.

83% participated in relevant, shared training opportunities offered by other organizations.

63% worked to develop inter-agency agreements to encourage communication about caregivers' needs between organizations.

43% supported the development and use of a data management and referral system that shares client data across organizations.



“The regional collaborative work has been an essential component of bringing organizations together to learn about each other’s services, identify gaps and to develop evaluation efforts to measure a caregiver’s circumstances, needs, strengths, goals, cognitive abilities, and cultural and spiritual situation.”

GOAL 1B FINDINGS

COMMUNICATION NETWORK

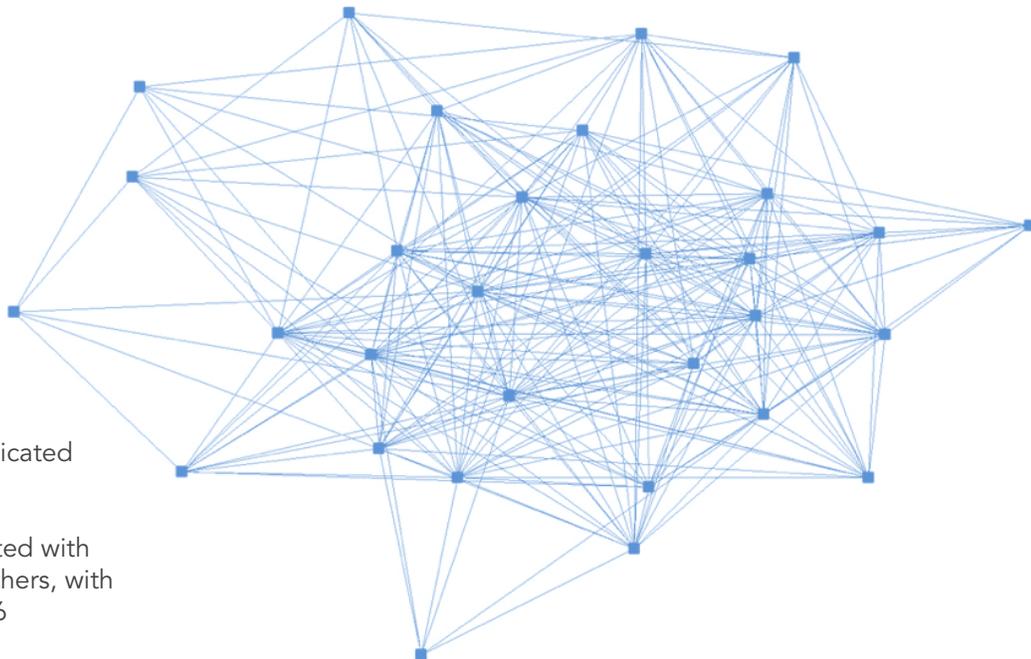
PARTNERS reported on how much they had communicated with each other partner.

11 All reported communicating with others. Of note, twenty-two report frequent communication with 1 to 5 others.

Data on 29 **PARTNERS** was analyzed using Social Network Analysis to characterize and create visual representations and descriptive measures of the CCI network.

Each square in these figures represent a partner organization, and a line exists when two partners said they had communicated...

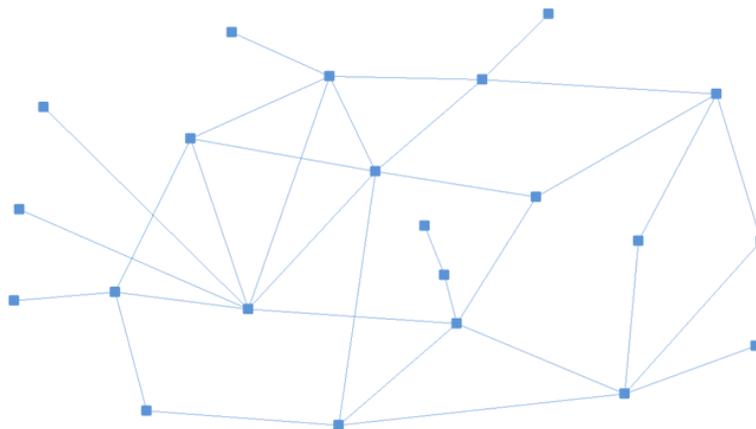
... at least once in six months



All partners communicated with at least 5 others

Partners communicated with between 5 and 25 others, with the average being 16

... more frequently (at least twice a month)



22 partners communicated at least twice a month with one to five other agencies

GOAL 1B FINDINGS

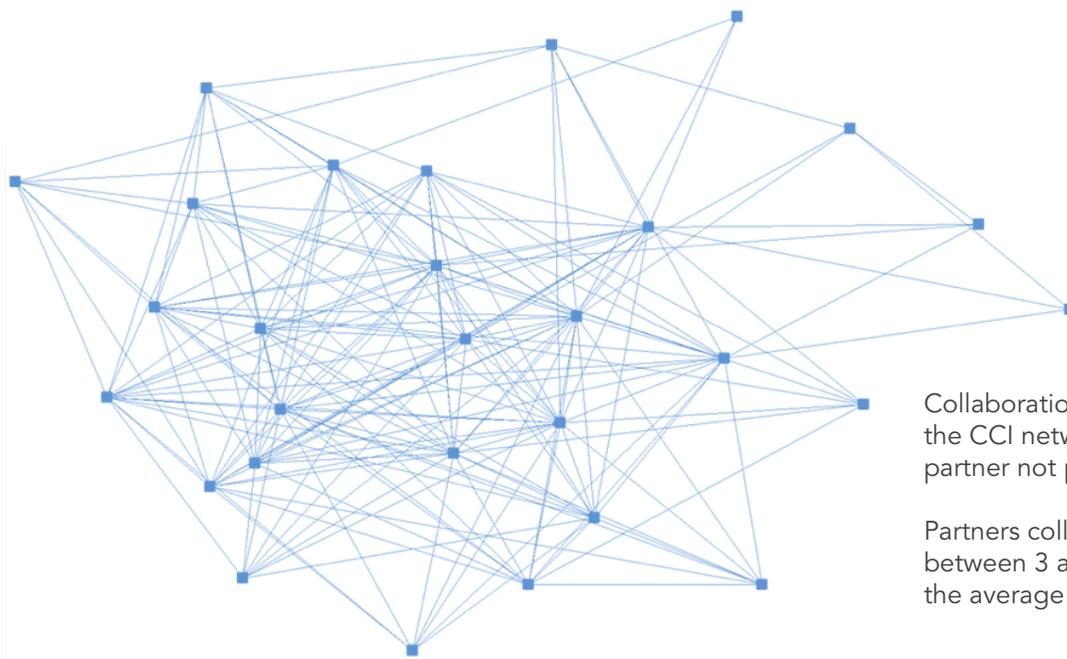
COLLABORATION NETWORK

PARTNERS also reported on collaboration. Collaboration goes beyond mere communication and demonstrates more in-depth relationships. It was defined as working together to make decisions, set goals, share resources, or work together on projects.

12 All partners reported collaborating with others. Of note, twenty-one report the highest possible amount of collaboration with one or more others.

Partners collaborating with each other in the past six months . . .

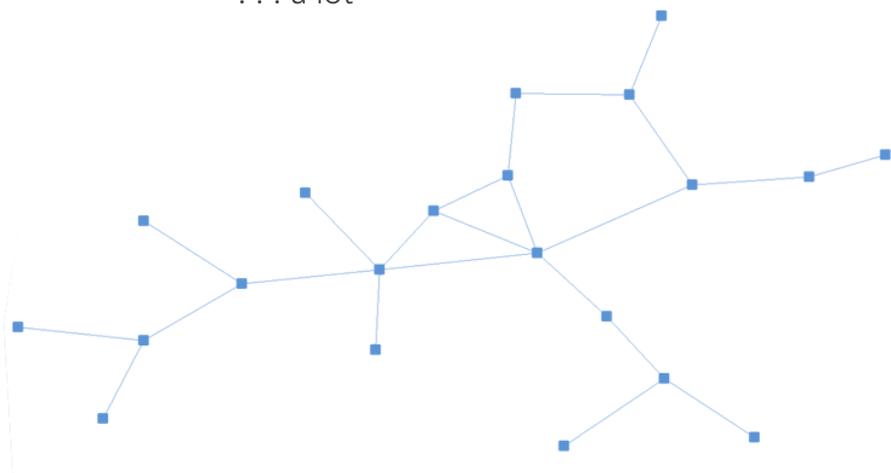
. . . even a small amount



Collaboration is common across the CCI network, with only one partner not participating

Partners collaborated with between 3 and 20 others, with the average being 16

. . . a lot



21 partners collaborated "a lot" (the highest amount possible) with 1 and 4 others

GOAL 1B FINDINGS

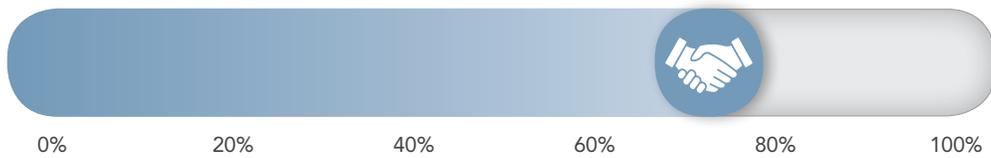
DESIRES FOR FUTURE COMPARED TO NOW

PARTNERS answered questions about their desires for the future.

13 On average, partners expressed a wish for a bit more communication and collaboration with others.

14 Many wanted to see increased referrals: two thirds wanted to make more and three quarters wanted to receive more.

Percentage wanting to receive a little or a lot more referrals



Percentage wanting to make more referrals to at least one other partner



Amount of communication desired



Amount of collaboration desired



GOAL 1B FINDINGS

STAKEHOLDER PERCEPTIONS OF THE NETWORK

- 15** Stakeholders emphasized the CCI's success in creating a healthy network. They believed funding and other types of support were key to network development. From their perspective, the CCI is fostering new connections among agency partners, with national funders like the AARP, and with businesses.



*The initiative was
"the glue that
binds the network."*



*"Without their support,
we couldn't do this.
They 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."*



*"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."*

The biggest challenge encountered as the network formed was a shortage of time.



"When we signed up for this we didn't fully know what we were signing up for... I understand why it's happening but it's still saturating. There's a lot more that's expected of the players and that can feel saturating for non-profits when we have so many other things we do."

However, several interviewees stated that they expected challenges since improving systems was inherently challenging work:



"System change is not something an individual agency can do. It requires a champion... to take the lead. CCI is doing this."



CCI IMPACTS ON CAREGIVERS

GOAL 2A SUMMARY

Improve caregiver appreciation of their role.

Definition of Approaching Success: Some caregivers report that the CCI-related services they received improved their opinions of their role as caregiver, and their perception that others recognize and value their role. Some CCI-staff and related stakeholders report that their organizational practices improve these caregiver opinions and perceptions.



CCI partners strongly believed their practices benefited caregivers by enhancing their awareness of their own contributions. This was supported by caregiver reports. For example, a majority of caregivers reported that services helped them feel a valued part of their loved ones' care. Similarly, many stated their service experiences led to a stronger belief in themselves as contributors to the health care system. Service experiences also increased caregivers' pride in caring for their loved one. Recognition of the important role of caregivers in the local community remains a weaker link. While some reported that service experiences led them to perceive greater local recognition as caregivers, most did not.

Many stakeholder impressions reflected these findings. Some saw awareness of the value of the caregiving role as high among caregivers themselves, but low elsewhere. For example, they expressed that medical providers were not aware of caregivers' important role in the health care system, often taking their efforts for granted. They felt this was also true of people in general. Other stakeholders believed that caregivers' valuing of their role was far from universal. For example, one stated that caregiving was "just part of what you signed up for" as a family member, particularly as a woman. Along with this, these stakeholders believed that even when caregivers recognized they were critical to their loved ones' wellbeing, they did not necessarily recognize themselves as part of the larger health care system.



"One of the CCI's aims is to "elevate the work of caregiving [so that caregivers are] recognized as a vital piece of the safety net... to shine a light on issues of people that are vital to the overall health of the community."

GOAL 2A FINDINGS

CONTRIBUTIONS TO CAREGIVER PERCEPTIONS

- 1 Almost all partners agreed or strongly agreed their practices increased clients' appreciation of their caregiving roles.

PARTNERS reported how much they agreed that...

"Our organizational practices increase awareness and appreciation among our clients of the important contributions of caregivers?"

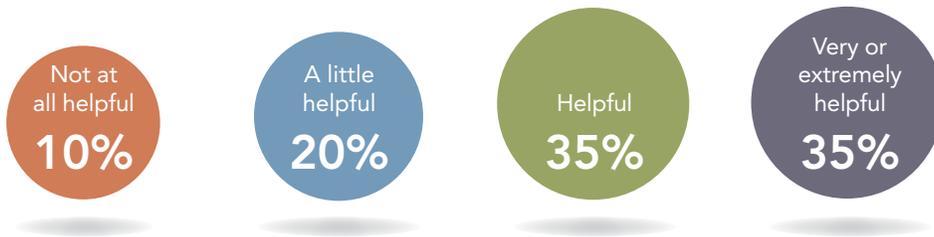


IMPROVEMENTS IN PERCEIVED VALUE OF CAREGIVING

- 2 Most caregivers reported that services received helped them to feel valued as part of their loved ones' care. A third said services were very or extremely helpful in this regard.
- 3 Half of caregivers reported that services received helped them take more pride in providing care, and three quarters said they changed their opinion that caregivers make an important contribution to the health care system.
- 4 Less than half of caregivers said services received changed their opinion that caregivers are receiving more recognition for the support they provide.

CAREGIVERS reported on the helpfulness of the information and services they and the person they care for received over the past six months.

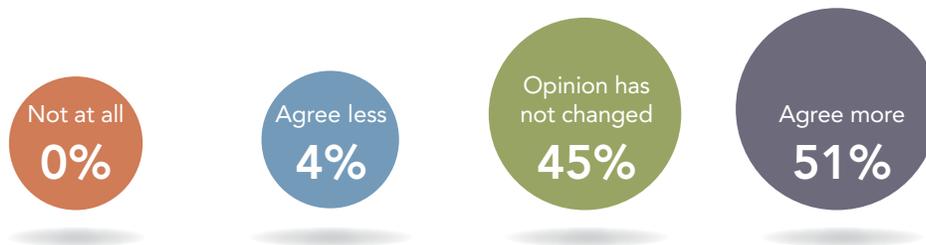
“How helpful were ... these service experiences in improving your perception of being a valued part of the their health care?”



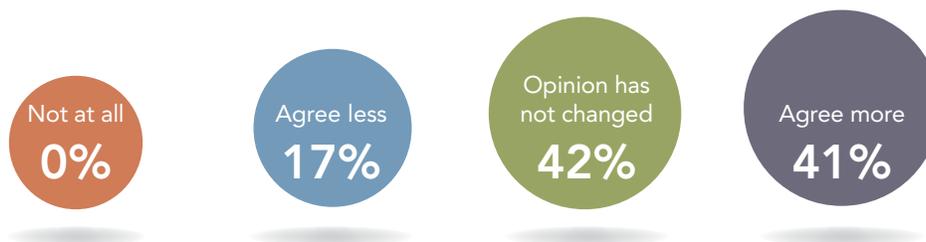
“How much have ... these service experiences changed your opinion that ... caregivers make an important contribution to the overall health care system?”



“How much have ... these service experiences changed your opinion that ... you take pride in providing care to your loved one?”



“How much have ... these service experiences changed your opinion that ... caregivers are receiving more recognition for the support they provide?”



GOAL 2B SUMMARY

Improve caregiver access to information needed to care for themselves.

Definition of Approaching Success: Many caregivers received the information they needed and were aware of services they needed to properly care for themselves. Many report that services received were helpful in improving their understanding of the challenges related to their role, and increasing their awareness of relevant community resources.



Gaps exist in terms of caregivers feeling they have information about their own self-care. While many did report receiving such information, a noticeable portion (typically a third or more) reported needing more. More than half did not perceive any changes in the past six months but found the information they received to be helpful.



*“Working full time, I find I find it **EXTREMELY** difficult to get the information I need.”*

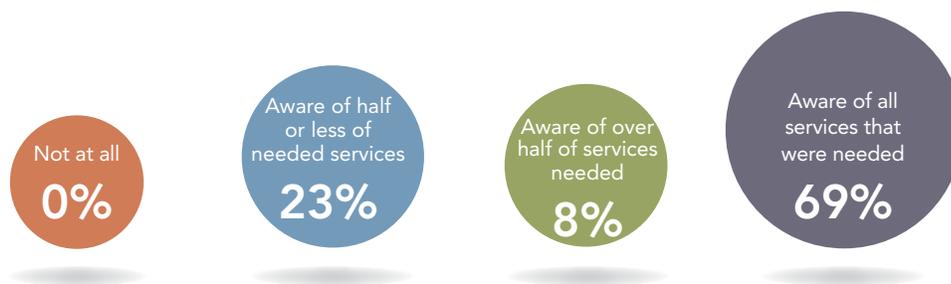
GOAL 2B FINDINGS

CAREGIVER AWARENESS OF NEEDED SERVICES TO ENHANCE SELF-CARE

- 5** Many caregivers received information about the importance of self-care and services available to support them, but a noticeable minority did not. Many caregivers agreed that they received the information and the services they needed to support self-care, but a noticeable minority did not.

CAREGIVERS reported about their need for services for themselves, as well as the availability of those services.

Two-thirds of caregivers were aware of the availability of services they needed for themselves.



Similarly, they reported if they had ever received information for caregivers intended to help support their self-care.

A little more than half of caregivers received enough Information about the following topics...

Why it is important to take care of themselves.



And a little less than half received enough Information about these topics ...

How family dynamics change with caregiving.



Community resources for caregivers.



Common stressors associated with caregiving.



GOAL 2B FINDINGS

HELPFULNESS OF INFORMATION RECEIVED

6 Among those Caregivers who received this information, most found it at least a little -- and the majority, very or extremely -- helpful.

CAREGIVERS rated the helpfulness of all the information and services they received over the past six months, in terms of improving their...

Understanding the importance of self-care when caregiving.



Awareness of community resources for caregiving.



Understanding how family dynamics change when caregiving.



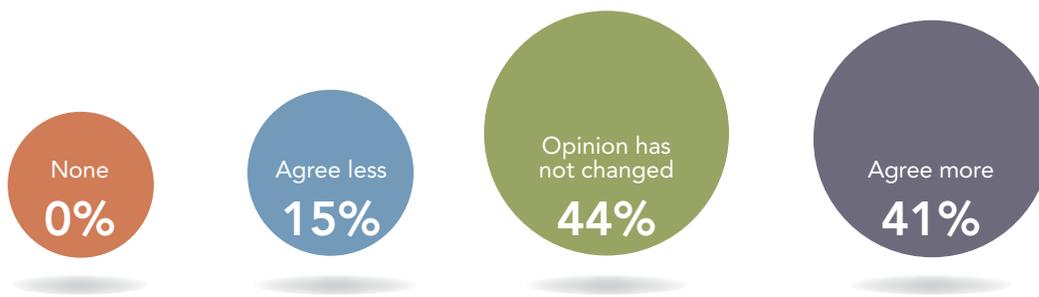
GOAL 2B FINDINGS

IMPROVEMENTS IN AVAILABILITY OF SERVICES

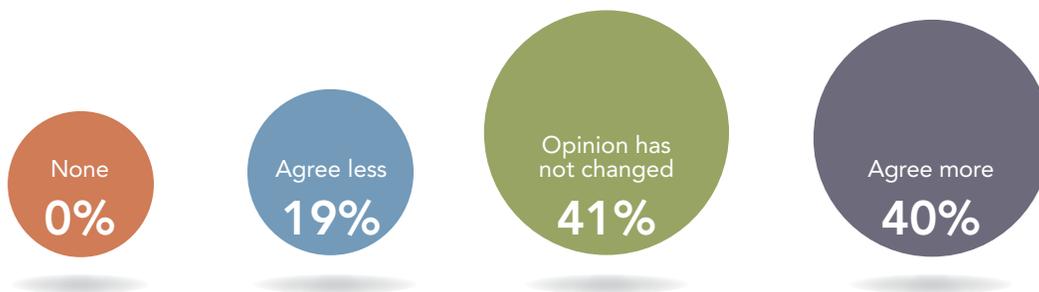
- 7 Compared to six months before, service experiences increased awareness of available services and skill-building opportunities for a portion of caregivers. However, an equal number had not changed their opinions, and a small number agreed less that the services were available.

CAREGIVERS reported how much their service experiences had changed their opinion, compared to six months ago, that...

There are a range of skill-building opportunities available locally to caregivers?



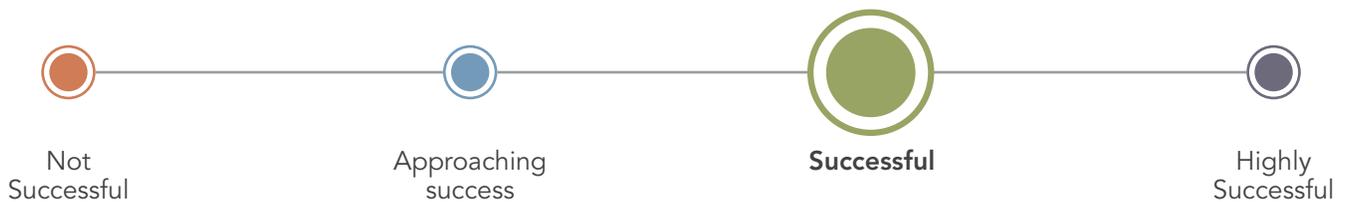
There are a range of services available to caregivers in my local community?



GOAL 2C SUMMARY

Improve caregiver skills and capacity to care for their themselves.

Definition of Successful: Many caregivers are able to access services they need to ensure appropriate care for themselves, and many feel that CCI services were helpful in improving their capacity to care for themselves.



Partners perceived the CCI as having positive effects in supporting caregivers self-care. Nevertheless, these efforts have not yet fully affected all caregivers. While about half of caregivers said that they received all the services they needed to assist themselves, the rest did not. In fact, a noticeable portion reported receiving less than half of what they needed.



“My needs are more for emotional support and to learn more about coping skills to deal with resentment, frustration, and stress from having my 95 year old mother in law moving in with us and changing our lives.”

GOAL 2C FINDINGS

USE OF SERVICES TO SUPPORT CAREGIVER SELF-CARE

- 8 While half of caregivers used all the services they needed to support their ability to care for themselves, an equal number used less – and even a lot less -- than they needed.
- 9 Caregiver need for and use of support services varied. While need exceeded use for all services, this gap was substantial for several services.

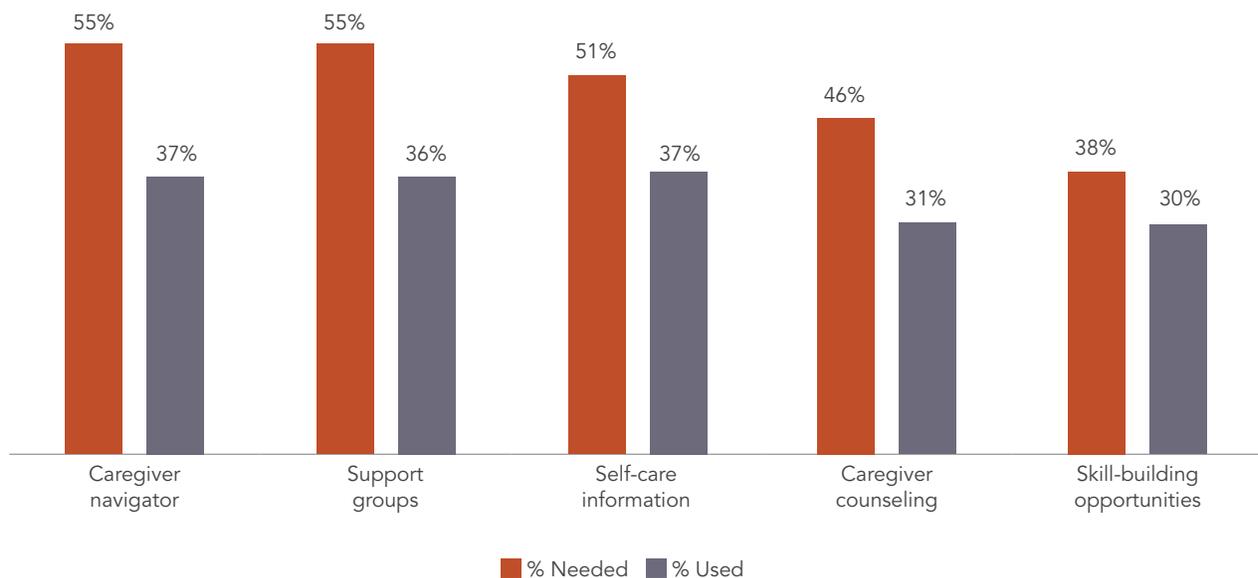
CAREGIVERS reported their need for services to support self-care in the last six months, as well their use of those services.

51% of Caregivers used all the services they needed.

6% used over half, but not all, of the services needed.

43% used less than half of the services needed.

This chart shows the percent of all **CAREGIVERS** that needed these services to support self-care in the past six months, and the percent that used them.



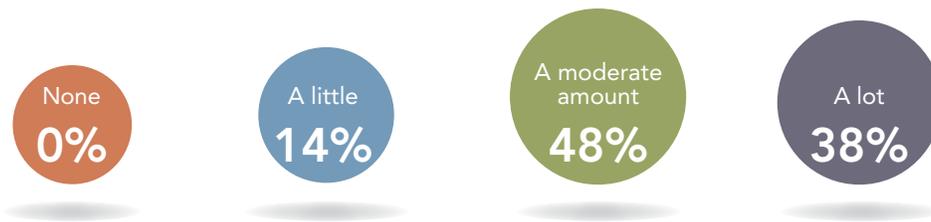
GOAL 2C FINDINGS

CCI EFFECTS ON CAREGIVER SELF-CARE

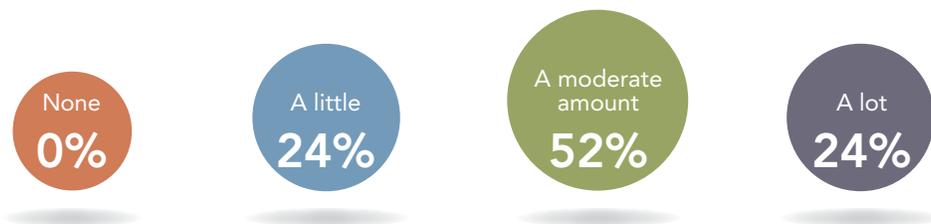
10 All CCI partners believed that CCI efforts had led to improvements in helping caregiver capacity for self-care. The majority rated these effects as moderate in magnitude.

PARTNERS reported how much they think the CCI has improved caregivers' ability to...

...receive needed services and support for themselves?



...and take care of themselves and their own needs?



GOAL 2D SUMMARY

Improve the well-being of caregivers.

Definition of Approaching Success: Some caregivers are able to regularly take care of their own physical and emotional needs and improve their own overall well-being. Some feel the CCI has been helpful in their efforts to do so.



Understandably, many caregivers reported feeling stressed due to their caregiving responsibilities. It is also not surprising that caregivers are only sometimes or often able to regularly ensure their own practical, physical, and emotional needs are met. In terms of action to address this, all partners believed that the CCI had improved caregivers' ability to engage in self-care. Caregiver reports corroborated that view. Many caregivers also reported that services had been helpful in reducing their stress and improving their well-being. However, there is room for improvement in the level of attention given to caregivers' needs by professionals. Only a minority of caregivers believed that improvements had occurred in this area.



“What we’re hoping will happen through this - 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.”

GOAL 2D FINDINGS

CAREGIVER SELF-CARE AND WELL-BEING

11 On average, Caregivers reported being able to meet their own practical, physical, and emotional needs only sometimes to often.

CAREGIVERS reported how regularly over the past six months...

they had been able to do a variety of practical activities to take care of themselves (e.g. attending to their own medical and financial needs, coping with home maintenance, and finding services for themselves)...

Practical self-care



... their physical needs had been met (e.g., getting enough sleep, having adequate shelter, and accessing healthcare)...

Meeting physical needs



...and their emotional needs had been met (e.g., taking time to have fun and feeling good about themselves).

Meeting emotional needs



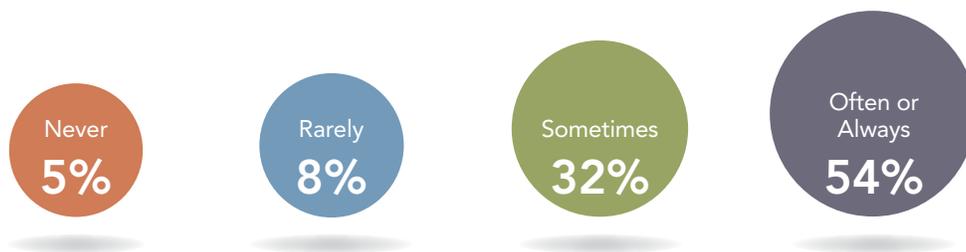
GOAL 2D FINDINGS

CAREGIVER STRESS AND HELPFULNESS OF SERVICES

12 Nearly all caregivers have felt stressed because of caregiving over the last six months, and more than half say they feel stressed often or always. However, for most the services they received have been a little, and in many cases extremely, helpful in reducing stress and improving personal well-being.

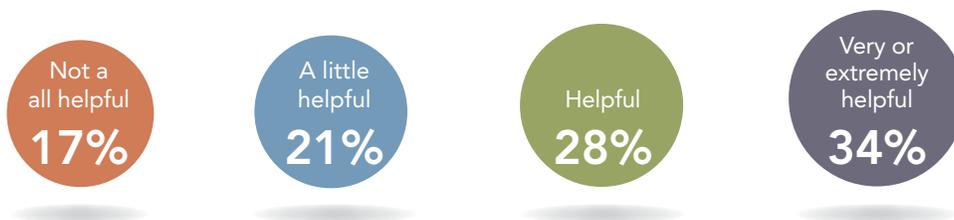
13 The helpfulness of services received by caregivers in addressing stress and well-being varied a lot. About a third said services were very or extremely helpful, about a quarter said they were helpful, and another third said they were only a little or not at all helpful.

CAREGIVERS reported how often they felt stressed because of caregiving in the past six months.



They also reported how helpful the services they received were in...

...addressing stress associated with caregiving,



... and improving personal well-being.



GOAL 2D FINDINGS

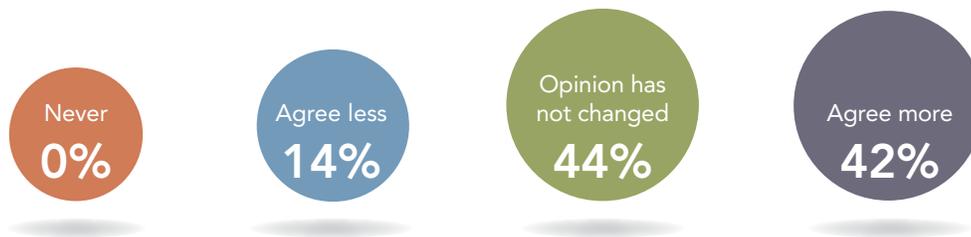
IMPROVEMENTS IN CAREGIVER INTERACTIONS WITH PROFESSIONALS

14

While some caregivers perceived improvements in professionals paying attention to their needs, the majority did not.

CAREGIVERS reported how much their service experiences had changed their opinion, compared to six months ago...

...less than half agreed more that the professionals serving the person they care for pay attention to their needs.



“Recently we had an adult patient share that she is struggling because she just became the full-time caregiver to her mother while trying to deal with her own health issues and be a single mom to her children...A few months ago, I would not have known where to refer her.”

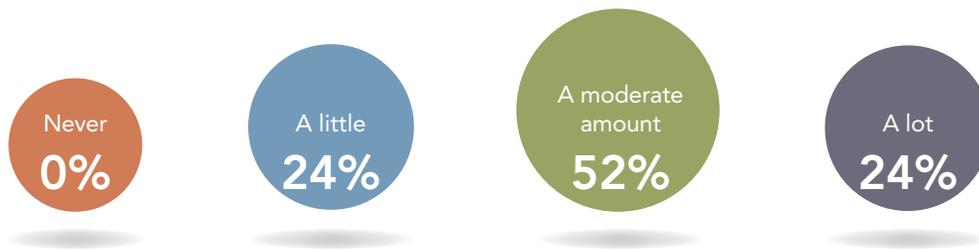
GOAL 2D FINDINGS

CCI EFFECTS ON IMPROVING CAREGIVER WELL-BEING

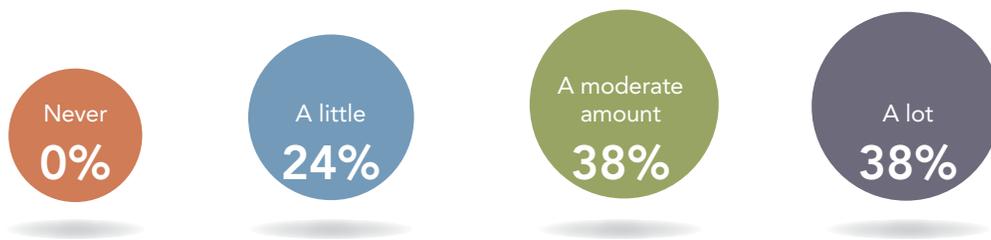
15 All CCI partners believed the CCI had led to improvements in enhancing caregiver self-care and well-being. The majority assessed the self-care effects as moderate in magnitude, and the well-being as moderate or greater.

PARTNERS reported how much the CCI had improved caregivers' ability to...

...take care of themselves and their own needs,



...and improve their personal well-being.



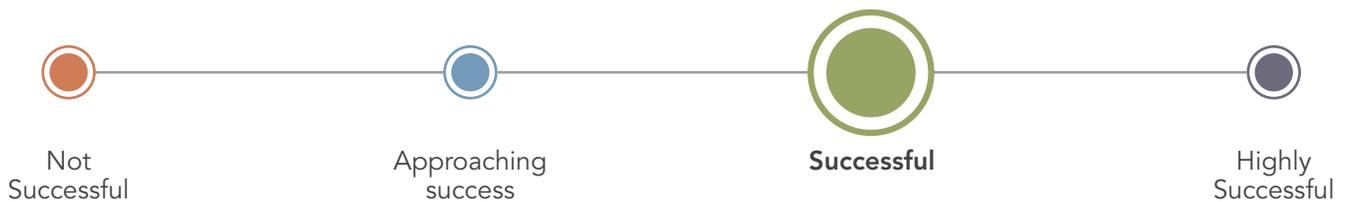


CCI IMPACTS ON CAREGIVING AND CARE RECIPIENTS

GOAL 3A SUMMARY

Improve caregiver access to information needed to care for their care recipient(s).

Definition of Successful: Many caregivers received the information they needed and were aware of services they needed to properly care for their care recipient(s). Many report that services received were helpful in increasing their awareness of relevant community resources.



Caregiver awareness of resources overall was high: three-quarters of caregivers stated they were aware of the services that they needed to provide care. Many said that the services they received were helpful in achieving this awareness. Many caregivers also report having received all the information they need, but gaps remain for others. Some continuing need for information exists: while over half received information that helped them care for their loved one, a substantial amount expressed a need for more.



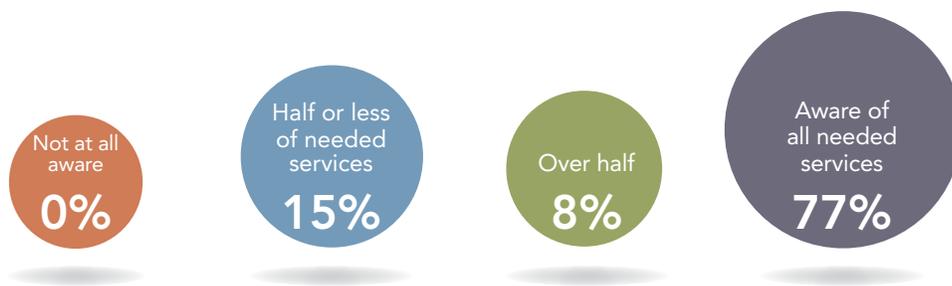
“I don’t seem to have time to look into some services that might be available. Everything takes so long, the routines of the day are time-consuming and emotionally draining.”

GOAL 3A FINDINGS

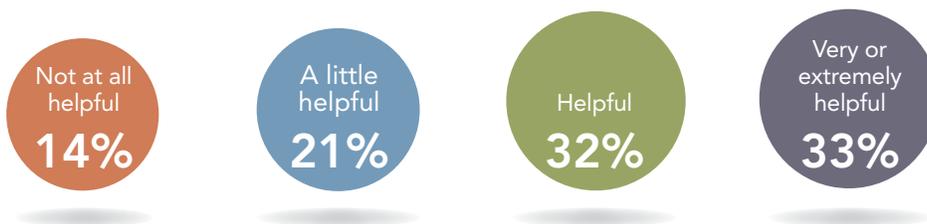
CAREGIVER AWARENESS OF NEEDED SERVICES FOR CARE RECIPIENT

- 1 Three-quarters of caregivers knew about the availability of most or all needed services.
- 2 Two-thirds of caregivers attributed their increased awareness of resources to services they received.

Most **CAREGIVERS** were aware of the availability of needed services.



Services received were helpful in increasing caregivers' awareness of community resources available to their care recipients.



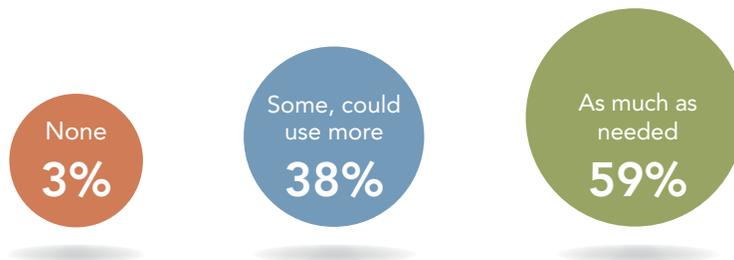
GOAL 3A FINDINGS

CAREGIVER RECEIPT OF INFORMATION ABOUT THEIR CARE RECIPIENT

3 Over half of caregivers received all the information they needed about several key topics. But at the same time, over a third wished they had received more. Information about resources for the person being cared for was the least received type.

Overall about half of **CAREGIVERS** received enough information about ...

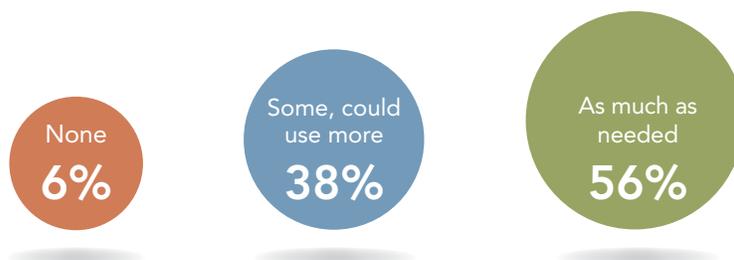
Their care recipients' specific illness or condition.



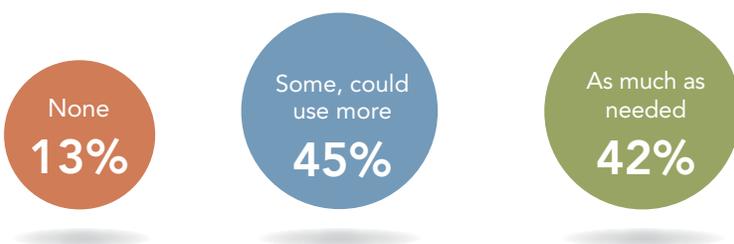
Their care recipients' specific care needs.



Their care recipients' treatment options.



Community resources available to the person being cared for.



GOAL 3B SUMMARY

Improve caregiver skills and capacity to care for their care recipient(s).

Definition of Approaching Success: Some caregivers are able to access services they need to provide appropriate care to their care recipient(s), and some report that the CCI improved their capacity to provide care.



Partners all believed that the CCI had contributed, at least a small amount, to caregiver capacity to provide care. Indeed, half or more of caregivers typically said they got the services they needed to provide specific types of care. However, gaps exist. A clear segment reported they did not receive all of the services they needed and that they were not able to provide specific types of care.



“I will need more support as Mom gets worse. I could definitely use more skills. I’m afraid of what will come.”

GOAL 3B FINDINGS

USE OF NEEDED SERVICES TO SUPPORT CAREGIVING

- 4** About half of caregivers used all the services they needed to care for their loved ones. The other half used only a portion of what they needed.
- 5** Caregivers were most likely to need and use in-home health services to support caregiving. The greatest gap between need and use was for respite services.

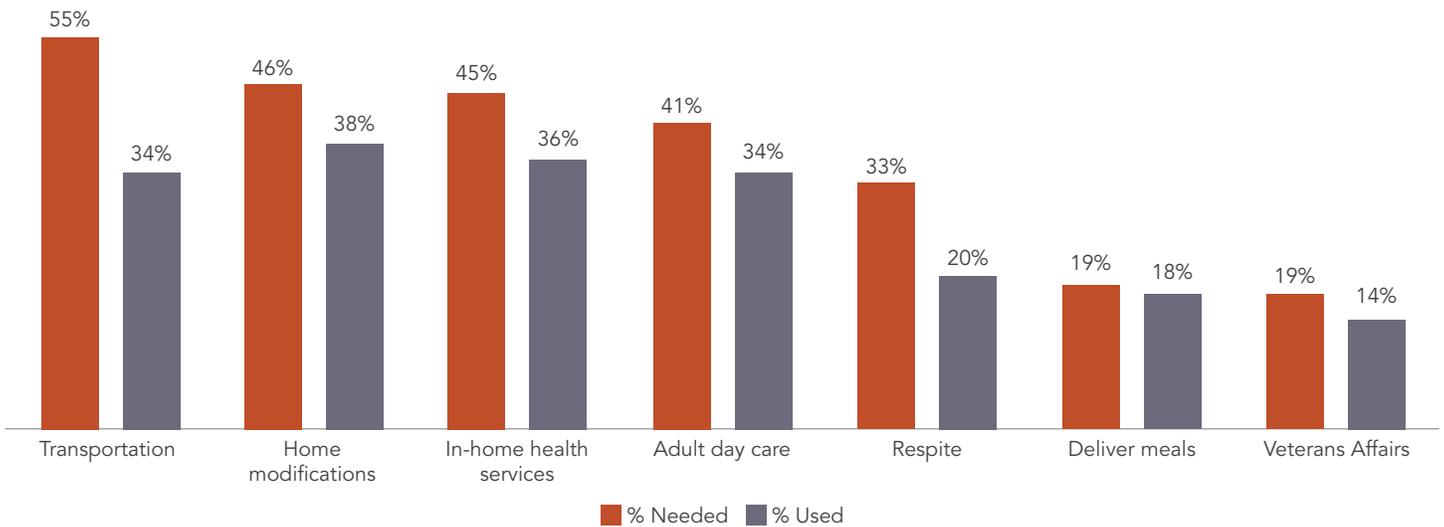
CAREGIVERS reported on their need for services to assist with providing care, in the last six months, as well their use of those services.

49% of CAREGIVERS used all the services they or their care recipient needed

19% used over half, but not all, of the services needed.

32% used less than half of the services needed.

This chart shows the percent of all **CAREGIVERS** that needed these services to assist with caregiving in the past six months, and the percent that used them.



GOAL 3B FINDINGS

CCI EFFECTS ON CAREGIVER ABILITY TO PROVIDE CARE

6 All CCI PARTNERS believed the CCI had led to improvements in helping caregivers provide needed care. The majority rated these effects as moderate in magnitude.

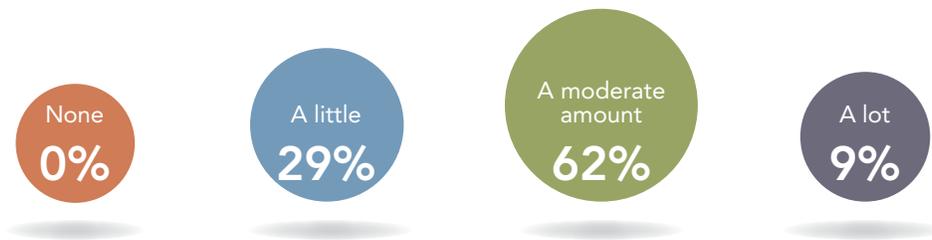
CAREGIVERS reported on the helpfulness of all the information and services they and the person they care for received over the past six months.

69% said services and information received were helpful in improving their ability to find and use services they need.

63% said they increased their ability to advocate for appropriate care for their care recipient.

PARTNERS rated how much they thought the CCI improved caregivers' ability to...

...navigate the health care system, and



...advocate for appropriate care for who they are caring for?



GOAL 3C SUMMARY

Caregivers are able to provide (and ensure provision of) the best possible care for their care recipients.

Definition of Approaching Success: Some caregivers are able to regularly take care of the needs of their care recipient(s) advocate for their care, improve their care recipients' overall well-being. Some caregivers feel the CCI helped them in their efforts to do this work.



All partners believed that the CCI helped to improve caregivers' abilities to ensure quality care for their loved ones. Caregivers agreed. Most saw services as being anywhere from a little to extremely helpful. Of concern is that about half of caregivers reported being unable to complete all of the tasks they needed to care for their loved one.



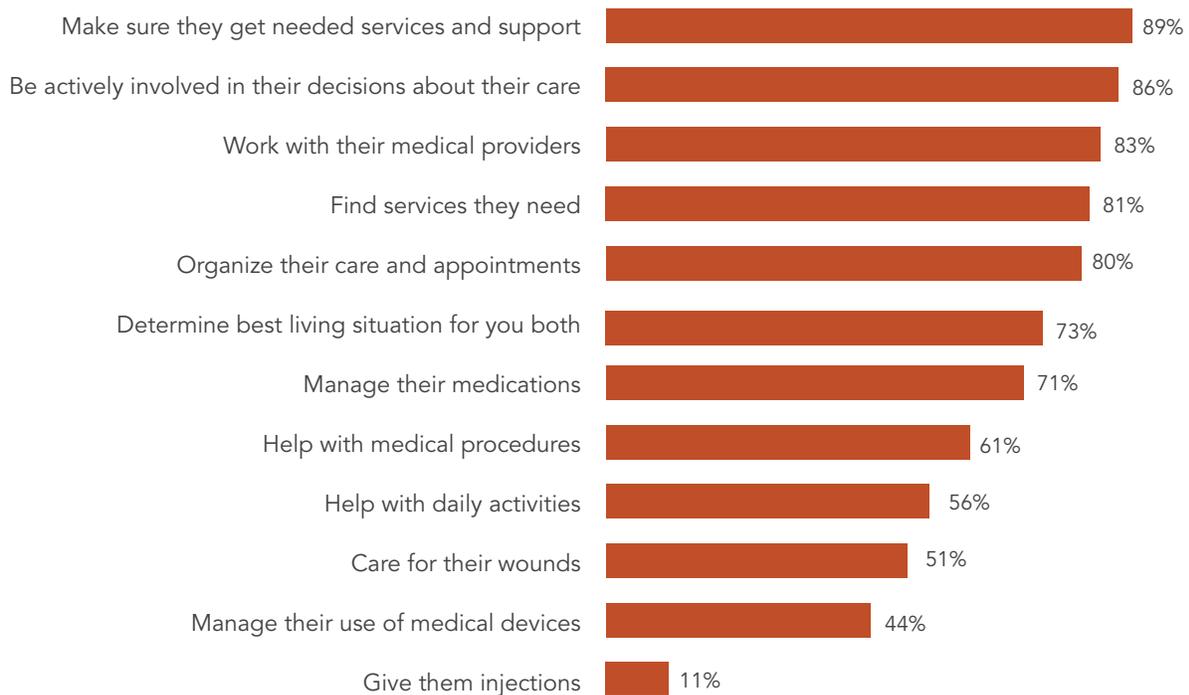
"I'm sure there are services available for which I am unaware. It would be marvelous if I could figure out how to ask for help caring for my Mother."

GOAL 3C FINDINGS

TYPES OF CARE CAREGIVERS NEEDED TO PROVIDE

7 More than half of all caregivers needed to provide 10 or more of the 12 types of care they were asked about over the past six months. The remaining two types of care -- managing use of medical devices and giving injections -- were provided by less than half of the caregivers.

This chart shows the percent of all **CAREGIVERS** that needed to provide each type of care over the past six months.

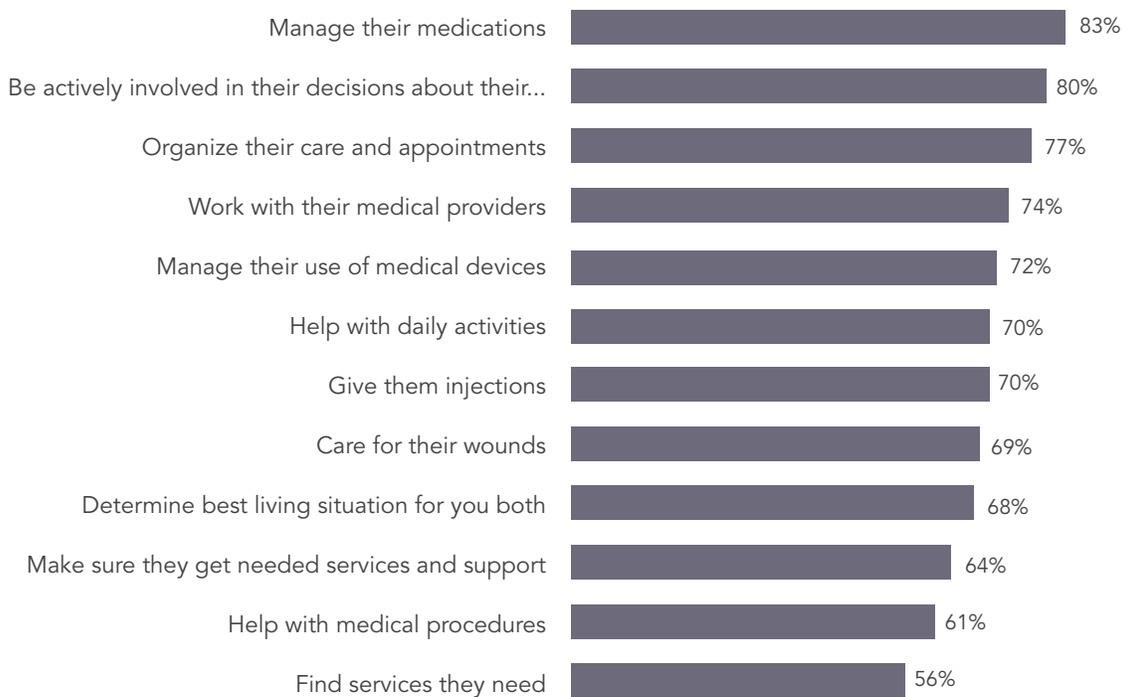


GOAL 3C FINDINGS

CAREGIVERS' ABILITY TO PROVIDE CARE WHEN IT WAS NEEDED

- 8** Across all the types of care needed, the majority of caregivers reported they were able or very able to provide it. However, a noticeable portion of caregivers were barely or only somewhat able to accomplish certain tasks.
- 9** Of particular relevance to the CCI, caregivers were least likely to report being very able to find where to go to get services they need and making sure their care recipients were getting the care they needed.
- 10** About half of caregivers said they were very able to do all the caregiving tasks their care recipient needed. However, others were only somewhat able to do a portion of the needed tasks for their care recipient.

This chart shows the percent of **CAREGIVERS** very able to provide care when needed over the past six months. For example, 83% of those who needed to manage medications were able to do so.



Of the above tasks, **CAREGIVERS** differed in how many they were very able to accomplish.

49% of CAREGIVERS said they were very able to do all the caregiving tasks that were needed.

29% were very able to do over half, but not all, of the needed caregiving tasks.

22% were very able to do less than half of the needed tasks.

GOAL 3C FINDINGS

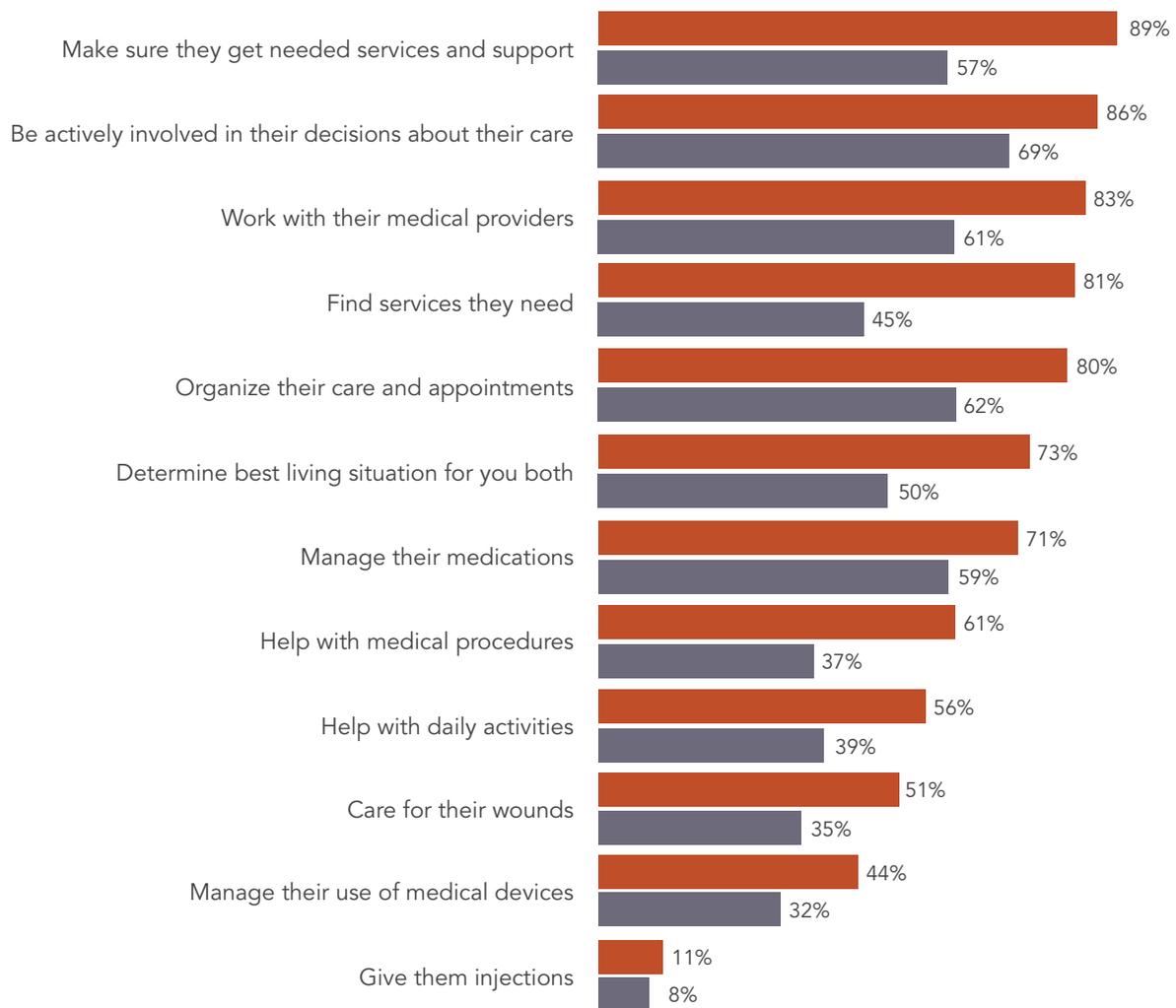
SHOWING THE INFORMATION TOGETHER FROM THE LAST TWO PAGES: WHERE CAREGIVER ABILITY FALLS SHORT OF NEED



Gaps between CAREGIVER need and ability existed for every activity we asked about. The largest gaps were in finding needed services for care recipients, making sure they received the services and supports they needed, and helping them with medical procedures.

This shows **CAREGIVERS** need and their ability to provide specific tasks. Showing these side-by-side allows us to see where the greatest gaps exist.

For example, 89% said they needed to make sure care recipients got needed services and support. However, of these, only 57% said they were very able to do so.



■ % Needed ■ % Very able to provide

GOAL 3C FINDINGS

PERCEIVED HELPFULNESS OF SERVICES

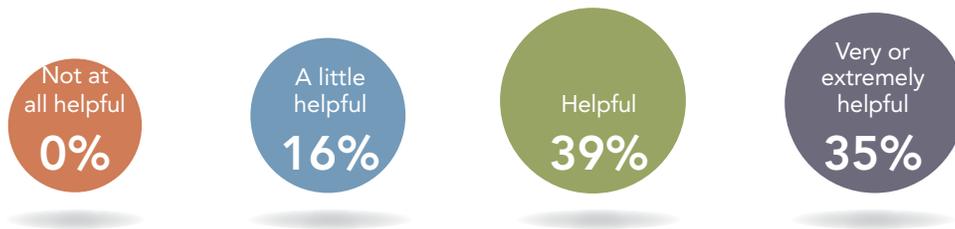
12 About a third of caregivers found services they received very or extremely helpful in enabling them to perform tasks important in caring for their loved ones. While almost another half found them helpful.

CAREGIVERS reported how helpful all the services received were in ...

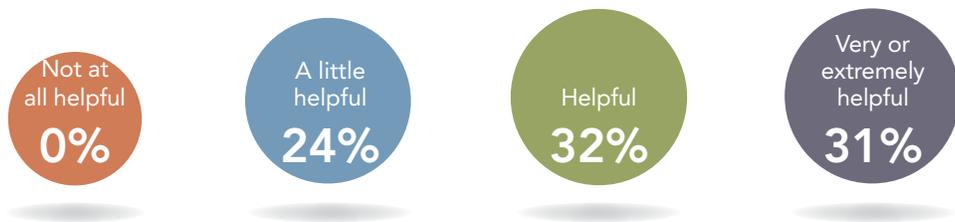
...supporting their care recipients' well-being,



...providing the care their loved ones need.



...and advocating for appropriate care for their loved ones.



GOAL 3C FINDINGS

PARTNER ASSESSMENT OF CCI EFFECTS ON CAREGIVING

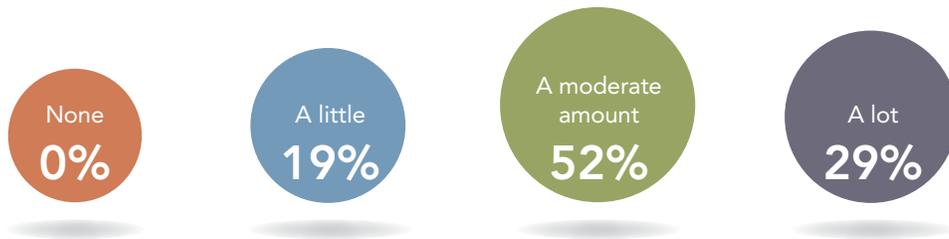
13 All CCI partners believed the CCI had led to improvements in caregivers' ability to provide, and ensure the provision of, needed care. The majority assessed these effects as moderate in magnitude.

PARTNERS reported how much they thought the CCI has improved caregivers' ability to...

...provide the best possible care



...and improve the well-being of who they are caring for.



WHAT WE'VE LEARNED ABOUT CAREGIVERS IN SANTA BARBARA COUNTY

CAREGIVER CHARACTERISTICS

We obtained survey data from 165 Santa Barbara County CAREGIVERS in the late fall of 2017.

29%

of these caregivers were under 49 years old

24%

between 50 and 59

24%

between 60 and 69

23%

were age 70 or older



82%

were women



18%

were men

EN

82% spoke English as their primary language

ES

14% spoke Spanish as their primary language

Other

4% spoke another language



61% identified themselves as white



32% as Latino



4% as Asian American



2% as African American



2% as other race-ethnicities

CARE RECEIVER CHARACTERISTICS

CAREGIVERS reported that the majority (90%) of the people they provided care for lived in SBC. Five percent lived outside SBC but within California, and the remaining 5% lived outside California.

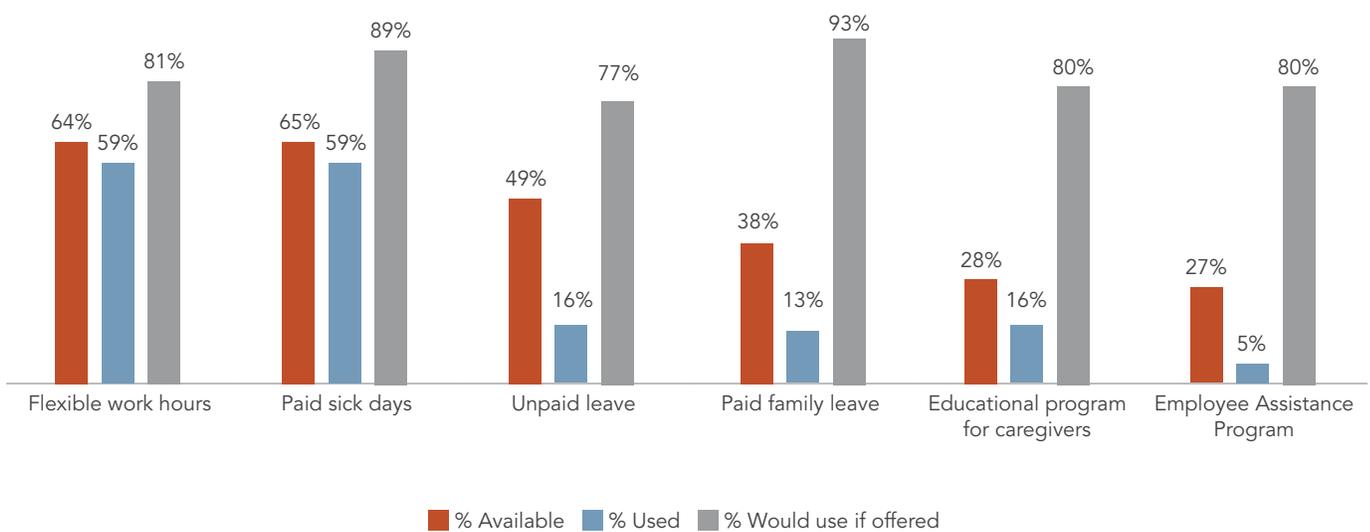
- Caregiving is a long-term commitment. More than half (55%) of caregivers had been caring for this person for 3 to 10 years, and 17% for more than 10 years. Only 9% had been providing care for less than 1 year.
- Care recipients were mostly over 80 years of age, with 27% being 60 to 74, 30% 75 to 84, and 33% over 85.
- 45% of caregivers were caring for a parent, 28% for a spouse, and 27% for a non-parent family member, friend, or other type of person.
- 61% of caregivers said there was another person who helped with care.

EMPLOYMENT BENEFITS

CAREGIVERS were asked about access to and use of supportive benefits from employers. More than three-quarters of caregivers would use all these services if offered by their employer.

- 37% of caregivers were employed full-time and 17% part-time, 4% were self-employed, 14% unemployed, and 28% retired.
- Of those who were employed, paid sick days and flexible work hours were the most common benefits offered and the most commonly used by those who received them.
- Paid family leave was offered to only 38% of caregivers, but 93% said they would use this benefit if it was offered.

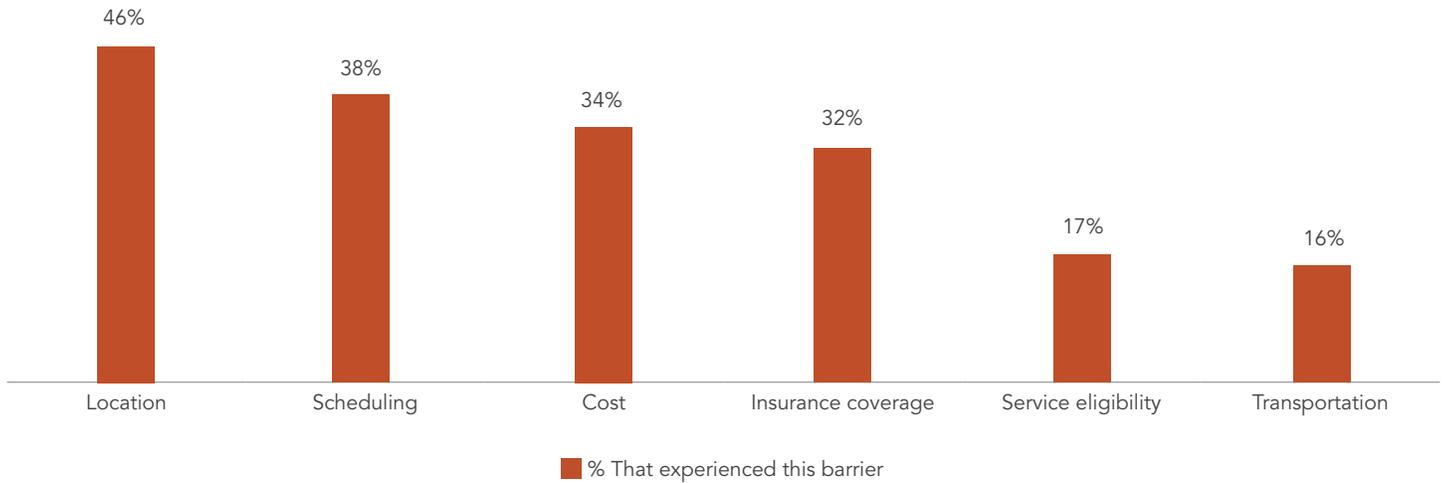
This chart shows the percent of employed CAREGIVERS that reported these benefits were available to them, the percent that used each, and the percent that would use the service if it was offered.



BARRIERS TO AND ACCEPTABILITY OF SERVICES

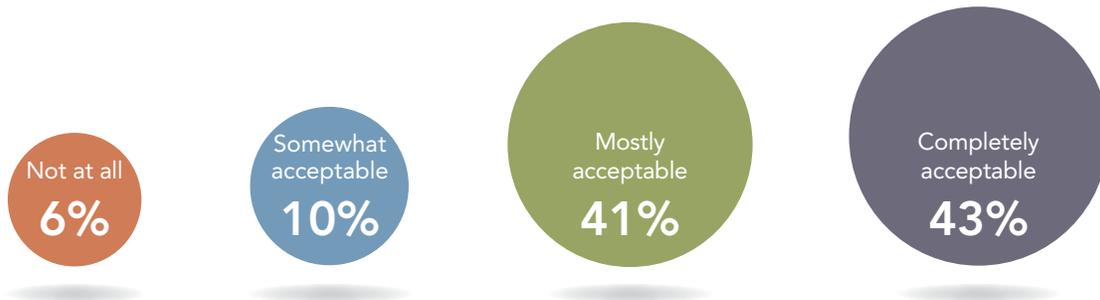
CAREGIVERS reported whether they or the person they cared for had faced challenges using services. Service location and scheduling were the most commonly identified barriers.

This chart shows the percent of all **CAREGIVERS** that faced these barriers using services for themselves or their care receiver.



CAREGIVERS were asked to think about things like language, cultural background, religion, sexual orientation, and age, and rate the acceptability of services they received.

The large majority of caregivers found the services received either completely (43%) or mostly (41%) acceptable.



Some CAREGIVERS also offered additional comments about the services they received. Most of these comments were strongly positive...



“Family therapy provided through [name of clinic] has been lifesaving. If I had not been able to get therapy there and have it covered by Medicare and Medi-cal, we would not have been able to survive.”

A few identified particular barriers...



“Too many people are living in terrible settings at home, unable to cook, walk, drive, get acceptable transportation to appointments.”



“Challenging to request copy of lab work to be sent to [name of pharmacy] in order to have special Rx filled.”

A few emphasized differences in priorities between care recipients and professionals...



“home health providers... obsess over patient risks and falling... creating an inordinate burden on my [age] mom who is very strong and sturdy on her feet.”

While others succinctly captured the caregiving experience...



“Hardest job I have ever had!”

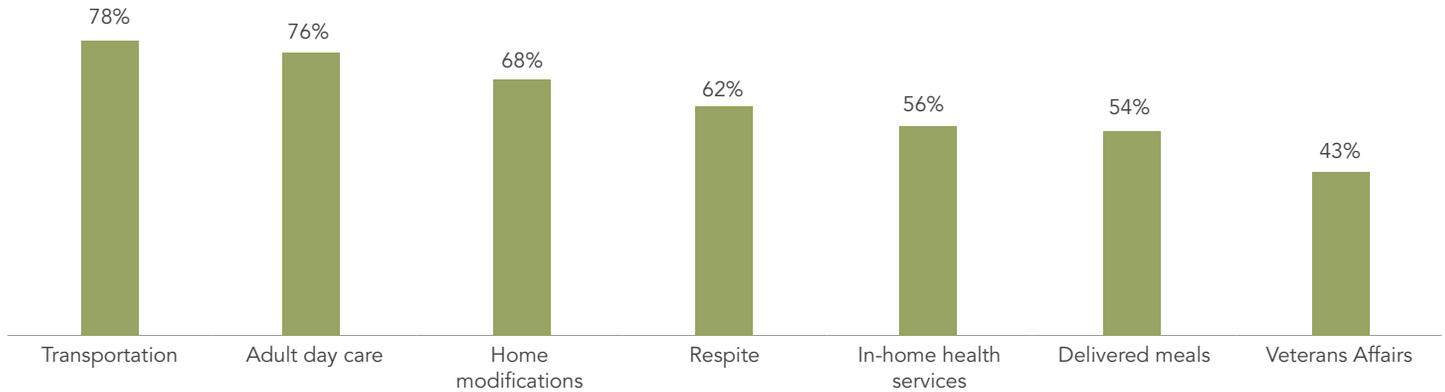


“It takes a toll on a person!”

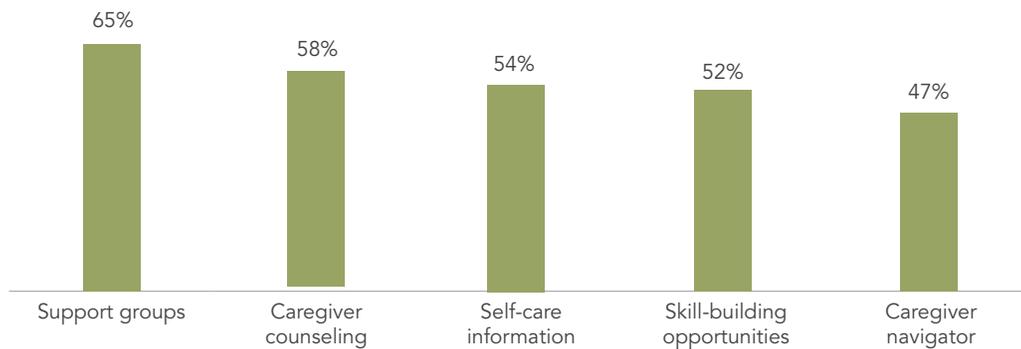
HELPFULNESS OF INDIVIDUAL SERVICES

Of **CAREGIVERS** who had used services, the majority found them at least helpful, and many found them very or extremely helpful.

This chart shows the percent of CAREGIVERS that used each service and found that service helpful or very helpful.



This chart shows the percent of CAREGIVERS that used each service and found that service helpful or very helpful.



CAREGIVERS DIFFER IN THEIR LEVEL AND TYPE OF SERVICE USE

Caregiver use of 12 services (such as respite care and delivered meals) for themselves and their care recipients differed greatly. We used Latent Class Analysis (LCA) to identify distinct groups among caregivers. Detailed LCA findings can be reviewed in Appendix D. Here's what we learned.

Caregivers in Santa Barbara County, over the past 6 months, used an average of between 3 and 4 of the 12 types of services available. But data suggest four subgroups within our caregivers with very different patterns of service use.

FOUR TYPES OF CAREGIVERS



HIGH SERVICE USERS (13% OF CAREGIVERS)

- Used an average of 7.5 of the 12 services
- This group used nearly all services, particularly respite and in-home health care
- Also used a lot of services for themselves, such as self-care information, skill building opportunities, and support groups
- **A key finding is that this group was 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.



MODERATE TO HIGH SERVICE USERS (32% OF CAREGIVERS)

- Used an average of 5 of the 12 services
- This group used a variety of services, especially the caregiver navigator, adult day care, and home modifications
- And like the High Service Users, they also used quite a few services for themselves, such as self-care information, skill building opportunities, and support groups



MODERATE SERVICE USERS (32% OF CAREGIVERS)

- Used an average of 3 of the 12 services
- This group was most likely to use transportation and caregiver counseling services
- But they used just some of the available services for caregivers



VERY LOW SERVICE USERS (23% OF CAREGIVERS)

- Used an average of less than one of the 12 services
- This group sometimes used meal delivery services
- They were very unlikely to use any caregiver services for themselves

Most caregivers in all four groups are caring for parents. But people in the High Services Users group are 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 are similar. All caregivers reported feeling stressed “sometimes” to “often” because of their caregiving responsibilities.



Questions raised by these subgroup findings include:

1. How can people move along the continuum from being Very Low Service Users to higher levels of service use?
2. Do caregivers in High and Moderate to High Service Use groups start by using more caregiver-focused services? Or do they begin using these services for themselves later in their caregiving journey?
3. Does being in the High Service Use group translate into better self-care and increased well-being over time, although it did not in this analysis?

EVALUATION METHODS

EVALUATIVE APPROACH

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

- Provide timely, ongoing information to Initiative partners to guide program improvement;
- Assess how effective the CCI is in meeting its key goals;
- Characterize how agencies across Santa Barbara County are working together to better support caregivers, specifically in relation to how they communicate and collaborate with one another to improve caregiver supports, 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.

ES designed the evaluation using a combination of developmental and utilization-focused evaluation approaches. Developmental Evaluation (DE) is an evaluation approach that is highly responsive to context. DE is used to assist social innovators develop social change initiatives in complex or uncertain environments, and facilitates frequent feedback to program staff to facilitate a continuous development loop. Utilization-focused evaluation engages stakeholders in determining the evaluation focus and methods. DE evaluations are conducted in ways that enhance the likely use of the findings to inform decisions and improve program performance.

To establish common goals for the CCI, ES engaged the partners in an interactive process to identify collective goals and an evaluative rubric. A rubric clearly identifies criteria and standards for assessing different levels of performance. Rubrics are used to synthesize evidence into an overall evaluative judgement. Rubrics were developed for each CCI goal. Each goal was then described in terms of performance at four levels: not successful, approaching success, successful, and highly successful. The purpose of the CCI rubric was 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. Data collected in the summer and fall of 2017 was systematically applied to the CCI evaluative rubric to characterize levels of success achieved in each goal area. This process will be repeated in year two at the conclusion of the evaluation.

DATA COLLECTION METHODS

Caregiver Survey

ES developed the caregiver survey in 2016, using a collaborative process that involved CCI partners, SBF staff, and Evaluation Specialists staff. The survey was pilot tested with caregivers. It was then refined to ensure the questions were clear and that the information collected would benefit the CCI Initiative and participating agency partners. The survey was designed to evaluate the combined efforts of partners participating in the Community Caregiving Initiative. The survey was not designed to evaluate the services and supports provided by individual Initiative partners. While the survey asks about services received by caregivers, it does not directly tie that support to any specific partner agency.

Specific information collected in the survey over the past six months, included:

- Awareness of types of information, services and supports available to caregivers
- Receipt of information
- Use of services and supports by caregivers in the past 6 months
- Perceived helpfulness of overall services and supports received by caregivers
- Perceived helpfulness of each type of service and support received by caregivers

Ways to improve the survey were identified after the first administration in spring 2017. These changes were incorporated into the fall 2017 caregiver survey.

Caregivers across Santa Barbara County who had received services or supports 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. Caregivers could choose between pen-and-paper and online surveys. At the start of the survey, a branching question led caregivers to either a Spanish or English version of the questions, based on their language preference. Caregivers that completed the survey were offered a \$5 emailed gift card for their participation.

Partner Organization Survey

ES developed the partner organizations survey and collected data from partner organizations using an online survey. 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 communicate and collaborate with one another to improve caregiver supports and referrals. We also collected information about CCI partner staff practices and beliefs.

First, an email requested CCI partner participation. It provided a link to the survey. Next, each partner was asked do the following to complete the survey:

1. Identify one person who will be responsible for completing the data collection process and entering the data into the online survey every 6 months. This was to be an employee involved in direct service for caregivers, who had the ability to gather information from program staff at the agency, and who could engage their colleagues in the process of completing the survey. This person should be well informed about the agency's participation in the Santa Barbara Caregiver grants and/or the Community Caregiver Initiative. Ideally, for consistency, the same person is to complete the survey each time it is administered.
2. Convene a small group to assist in completing the survey. This group was to include a manager that is familiar with the Community Caregiving Initiative, and staff that are responsible for, or familiar with, providing services to caregivers. The goal was to include staff that could provide an assessment of communication and collaboration between their program and other CCI program partners. We recommended printing a paper copy of the survey for each member of the small group, and asking them to complete it individually before participating in the group discussion. We provided discussion questions to engage the small groups in discussion.

3. Enter the final information collected from the small group into the online survey. Final responses from the discussion were to be recorded on a paper survey. Final group responses were recorded in the online survey.

Formative Key Informant Interviews

To get formative input from CCI stakeholders, Evaluation Specialists conducted 17 interviews (with 26 CCI partners and stakeholders, some of whom were interviewed together at their request) in the late summer of 2017. We invited a group of key informants to be interviewed that comprised the project directors of 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. In cases where SBF staff believed additional interviews would add important perspectives, we included more than one person per organization. Interviewees had the option of participating in audio only or video interviews via telephone or computer. ES staff audio-recorded the interviews while conducting them, and afterward took notes to further document and summarize each interview.

DATA ANALYSIS

Application of Data to the Evaluative Rubric

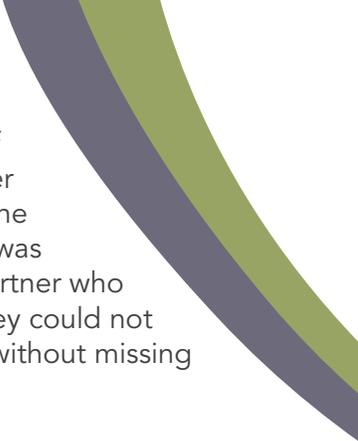
After data from the caregiver survey, the partner survey, and the key informant interviews were analyzed, these data findings were applied to the evaluative rubric. The CCI evaluative rubric, as mentioned above, was developed using a collaborative process that engaged CCI partners, SBF staff and ES staff. One part of that process was defining the level of success for each goal area in detail. Each goal was assigned four levels of success: not successful, approaching success, successful, and highly successful. Thus, the evaluative criteria for each goal, and as a result the criteria for the success of the overall Initiative was established using a stakeholder informed process to describe and establish thresholds for success. The thresholds established to meet success for each goal were either determined or informed by CCI partners.

ES then mapped each question from the caregiver and partner surveys, and formative interviews, to their aligned goals. Findings from all data sources were then applied to the rubric, thresholds were evaluated, and current levels of success for each goal was determined. In cases where data from different sources scored at different levels of success, data from caregivers was given more weight in the final decision. This process resulted in the rubric dashboard. This dashboard summarizes current CCI success on all stated goals. The rubric dashboard for data collected in the summer and fall of 2017 is shown in the CCI PERFORMANCE - SETTING AND MEETING OUR GOALS section of this report.

Partner Survey Social Network Analysis

The partner survey contained two types of questions. One type was social network (SN) questions. These involved each partner reporting on how much they had communicated, collaborated, and made referrals to each other CCI partner. SN questions also included 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 to the CCI.

We used three types of statistical software to analyze the data. We used SPSS to clean and prepare data for analyses. Then, we processed SN data and created visual representations of the partner's communication and collaboration using UCINET and Netdraw. For all other data, we used SPSS to create descriptive information (e.g., frequencies and means).



SN data often requires decisions to where partners disagree with each other and missing data. Partner disagreements were possible in that one partner might report a frequency of communication with another (or amount of collaboration) that differed from what that other partner reported. In such cases, we used a commonly used SN method in which we took the average of the two partners reports. Missing data existed due to two circumstances. One was when a partner did not participate but others answered about it. The other was when a partner who was not expected participated. In that case, the partner could answer about others but they could not answer about it. In both missing data cases, we used the answer provided by the partner without missing data.

Latent Class Analysis

We used a statistical technique called Latent Class Analysis (LCA) and data from the spring 2017 caregiver survey to empirically identify subgroups of caregivers based on their service use. We used two types of statistical software to analyze the data: SPSS to clean and prepare data for analyses, then Mplus to identify classes of individuals and test them for differences on well-being and other outcome variables. We estimated models iteratively; each specifying an increased number of groups (or “classes”). We then compared models to identify the best solution using standard criteria including classification quality (entropy), likelihood ratio tests, fit to the data as reflected by Bayesian and Akaike Information Criteria values (BIC and AIC), and classes’ interpretability and meaningfulness. Details on LCA model fit appear in the appendix.

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APPENDIX A: THEORY OF CHANGE

| Activities | Short-Term Outcomes | Medium-Term Outcomes | Long-Term Outcomes/Vision |
|---|--|---|--|
| <p>Community Caregiving Initiative (CCI)</p> | <p>Improve caregiver appreciation of their role and access to information</p> <p>Generate partner organization commitment and buy-in to CCI as a mechanism to improve system of care for caregivers</p> | <p>Improve caregiver skills and capacity to care for self and care recipient(s)</p> <p>Create systems that support effective communication, collaboration, and referrals across CCI partners as a mechanism to develop a system of care for caregivers.</p> | <p>Improve the wellbeing of caregivers and the care of their care recipient(s)</p> <p>Develop a sustainable system of care to support caregivers in their work.</p> |
| <ul style="list-style-type: none"> • Public Awareness and Engagement Campaign to encourage self-identification and appreciation of role of caregiver. • Regular meetings to bring partner organizations together. • Caregiver Navigators, Centralized Caregiver “Hub”, Promotores, caregiver access to information, training and skill-building, and other support. • Bring together partner organizations to coordinate efforts and referrals at regional and initiative levels. • Introduction of Care Maps to enhance self-identification and caregiver needs. • Integrating the caregiver as a member of the healthcare team. | <ul style="list-style-type: none"> • Partner organization staff are committed and buy-in to CCI goals. • Partner organization staff are committed to working towards more effective communication, collaboration, and referrals among partner organizations. • Partner organizations are committed to expanding staff knowledge of patient and caregiver services available at other partner organizations. • Partner organization staff understand and work to meet a wide range of caregiver needs. • Caregivers receive information they need about caring for their care recipients. • Caregivers see the importance of their role and feel appreciated for the work they do. • Caregivers receive information they need about caring for themselves in the role of caregiver. • Caregivers know about a range of relevant services and supports available for themselves and their care recipients. | <ul style="list-style-type: none"> • There is effective communication, collaboration, and referrals among partner organizations. • Caregivers use a range of needed services and supports for themselves and their care recipients; and gain needed skills and capacity to care for themselves and their care recipients. • Caregivers can navigate the system of care with ease. • Caregivers are integrated into medical teams of care for themselves and their care recipients. • Partner organization staff participate in efforts to improve the CCI network. | <ul style="list-style-type: none"> • Caregivers do not feel overly burdened or stressed by their caregiving responsibilities. • Caregivers and their care recipients receive needed care. • Caregivers are able to provide (and ensure provision of) the best possible care for their care recipients. • Partner organizations are committed to sustaining and improving a developed and effective system and network of communication, collaboration, and referrals. • Caregivers’ and their care recipients experience improved well-being. |

APPENDIX B: CCI EVALUATIVE RUBRICS

| CCI IMPACTS ON THE DEVELOPMENT OF A CAREGIVER SUPPORT SYSTEM IN SANTA BARBARA COUNTY – Evaluative Rubric 1 | | | | |
|--|--|--|--|--|
| | Not Successful | Approaching Success | Successful | Highly Successful |
| Goal 1A | Few caregivers report that the CCI-related services they received improved their opinions of their role as caregiver, and their perception that others recognize and value their role. Few CCI-staff and related stakeholders report that their organizational practices improve these caregiver opinions and perceptions. | Some caregivers report that the CCI-related services they received improved their opinions of their role as caregiver, and their perception that others recognize and value their role. Some CCI-staff and related stakeholders report that their organizational practices improve these caregiver opinions and perceptions. | Many caregivers report that the CCI-related services they received improved their opinions of their role as caregiver, and their perception that others recognize and value their role. Many CCI-staff and related stakeholders report that their organizational practices improve these caregiver opinions and perceptions. | Nearly all caregivers report that the CCI-related services they received improved their opinions of their role as caregiver, and their perception that others recognize and value their role. Most CCI-staff and related stakeholders report that their organizational practices improve these caregiver opinions and perceptions. |
| Goal 1B Create systems that support effective communication, collaboration, and referrals across Partner organizations to develop a system of care for caregivers. | A system of communication, collaboration, and referrals has not been developed across the CCI partner organizations. | A system of communication, collaboration, and referrals has been developed across CCI partner organizations, but may not be effective or practical. The system may or may not be easing caregivers' integration into and navigation of the system of care for their care recipients. | An effective and practical system of communication, collaboration, and referrals has been developed across CCI Partner organizations. This system has eased caregivers' integration into and navigation of the system of care for their care recipients. | An effective and practical system of communication, collaboration, and referrals has been developed across CCI Partner organizations. Many partner organizations report that amounts of communication, collaboration, and referrals with others are ideal. This system has eased caregivers' integration into and navigation of the system of care for their care recipients. It has also eased partner organizations' experiences in providing cross-organization care to the caregivers. |
| Goal 1C Develop a sustainable system of care to support caregivers in their work. | The work for the CCI cannot be sustained without SBF funding and is not positioned to evolve as community needs shift. | The work of the CCI may be sustained without SBF funding, but partner organizations are not currently aware of how to ensure this happens. The work may or may not be positioned to evolve as needs shift. | The system of communication, collaboration, and referrals across Partner organizations can be sustained beyond SBF funding, and is positioned to evolve in response to the caregiving community's needs. | New funding streams and/or strategic plans have been tapped into and/or created to ensure that the system of communication, collaboration, and referrals across Partner organizations will be sustained beyond SBF funding, and is positioned to evolve in response to the caregiving community's needs. |

CCI IMPACTS ON CAREGIVERS – Evaluative Rubric 2

| | Not Successful | Approaching Success | Successful | Highly Successful |
|---|--|--|--|--|
| Goal 2A Improve caregiver appreciation of their role | Few caregivers report that the CCI-related services they received improved their opinions of their role as caregiver, and their perception that others recognize and value their role. Few CCI-staff and related stakeholders report that their organizational practices improve these caregiver opinions and perceptions. | Some caregivers report that the CCI-related services they received improved their opinions of their role as caregiver, and their perception that others recognize and value their role. Some CCI-staff and related stakeholders report that their organizational practices improve these caregiver opinions and perceptions. | Many caregivers report that the CCI-related services they received improved their opinions of their role as caregiver, and their perception that others recognize and value their role. Many CCI-staff and related stakeholders report that their organizational practices improve these caregiver opinions and perceptions. | Nearly all caregivers report that the CCI-related services they received improved their opinions of their role as caregiver, and their perception that others recognize and value their role. Most CCI-staff and related stakeholders report that their organizational practices improve these caregiver opinions and perceptions. |
| Goal 2B Improve caregiver access to information needed to care for themselves | Few caregivers received the information they needed and were aware of services they needed to properly care for themselves. Few report that services received were helpful in improving their understanding of the challenges related to their role, and increasing their awareness of relevant community resources. | Some caregivers received the information they needed and were aware of services they needed to properly care for themselves. Some report that services received were helpful in improving their understanding of the challenges related to their role, and increasing their awareness of relevant community resources. | Many caregivers received the information they needed and were aware of services they needed to properly care for themselves. Most report that services received were helpful in improving their understanding of the challenges related to their role, and increasing their awareness of relevant community resources. | Nearly all caregivers received the information they needed and were aware of services they needed to properly care for themselves. They also report that services received were helpful in improving their understanding of the challenges related to their role, and increasing their awareness of relevant community resources. |
| Goal 2C Improve caregiver skills and capacity to care for themselves. | Few caregivers are able to access services they need to ensure appropriate self-care, and few felt that CCI services were helpful in improving their capacity to care for themselves. | Some caregivers are able to access services they need to ensure appropriate care for themselves, and some feel that CCI services were helpful in improving their capacity to care for themselves. | Many caregivers are able to access services they need to ensure appropriate care for themselves, and many feel CCI services were helpful in improving their capacity to care for themselves. | Nearly all caregivers are able to access services they need to ensure appropriate care for themselves, and nearly all feel that CCI services were helpful in improving their capacity to care for themselves. |
| Goal 2D Improve the well-being of caregivers | Few caregivers are able to regularly take care of their own physical and emotional needs and improve their own overall well-being. Few feel the CCI has been helpful in their efforts to do so. | Some caregivers are able to regularly take care of their own physical and emotional needs and improve their own overall well-being. Some feel the CCI has been helpful in their efforts to do so. | Many caregivers are able to regularly take care of their own physical and emotional needs and improve their own overall well-being. Many feel the CCI has been helpful in their efforts to do so. | Nearly all caregivers are able to regularly take care of their own physical and emotional needs and improve their own overall well-being. Nearly all feel the CCI has been helpful in their efforts to do so. |

CCI IMPACTS ON CAREGIVING AND CARE RECIPIENTS – Evaluative Rubric 3

| | Not Successful | Approaching Success | Successful | Highly Successful |
|--|--|--|--|--|
| Goal 3A Improve caregiver access to information needed to care for their care recipient(s). | Few caregivers received the information they needed, and were aware of services they needed, to properly care for their care recipient(s). Few report that services received were helpful in increasing their awareness of relevant community resources. | Some caregivers received the information they needed and were aware of services they needed to properly care for their care recipient(s). Many report that services received were helpful in increasing their awareness of relevant community resources. | Many caregivers received the information they needed and were aware of services they needed to properly care for their care recipient(s). Many report that services received were helpful in increasing their awareness of relevant community resources. | Nearly all caregivers received the information they needed and were aware of services they needed to properly care for their care recipient(s). They report that services received were helpful in increasing their awareness of relevant community resources. |
| Goal 3B Improve caregiver skills and capacity to care for their care recipient(s). | Few caregivers are able to access services they need to provide appropriate care to their care recipient(s), and few report that the CCI improved their capacity to provide care. | Some caregivers are able to access services they need to provide appropriate care to their care recipient(s), and some report that the CCI improved their capacity to provide care. | Many caregivers are able to access services they need to provide appropriate care to their care recipient(s), and many report that the CCI improved their capacity to provide care. | Nearly all caregivers are able to access services they need to provide appropriate care to their care recipient(s), and nearly all report that the CCI improved their capacity to provide care. |
| Goal 3C Caregivers are able to provide (and ensure provision of) the best possible care for their care recipients. | Few caregivers are able to take care of all of the needs of their care recipient(s), advocate for their care, improve their care recipients' overall well-being. Few caregivers feel the CCI helped them in their efforts to do this work. | Some caregivers are able to take care of all of the needs of their care recipient(s) advocate for their care, improve their care recipients' overall well-being. Some caregivers feel the CCI helped them in their efforts to do this work. | Many caregivers are able to take care of all of the needs of their care recipient(s) advocate for their care, improve their care recipients' overall well-being. Many caregivers feel the CCI helped them in their efforts to do this work. | Nearly all caregivers are able to take care of all of the needs of their care recipient(s) advocate for their care, improve their care recipients' overall well-being. Nearly all caregivers feel the CCI helped them in their efforts to do this work. |

APPENDIX C: FINDINGS BY INDIVIDUAL AGENCIES ABOUT REFERRALS

Depending on their missions and staffing, partners vary considerably on how much referrals they make and receive. The information here and on the next page describes each partner's referral activity as well as their desires for the future. This information can guide partners in knowing who to refer to and seek referrals from.

| Making referrals: Those each partner made in the past six months | |
|--|---|
| Wish to refer more?* | Partner making referral |
| More  | Sansum Clinic |
| | Atterdag Village of Solvang/Atterdag at Home |
| | Marian Regional Medical Center |
| | Santa Barbara County Public Health Department |
| | Coast Caregiver Resource Center |
| | Family Service Agency |
| | Alzheimer's Association |
| | Lompoc Valley Medical Center/Lompoc Family Caregiver Support Center |
| | Santa Barbara County Coalition in Support of Promotores de Salud |
| | Rona Barrett Foundation |
| | Friendship Center |
| | Solvang Friendship House |
| Same as now  | Life Steps Foundation – Santa Monica Wisdom Center |
| | Community Action Commission |
| | Adult and Aging Network |
| | Valley Haven |
| | Partners in Caring Foundation |
| | Adult and Aging Network |
| | Atlas of Caregiving |
| | Antioch University |
| Lompoc Valley Community Healthcare Organization | |

*reported wishing to refer more to at least one other partner
 Note: Table only includes partners who responded in the Fall 2017 survey."

| Receiving referrals: Those received from other partner in the past six months | |
|--|---|
| Wish to receive more? | Partner making referral |
| More  | Alzheimer's Association |
| | AAA |
| | Coast Caregiver Resource Center |
| | Family Service Agency |
| | Friendship Center |
| | Sansum Clinic |
| | Community Action Commission |
| | Marian Regional Medical Center |
| | Lompoc Valley Medical Center/Lompoc Family Caregiver Support Center |
| | Life Steps Foundation – Santa Monica Wisdom Center |
| | Santa Barbara County Coalition in Support of Promotores de Salud |
| | Valley Haven |
| | Partners in Caring Foundation |
| | Atterdag Village of Solvang/Atterdag at Home |
| | Rona Barrett Foundation |
| Solvang Friendship House | |

| Receiving referrals: Those received from other partner in the past six months | |
|---|---|
| Wish to receive more? | Partner making referral |
| Same as now  | Adult and Aging Network |
| | Atlas of Caregiving |
| | Lompoc Valley Community Healthcare Organization |
| | Santa Barbara County Public Health Department |
| | Antioch University |
|  ^b | Visiting Nurse and Hospice Care |
| | Santa Barbara County Adult Protective Services |
| | Dick DeWees Community and Senior Center |
| | Lompoc Skilled Nursing and Rehabilitation |
| | Santa Barbara Cottage Hospital |
| | Community Partners in Aging |
| | Cottage Rehabilitation Hospital |
| | Santa Barbara Parkinson's Foundation |
| | Godeta Valley Cottage Hospital |

*Numbers are unknown; partner participated in survey but was not in the list others answered about.

^bUnknown whether want to receive more referrals; partner did not participate in Fall 2017 survey.

APPENDIX D: LCA TABLES

| Comparing LCA models to determine best fit (denoted in bold) | | | | | |
|--|-------------|-------------|-------------|-----------------------|-----------|
| Model | BICssa | AIC | Entropy | Class Sizes | LMR |
| 2-class | 4416 | 4406 | 0.82 | 120, 136 | 388** |
| 3-class | 4266 | 4251 | 0.89 | 88, 132, 36 | 181** |
| 4-class | 4222 | 4201 | 0.88 | 83, 83, 58, 32 | 76 |
| 5-class | 4180 | 4154 | 0.93 | 70, 58, 93, 31, 4 | 74 |

* p < 0.05, ** p < 0.01, *** p < 0.001

BICssa = Sample-size adjusted Bayesian Information Criterion, AIC = Akaike Information Criterion, LMR = Lo-Mendell-Rubin adjusted likelihood ratio test.

| Subgroups of caregivers based on their service use over the past 6 months, empirically identified using Latent Class Analysis (LCA) | | | | | |
|---|------------------------|----------------------------|------------------------------|-------------|-----------------------|
| Service use indicator variables | Service use subgroups | | | | Full sample (n = 256) |
| | Very low (n = 58, 23%) | Low moderate (n = 83, 32%) | High moderate with self-care | Class Sizes | |
| Number of services used (mean) | 0.62 | 2.87 | 4.91 | 7.53 | 3.57 |
| Likelihood used each service | | | | | |
| In-home health services | 0.05 | 0.28 | 0.31 | 0.88 | 0.31 |
| Delivered meals | 0.12 | 0.26 | 0.23 | 0.19 | 0.21 |
| Transportation | 0.06 | 0.34 | 0.35 | 0.32 | 0.28 |
| Adult day care | 0.06 | 0.27 | 0.47 | 0.59 | 0.33 |
| Home modifications | 0.04 | 0.23 | 0.47 | 0.33 | 0.28 |
| Respite care | 0.07 | 0.13 | 0.26 | 0.65 | 0.22 |
| Veterans Affairs services | 0.06 | 0.11 | 0.23 | 0.19 | 0.15 |
| Caregiving skill building | 0.02 | 0.22 | 0.42 | 0.88 | 0.32 |
| Navigator | 0.03 | 0.12 | 0.50 | 0.80 | 0.31 |
| Caregiver counseling | 0.02 | 0.38 | 0.52 | 0.80 | 0.40 |
| Caregiver self-care information | 0.06 | 0.26 | 0.70 | 1.00 | 0.45 |
| Caregiver support groups | 0.08 | 0.30 | 0.50 | 0.93 | 0.39 |

Caregiver service use subgroups compared on how often (past 6 months) they were able to accomplish caregiving tasks

| Caregiving tasks | Chi-square | Service use subgroups | | | | Full sample (n = 256) |
|--|------------|---|----------------------------|--|-----------------------------------|-----------------------|
| | | Very low (n = 58, 23%) | Low moderate (n = 83, 32%) | High moderate with self-care (n = 83, 32%) | High with self-care (n = 32, 13%) | |
| Figure out where to get services they need | 7.87* | 3.41 | 3.74 | 3.66 | 3.98 | 3.67 |
| Make sure they get services they need | 10.93* | 3.56 | 3.66 | 3.79 | 4.19 | 3.74 |
| Work with their medical providers | 8.05* | 3.67 | 4.06 | 3.94 | 4.32 | 3.96 |
| Be actively involved in decisions about their care | 8.77* | 3.81 | 3.96 | 3.93 | 4.39 | 3.94 |
| Help them with daily activities | 5.24 | No significant mean differences between groups on these caregiving tasks indicators All means in 2.90 to 4.02 range (equivalent to "sometimes" (3) to "often" (4) on 1 to 5 scale) | | | | 3.41 |
| Organize their care and appointments | 4.25 | | | | | 3.78 |
| Determine the living situation that balances their needs and yours | 3.14 | | | | | 3.75 |

* p < 0.05, ** p < 0.01, *** p > 0.001

Caregiver service use subgroups compared on self-care and wellbeing over the past 6 months

| Caregiver self-care & wellbeing | Chi-square | Service use subgroups | | | | Full sample (n = 256) |
|--|------------|---|----------------------------|--|-----------------------------------|-----------------------|
| | | Very low (n = 58, 23%) | Low moderate (n = 83, 32%) | High moderate with self-care (n = 83, 32%) | High with self-care (n = 32, 13%) | |
| How often felt stressed caring for your loved one | 4.29 | No significant mean differences between groups on any caregiver self-care and wellbeing indicators All means in 3.2 to 3.7 range (equivalent to "sometimes" on 1 to 5 scale) | | | | 3.45 |
| Practical self-care (e.g., daily activities, medical, financial) | 2.40 | | | | | 3.51 |
| Meeting physical needs (e.g., eating right, sleeping, shelter) | 1.32 | | | | | 3.63 |
| Meeting emotional needs (e.g., feeling good about yourself) | 2.60 | | | | | 3.37 |

Caregiver service use subgroups compared on characteristics of their caregiving experience

| Characteristics of caregiving experience | Chi-square (df) | Service use subgroups | | | | Full sample (n = 256) |
|--|---|------------------------|----------------------------|--|-----------------------------------|-----------------------|
| | | Very low (n = 58, 23%) | Low moderate (n = 83, 32%) | High moderate with self-care (n = 83, 32%) | High with self-care (n = 32, 13%) | |
| Help with caregiving | 15.81 (6)* | 0.36 | 0.29 | 0.30 | 0.66 | 0.36 |
| No | | 0.62 | 0.70 | 0.66 | 0.34 | 0.62 |
| Yes | | 0.02 | 0.01 | 0.04 | 0 | 0.02 |
| Not sure | | | | | | |
| Time spent caregiving | 11.71 (12) Differences not significant | 0.05 | 0.10 | 0.16 | 0.04 | 0.10 |
| Less than 1 year | | 0.32 | 0.38 | 0.34 | 0.34 | 0.35 |
| 1-2 years | | 0.39 | 0.36 | 0.27 | 0.41 | 0.34 |
| 3-5 years | | 0.12 | 0.10 | 0.17 | 0.18 | 0.14 |
| 5-10 years | | 0.13 | 0.06 | 0.07 | 0.03 | 0.07 |
| 10 or more years | | | | | | |
| Care recipient | 25.55 (9)** | 0.29 | 0.33 | 0.25 | 0.40 | 0.30 |
| Spouse | | 0.59 | 0.54 | 0.54 | 0.57 | 0.56 |
| Parent | | 0.07 | 0.08 | 0.13 | 0 | 0.09 |
| Family member | | 0.05 | 0.05 | 0.07 | 0.03 | 0.05 |
| Other person | | | | | | |

* p < 0.05, ** p < 0.01, *** p > 0.001

APPENDIX E: CAREGIVER SURVEY

CC Fall 2017 Santa Barbara County Community Caregiving Initiative

Caregiver Survey

Thank you for taking this survey!

We want to better understand the experiences of caregivers in Santa Barbara county.

This survey will ask about the older adult (age 60 or older) you're caring for. It's also going to ask about you and your experiences caring for that person. The purpose of these questions is to learn about your experiences to improve programs for people like you.

Your participation is completely voluntary.

If you choose to participate, your answers will be used to improve services to caregivers across the county and evaluate the efforts of the Santa Barbara County Community Caregiving Initiative.

2

CC Fall 2017 Santa Barbara County Community Caregiving Initiative

Before you get started...

We have a few questions to help determine if it makes sense for you to take the survey. And also, to make sure you get only questions that are relevant to you. The questions ask about things such as your gender, race, where you live, and what language you speak. Click next if you want to continue.

5

CC Fall 2017 Santa Barbara County Community Caregiving Initiative

Eligibility to participate

2. Which county do you live in?

Kern County
 Los Angeles County
 Santa Barbara County
 San Luis Obispo County
 Ventura County
 Other

3. Which county do you work in?

I do not currently work
 Kern County
 Los Angeles County
 Santa Barbara County
 San Luis Obispo County
 Ventura County
 Other

4. What is your age?

Less than 30
 30 to 39
 40 to 49
 50 to 59
 60 to 69
 70 to 79
 80 or older

4

5. What is your gender?

Male
 Female
 Other (please specify)

6. How would you describe your racial/ethnic background? (Please check all that apply)

African-American, Black, or African
 American Indian, Native American, or Alaskan Native
 Asian or Asian-American
 Latina, Latinx, or Hispanic
 Native Hawaiian or other Pacific Islander
 White or Caucasian
 Other (please specify)

7. What is your primary language?

English
 Spanish
 Other (please specify)

5

CC Fall 2017 Santa Barbara County Community Caregiving Initiative

Eligibility to participate

8. In this survey, the word caregiver refers to someone who provides care and support to an older adult (age 60 or older)—a parent, spouse, partner, relative, friend, or neighbor—who needs help because of a limitation in their physical, mental, or cognitive functioning.

Many older adults receive care from more than one family caregiver, and some caregivers may help more than one older adult. Caregivers may live with, nearby, or far away from the person receiving care. The care they provide may be occasional, daily, or of short or long duration.

Regardless, the caregiver's involvement is determined primarily by a personal relationship rather than because of getting paid.

Considering the definition provided above, are you a caregiver of an older adult (age 60 or older)?

Yes
 No
 Not sure

9. Have you taken this survey in the past 2 months?

Yes
 No
 Not sure

10. What is your zip code?
 Your home zip code if you live in Santa Barbara County, otherwise your work zip code.

6

11. Thank you on behalf of all Santa Barbara County Community Caregiving Initiative partners. Please select the partner that has invited you to complete this survey:

Adult and Aging Network
 Alzheimer's Association
 Antioch University
 Area Agency on Aging
 Atlas of Caregiving
 Coast Caregiver Resource Center
 Community Action Commission
 Community Partners in Caring
 Cottage Rehabilitation Hospital
 Dick DeWes Community & Senior Center
 Family Service Agency
 Friendship Center
 Gotsis Valley Cottage Hospital
 Life Steps Foundation - Santa Maria Wisdom Center
 Lompoc Skilled Nursing & Rehabilitation
 Lompoc Valley Community Healthcare Organization
 Lompoc Valley Medical Center/Lompoc Family Caregiver Support Center
 Marian Regional Medical Center
 Partners in Caring Foundation
 Sarsium Clinic
 Santa Barbara Cottage Hospital
 Santa Barbara County Coalition in Support of Promotes de Salud
 Santa Barbara County Adult Protection Services
 Santa Barbara County Public Health Department
 Santa Barbara Parkinson's Foundation
 Valley Haven
 Visiting Nurse & Hospice Care
 Other (please specify)

9

CC Fall 2017 Santa Barbara County Community Caregiving Initiative

About you

12. Where does the person you care for live?

In Santa Barbara County
 Outside of Santa Barbara County but in California
 Outside of California

13. What is the age of the person you care for?

60-64
 65-69
 70-74
 75-79
 80-84
 85 or older

14. For whom are you a caregiver? (check all that apply)

Spouse
 Parent
 Family member (not parent or spouse)
 Friend
 Neighbor
 Other (please specify)

11

15. Is there anyone else who helps care for this person?

Yes
 No
 Not sure

16. How long have you been caring for this person(s)? If you are caring for more than one person, answer for the person you have been caring for the longest.

Less than 6 months
 6 months to 1 year
 1 to 2 years
 3 to 5 years
 5 to 10 years
 More than 10 years

17. What is your current employment status?

Employed part-time
 Employed full-time
 Self employed
 Not employed
 Retired

12

CC Fall 2017 Santa Barbara County Community Caregiving Initiative

Employer benefits

18. Does your employer offer any of the following benefits for caregivers?

| | Yes | No | Not sure |
|------------------------------------|-----------------------|-----------------------|-----------------------|
| Flexible hours | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Paid sick days | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Paid family leave | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Unpaid leave | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Telecommuting | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Employee Assistance Program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Educational program for caregivers | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Other (please specify)

13

CC Fall 2017 Santa Barbara County Community Caregiving Initiative

Employer benefits

19. Which employer benefits do you use?

I use this benefit I do not use this benefit

| | | |
|------------------------------------|-----------------------|-----------------------|
| Flexible work hours | <input type="radio"/> | <input type="radio"/> |
| Paid sick days | <input type="radio"/> | <input type="radio"/> |
| Paid family leave | <input type="radio"/> | <input type="radio"/> |
| Unpaid leave | <input type="radio"/> | <input type="radio"/> |
| Telecommuting | <input type="radio"/> | <input type="radio"/> |
| Employee Assistance Program | <input type="radio"/> | <input type="radio"/> |
| Educational program for caregivers | <input type="radio"/> | <input type="radio"/> |

20. Which employer benefits would you use if they were offered?

I would use if offered I would not use if offered

| | | |
|------------------------------------|-----------------------|-----------------------|
| Flexible work hours | <input type="radio"/> | <input type="radio"/> |
| Paid sick days | <input type="radio"/> | <input type="radio"/> |
| Paid family leave | <input type="radio"/> | <input type="radio"/> |
| Unpaid leave | <input type="radio"/> | <input type="radio"/> |
| Telecommuting | <input type="radio"/> | <input type="radio"/> |
| Employee Assistance Program | <input type="radio"/> | <input type="radio"/> |
| Educational program for caregivers | <input type="radio"/> | <input type="radio"/> |

CC Fall 2017 Santa Barbara County Community Caregiving Initiative

Caring for yourself

21. Below are a number of activities we all do to take care of ourselves. Over the past 6 months, how regularly have you been able to take care of yourself in these ways?

| | Never | Rarely | Sometimes | Often | Always |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Taking care of personal daily activities (drying food, preparing meals, hygiene, laundry) | <input type="radio"/> |
| Attending to your own medical and financial needs | <input type="radio"/> |
| Attending to your own emotional needs | <input type="radio"/> |
| Keeping up with home maintenance (cleaning, house repairs, lawn, etc.). This can be done by you or someone else. | <input type="radio"/> |
| Taking time to relax or have fun with friends or family, at church or community events, or just to treat or reward yourself. | <input type="radio"/> |

22. Below are a number of needs we all have. Over the past 6 months, how regularly has each of these needs been met for you?

| | Never | Rarely | Sometimes | Often | Always |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Eating a well balanced diet | <input type="radio"/> |
| Getting enough sleep | <input type="radio"/> |
| Coping with emotional stress | <input type="radio"/> |
| Receiving appropriate health care | <input type="radio"/> |
| Having adequate shelter | <input type="radio"/> |
| Feeling good about yourself | <input type="radio"/> |
| Feeling secure about your financial future | <input type="radio"/> |

23. Below are several things we all do to take care of ourselves. Over the past 6 months, how regularly have you been able to do the following to care for yourself?

| | Never | Rarely | Sometimes | Often | Always |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Find where to go to get services you need | <input type="radio"/> |
| Make sure you get the services, support and care you need | <input type="radio"/> |
| Be actively involved in decisions about your own care | <input type="radio"/> |
| Cope with challenging situations | <input type="radio"/> |
| Manage stress | <input type="radio"/> |
| Relax | <input type="radio"/> |

CC Fall 2017 Santa Barbara County Community Caregiving Initiative

Providing care

We know that caregivers provide care to a variety of loved ones, family and friends.

As you answer the rest of the questions, please think specifically about the person you provide care to. If you are a caregiver for more than one person, think about the person you provide the most care for.

24. Below are several things caregivers do for the person they care for. Over the past 6 months, have you needed to do the following?

| | No | Yes |
|--|-----------------------|-----------------------|
| Find where to go to get services they need | <input type="radio"/> | <input type="radio"/> |
| Make sure they are getting the services, support and care they need | <input type="radio"/> | <input type="radio"/> |
| Work with their medical providers | <input type="radio"/> | <input type="radio"/> |
| Be actively involved in decisions about their care | <input type="radio"/> | <input type="radio"/> |
| Help them with daily activities (bathing, dressing and grooming) | <input type="radio"/> | <input type="radio"/> |
| Organize their care and appointments | <input type="radio"/> | <input type="radio"/> |
| Manage their medications | <input type="radio"/> | <input type="radio"/> |
| Give them injections | <input type="radio"/> | <input type="radio"/> |
| Care for their wounds | <input type="radio"/> | <input type="radio"/> |
| Manage their use of medical devices | <input type="radio"/> | <input type="radio"/> |
| Help them with other medical procedures | <input type="radio"/> | <input type="radio"/> |
| Determine the best living situation for them that balances both their and your needs | <input type="radio"/> | <input type="radio"/> |

CC Fall 2017 Santa Barbara County Community Caregiving Initiative

Providing care

25. Over the past 6 months, how able were you to do the following for the person you care for?

| | Barely able | To some extent able | Very able |
|--|-----------------------|-----------------------|-----------------------|
| Find where to go to get services they need | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Make sure they are getting the services, support and care they need | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Work with their medical providers | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Be actively involved in decisions about their care | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Help them with daily activities (bathing, dressing and grooming) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Organize their care and appointments | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Manage their medications | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Give them injections | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Care for their wounds | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Manage their use of medical devices | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Help them with other medical procedures | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Determine the best living situation for them that balances both their and your needs | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

26. Over the past 6 months, how often have you felt stressed because of caregiving?

Never
 Rarely
 Sometimes
 Often
 Always

CC Fall 2017 Santa Barbara County Community Caregiving Initiative

Information

27. How much information for caregivers have you received on the following topics?

| | None | Some, but I could use more | As much as I need |
|---|-----------------------|----------------------------|-----------------------|
| Common stressors associated with caregiving | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Why it's important to take care of yourself | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| How to take care of yourself | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| How family dynamics change with caregiving | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Community resources for caregivers | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

28. Have much information have you received about the person you care for on the following topics?

| | None | Some, but I could use more | As much as I need |
|---|-----------------------|----------------------------|-----------------------|
| Information about their specific illness or condition | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Their treatment options | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Their specific care needs | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Community resources available to them | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

CC Fall 2017 Santa Barbara County Community Caregiving Initiative

Services

29. Over the past 6 months, did you or the person you care for need any of the following services?

| | Yes | No | Not sure |
|--|-----------------------|-----------------------|-----------------------|
| In-home health services | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Delivered meals | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Transportation | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Adult day care | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Home modifications (e.g. installing ramps or grab bars) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Respite (e.g. short-term care for your loved one) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Veterans Affairs | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Caregiver skill-building opportunities | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Caregiver navigator (e.g. someone who can help you find information or services) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Caregiver counseling | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Caregiver self-care information | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Caregiver support groups | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

30. Over the past 6 months, were the following services available, and did you or the person you care for use them?

| | Not available that I know of | Available and have used | Available and have <u>not</u> used |
|---|------------------------------|-------------------------|------------------------------------|
| In-home health services | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Delivered meals | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Transportation | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Adult day care | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Home modifications (such as installing ramps or grab bars) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Respite (short-term care for the person you care for) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Veterans Affairs | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Caregiving skill-building opportunities | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Caregiver navigator (someone who can help you find information or services) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Caregiver counseling | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Caregiver self-care information | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Caregiver support groups | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

23

31. Think about organizations that provide information, services, or support to caregivers and those they care for.

Over the past 6 months, about how many organizations did you and the person you care for receive services from?

0
 1
 2
 3
 4
 5
 6-10
 11 or more

24

Fall 2017 Santa Barbara County Community Caregiving Initiative

Helpfulness of individual services

32. Over the past 6 months, how helpful were each of the services received?

| | Not at all helpful | A little helpful | Helpful | Very helpful | Extremely helpful |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| In-home health services | <input type="radio"/> |
| Delivered meals | <input type="radio"/> |
| Transportation | <input type="radio"/> |
| Adult day care | <input type="radio"/> |
| Home modifications (such as installing ramps or grab bars) | <input type="radio"/> |
| Respite (short-term care for the person you care for) | <input type="radio"/> |
| Veterans Affairs | <input type="radio"/> |
| Caregiving skill-building opportunities | <input type="radio"/> |
| Caregiver navigator (someone who can help you find information or services) | <input type="radio"/> |
| Caregiver counseling | <input type="radio"/> |
| Caregiver self-care information | <input type="radio"/> |
| Caregiver support groups | <input type="radio"/> |

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Fall 2017 Santa Barbara County Community Caregiving Initiative

Agency practices

33. Think about the services you and the person you care for received over the past 6 months.

How much do you agree with the following statements?

| | Strongly disagree | Disagree | Agree | Strongly agree | Not applicable |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| I was asked about my needs | <input type="radio"/> |
| I was told about organizations with services that would be helpful | <input type="radio"/> |
| I was referred to other organizations that could provide help | <input type="radio"/> |
| Other organizations were contacted on my behalf | <input type="radio"/> |
| Relevant information was shared with other organizations providing me services | <input type="radio"/> |

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Fall 2017 Santa Barbara County Community Caregiving Initiative

Challenges and acceptability of services

34. Think about your attempts to use services over the past 6 months.

What challenges, if any, did you or the person you care for have using these services? (select all that apply)

Transportation
 Cost
 Inconvenient location
 Was not eligible to receive a service
 Service not covered by insurance
 Unable to schedule an appointment
 Not being sure what services were available
 Unable to leave the person I care for to use the services
 Other (please specify) _____

35. Think about things like your language, cultural background, religion, sexual orientation, and age. With those in mind...

How acceptable were services received over the past 6 months to you and the person you care for?

Not at all acceptable
 Somewhat acceptable
 Mostly acceptable
 Completely acceptable

27

36. Is there anything you want to tell us about your answer to the last question?

28

Fall 2017 Santa Barbara County Community Caregiving Initiative

Helpfulness of services for caregivers

37. Think about all the information and services for caregivers you've received over the past six months.

How helpful were they in improving your...

| | Not at all helpful | A little helpful | Helpful | Very helpful | Extremely helpful |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Understanding the importance of self-care when caregiving | <input type="radio"/> |
| Awareness of community resources for caregivers | <input type="radio"/> |
| Ability to find and use services you need for yourself | <input type="radio"/> |
| Ability to take care of yourself and meet your own needs | <input type="radio"/> |
| Stress associated with caregiving | <input type="radio"/> |
| Personal well-being | <input type="radio"/> |
| Understanding how family dynamics change when caregiving | <input type="radio"/> |

29

Fall 2017 Santa Barbara County Community Caregiving Initiative

Helpfulness of services for care recipients

38. Think about all the information and services the person you care for has received over the past six months.

How helpful were they in improving your...

| | Not at all helpful | A little helpful | Helpful | Very helpful | Extremely helpful |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Awareness of community resources for them | <input type="radio"/> |
| Ability to find and use services they need | <input type="radio"/> |
| Ability to advocate for appropriate care for them | <input type="radio"/> |
| Ability to provide the care they need | <input type="radio"/> |
| Ability to support their well-being | <input type="radio"/> |
| Sense of being a valued part of their health care | <input type="radio"/> |

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Fall 2017 Santa Barbara County Community Caregiving Initiative

Perceptions of caregiving

39. Think about the services you or the person you care for have received over the past 6 months. How much have these service experiences changed your opinions about the following?

| | I agree less | My opinion hasn't changed | I agree more |
|--|-----------------------|---------------------------|-----------------------|
| I take pride in providing care to my loved one | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I think caregivers locally are receiving more recognition for the support they provide | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| There are a range of skill-building opportunities available locally to caregivers | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| In my community there are a range of services available to caregivers | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| The professionals serving the person I care for pay attention to my needs | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I believe caregivers make an important contribution to the overall health care system | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

40. Is there anything else you want to tell us about your experience as a caregiver?

31



Thank you!

41. In appreciation for your participation in this survey, we are offering a \$5 electronic gift card. Please provide your email address if you would like to receive the electronic gift card. Gift cards will be mailed to you within 3 weeks.

42. Which of the following gift cards would you prefer to receive?

- Amazon
- Starbucks

APPENDIX F: PARTNER ORGANIZATION SURVEY

CC Fall 2017 Community Caregiving Initiative of Santa Barbara County
Partner Organization Survey

Welcome

Thank you for taking this Survey for the Community Caregiving Initiative of Santa Barbara County. As you know, the purpose of the Community Caregiving Initiative (CCI) is to establish effective caregiver support systems through the development of cross-sector networks of community organizations, including but not limited to health, social and education sectors.

Your participation in this survey is a meaningful part of improving care for our caregivers. We expect completing this survey will take about 1-2 hours every six months, including the time required to engage with managers and staff about the survey questions.

CC Fall 2017 Community Caregiving Initiative of Santa Barbara County
Partner Organization Survey

Survey purpose

This survey will help us understand how organizations across Santa Barbara County are working together to better support caregivers. Information from this survey will be used to characterize how organizations communicate and collaborate with one another to improve caregiver supports and referrals. It will also collect important information about CCI partners.

We plan to continue collecting this information now, and again every 6 months. This will allow us to characterize and understand how our caregiver service provider network grows and changes over time. The results of this survey will assist in developing a clear picture of our progress toward our goals. This will help us create a reflective practice to help inform the ongoing development of the Community Caregiving Initiative (CCI).

Results from this survey will be shared with grantees, participating organizations, and other key stakeholders in December, 2017. Evaluation Specialists will analyze the responses from the survey and develop a series of graphic "maps". They will then present these "maps," along with other survey findings, to grantees and other key stakeholders and facilitate a process to explore and interpret them to understand the types and levels of systems change that occurred.

CC Fall 2017 Community Caregiving Initiative of Santa Barbara County
Partner Organization Survey

Survey instructions

We ask that each partner organization do the following 3 steps to complete the survey:

Step 1: Identify one person who will be responsible for completing the data collection process and entering the data into Survey Monkey every 6 months.

- This should be an employee involved in direct service for caregivers, who has the ability to gather information from program staff at the organization, and who can engage their colleagues in the process of completing the survey.
- This person should be well informed about the organization's participation in the Santa Barbara Caregiver grants and/or the Community Caregiving Initiative.
- Ideally, for consistency, this will be the same person each time the survey is administered.

Step 2: Convene a small group from your organization to assist in completing the survey.

- This group should include a manager that is familiar with the Community Caregiving Initiative, and staff that are responsible for, or familiar with, providing services to caregivers. The goal is to include staff that can provide an assessment of communication and collaboration between your organization and other organizations that serve caregivers.
- We recommend printing a paper copy of the survey for each member of your small group, and asking them to complete it individually before participating in the group discussion. We have found this ultimately saves time, by allowing you to quickly identify areas of agreement and areas that need to be discussed to determine the best answer for your organization.
- We have provided a discussion guide for you to use if you find it helpful. As you engage in your small group discussion, record your organization's final response to each question. Have a designated person enter the final data for your organization into this survey.

Step 3: Enter the final information collected from your small group into this online survey.

- If you start filling out the survey and find you need to collect more information before finishing, you can return to the survey multiple times and your information will be saved.

CC Fall 2017 Community Caregiving Initiative of Santa Barbara County
Partner Organization Survey

Survey confidentiality

Who will see how your organization answered? Staff at the Santa Barbara Foundation, AARO, and Evaluation Specialists (an independent evaluation firm) will see the data you provide. Findings will be reported in two ways.

Other people will see what you say about your relationships with other agencies. One purpose of the survey is to create "maps" showing how connected organizations are to each other currently. This will help us understand how the caregiver service network can improve, as well as how it changes and grows over time. To do this, the first set of questions ask you to describe how much your organization shares information, communicates, collaborates, and makes referrals to other organizations in Santa Barbara County that serve caregivers. This information will be used to make the network "maps", so how you answer will be apparent to others who see the results.

Nothing else will be reported in a way that others will know what you said. Your responses to the second set of questions will not be reported in a way that others can know how any individual organization answered. Responses to these questions will only be reported in a summary manner.

CC Fall 2017 Community Caregiving Initiative of Santa Barbara County
Partner Organization Survey

Definition of caregiver

There will be many questions about "caregivers" throughout this survey. In all cases, this refers to people whose involvement is determined by a personal relationship rather than because of getting paid.

CC Fall 2017 Community Caregiving Initiative of Santa Barbara County
Partner Organization Survey

Characteristics of your organization

* 1. Which organization are you answering for?

- Adult and Aging Network
- Alzheimer's Association
- Antioch University
- Area Agency on Aging
- Atlas of Caregiving
- Coast Caregiver Resource Center
- Community Action Commission
- Community Partners in Caring
- Cottage Rehabilitation Hospital
- Dick DeWaves Community and Senior Center
- Family Service Agency
- Friendship Center
- Golden Valley Cottage Hospital
- Life Steps Foundation - Santa Maria Wisdom Center
- Lompoc Skilled Nursing & Rehabilitation
- Lompoc Valley Community Healthcare Organization
- Lompoc Valley Medical Center/Lompoc Family Caregiver Support Center
- Marian Regional Medical Center
- Partners in Caring Foundation
- Sansum Clinic
- Santa Barbara Cottage Hospital
- Santa Barbara County Coalition in Support of Promotores de Salud
- Santa Barbara County Adult Protective Services
- Santa Barbara County Public Health Department
- Santa Barbara Parkinson's Foundation
- Valley Haven
- Visiting Nurse & Hospice Care
- Other (please specify)

* 2. Please select one option that best describes your organization, in relation to the Santa Barbara Community Caregiving Initiative (CCI). If you have received direct funding from the Santa Barbara Foundation to work with caregivers, please select "we are a funded CCI grantee" below.

- We are a funded CCI grantee
- We are a funded collaborative partner of a CCI grantee
- We are a non-funded collaborative partner of a CCI grantee
- We are a service provider working with caregivers, but are not affiliated with a CCI grantee
- Other (please specify)

3. Which Santa Barbara Foundation funded project are you involved in? This could include your role as a named grantee, or as a funded or non-funded stakeholder. (check all that apply)

- Encouraging Caregiver Self-identification and Engagement in the Lompoc Valley LVCH
- Integrating the Caregiver as a Medical Team Member: Marian Regional Medical Center
- Broadening Access to Therapy for Caregivers: FSA, Antioch University, and Alzheimer's Association
- Increasing the Effectiveness of Lay Health Workers: Promotores/Santa Barbara Regional Authority and Doorway to Health
- Helping Families of Patients Diagnosed with Alzheimer's: Alzheimer's Association
- Enhancing Care for Medically Fragile and Dementia Patients: Santa Barbara Cottage Hospital and Cottage Rehabilitation Hospital
- Atlas of Caregiving
- Not involved with any of these projects

* 4. What type of organization is this? (check all that apply)

- Non-profit social service provider
- Non-profit health care organization
- Information and referral organization
- Education institution
- Private sector entity
- Government/public sector entity
- Research organization
- Other (please specify)

* 5. Please tell us the names and job titles of all the people in your small group that have contributed to your organization's answers on this survey.

CC Fall 2017 Community Caregiving Initiative of Santa Barbara County Partner Organization Survey

Communication with CCI partners and other organizations serving caregivers

* 6. Below is a list of CCI partners and other organizations that serve caregivers. In the last 6 months, how frequently have you **communicated** with each organization?

Communication can include email, phone calls, instant messaging, meeting together, or any other ways of exchanging information.

| | Never | 1-3 times in the past 6 months | 4-5 times in the past 6 months | About once a month | 2-3 times a month | Weekly or more frequently |
|---|-----------------------|--------------------------------|--------------------------------|-----------------------|-----------------------|---------------------------|
| Adult and Aging Network | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Alzheimer's Association | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Antioch University | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Area Agency on Aging | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Atlas of Caregiving | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Coast Caregiver Resource Center | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Community Action Commission | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Community Partners in Caring | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Cottage Rehabilitation Hospital | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Dick DeWees Community and Senior Center | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Family Service Agency | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Friendship Center | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Goleta Valley Cottage Hospital | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Life Steps Foundation - Santa Maria Wisdom Center | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Lompoc Skilled Nursing & Rehabilitation | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

CC Fall 2017 Community Caregiving Initiative of Santa Barbara County Partner Organization Survey

Referrals made to CCI partners and other organizations that serve caregivers

* 8. In the last 6 months, approximately how many **referrals** have you made to each of these organizations?

| | 0 | 1-3 | 4-6 | 7-9 | 10 or more |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Adult and Aging Network | <input type="radio"/> |
| Alzheimer's Association | <input type="radio"/> |
| Antioch University | <input type="radio"/> |
| Area Agency on Aging | <input type="radio"/> |
| Atlas of Caregiving | <input type="radio"/> |
| Coast Caregiver Resource Center | <input type="radio"/> |
| Community Action Commission | <input type="radio"/> |
| Community Partners in Caring | <input type="radio"/> |
| Cottage Rehabilitation Hospital | <input type="radio"/> |
| Dick DeWees Community and Senior Center | <input type="radio"/> |
| Family Service Agency | <input type="radio"/> |
| Friendship Center | <input type="radio"/> |
| Goleta Valley Cottage Hospital | <input type="radio"/> |
| Life Steps Foundation - Santa Maria Wisdom Center | <input type="radio"/> |
| Lompoc Skilled Nursing & Rehabilitation | <input type="radio"/> |
| Lompoc Valley Community Healthcare Organization | <input type="radio"/> |

CC Fall 2017 Community Caregiving Initiative of Santa Barbara County Partner Organization Survey

Collaboration with CCI partners and other organizations that serve caregivers

* 7. In the last 6 months, how much have you **collaborated** with each organization?

*"Collaborating" means working together to make decisions, set goals, share resources, or work together on projects.

| | Not at all | A little | A moderate amount | A lot |
|---|-----------------------|-----------------------|-----------------------|-----------------------|
| Adult and Aging Network | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Alzheimer's Association | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Antioch University | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Area Agency on Aging | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Atlas of Caregiving | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Coast Caregiver Resource Center | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Community Action Commission | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Community Partners in Caring | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Cottage Rehabilitation Hospital | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Dick DeWees Community and Senior Center | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Family Service Agency | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Friendship Center | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Goleta Valley Cottage Hospital | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Life Steps Foundation - Santa Maria Wisdom Center | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Lompoc Skilled Nursing & Rehabilitation | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Lompoc Valley Community Healthcare Organization | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

CC Fall 2017 Community Caregiving Initiative of Santa Barbara County Partner Organization Survey

Desired communication with CCI partners and other organizations serving caregivers

The questions you have just answered are about your recent interactions with other organizations that serve caregivers. The next questions are different. Now we want you to think about how you would **ideally** like these interactions to be in the future.

* 9. Ideally, how much **communication** with CCI partners and other organizations serving caregivers would you like to have?

| | Less than we have now | About the same amount as we have now | A little more than we have now | A lot more than we have now |
|---|-----------------------|--------------------------------------|--------------------------------|-----------------------------|
| Adult and Aging Network | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Alzheimer's Association | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Antioch University | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Area Agency on Aging | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Atlas of Caregiving | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Coast Caregiver Resource Center | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Community Action Commission | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Community Partners in Caring | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Cottage Rehabilitation Hospital | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Dick DeWees Community and Senior Center | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Family Service Agency | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Friendship Center | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Goleta Valley Cottage Hospital | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

CC Fall 2017 Community Caregiving Initiative of Santa Barbara County Partner Organization Survey

Referrals made to CCI partners and other organizations that serve caregivers

* 8. In the last 6 months, approximately how many **referrals** have you made to each of these organizations?

| | 0 | 1-3 | 4-6 | 7-9 | 10 or more |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Adult and Aging Network | <input type="radio"/> |
| Alzheimer's Association | <input type="radio"/> |
| Antioch University | <input type="radio"/> |
| Area Agency on Aging | <input type="radio"/> |
| Atlas of Caregiving | <input type="radio"/> |
| Coast Caregiver Resource Center | <input type="radio"/> |
| Community Action Commission | <input type="radio"/> |
| Community Partners in Caring | <input type="radio"/> |
| Cottage Rehabilitation Hospital | <input type="radio"/> |
| Dick DeWees Community and Senior Center | <input type="radio"/> |
| Family Service Agency | <input type="radio"/> |
| Friendship Center | <input type="radio"/> |
| Goleta Valley Cottage Hospital | <input type="radio"/> |
| Life Steps Foundation - Santa Maria Wisdom Center | <input type="radio"/> |
| Lompoc Skilled Nursing & Rehabilitation | <input type="radio"/> |
| Lompoc Valley Community Healthcare Organization | <input type="radio"/> |

CC Fall 2017 Community Caregiving Initiative of Santa Barbara County Partner Organization Survey

Desired collaboration with CCI partners and other organizations serving caregivers

* 10. Ideally, how much **collaboration** with CCI partners and other organizations serving caregivers would you like to have?

| | Less than we have now | About the same amount as we have now | A little more than we have now | A lot more than we have now |
|---|-----------------------|--------------------------------------|--------------------------------|-----------------------------|
| Adult and Aging Network | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Alzheimer's Association | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Antioch University | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Area Agency on Aging | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Atlas of Caregiving | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Coast Caregiver Resource Center | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Community Action Commission | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Community Partners in Caring | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Cottage Rehabilitation Hospital | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Dick DeWees Community and Senior Center | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Family Service Agency | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Friendship Center | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Goleta Valley Cottage Hospital | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Life Steps Foundation - Santa Maria Wisdom Center | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Lompoc Skilled Nursing & Rehabilitation | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Lompoc Valley Community Healthcare Organization | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

| | Less than we have now | About the same amount as we have now | A little more than we have now | A lot more than we have now |
|---|-----------------------|--------------------------------------|--------------------------------|-----------------------------|
| Lompoc Valley Medical Center/Lompoc Family Caregiver Support Center | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Marian Regional Medical Center | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Partners in Caring Foundation | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Sansum Clinic | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Santa Barbara Cottage Hospital | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Santa Barbara County Coalition in Support of Promotores de Salud | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Santa Barbara County Adult Protective Services | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Santa Barbara County Public Health Department | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Santa Barbara Parkinson's Foundation | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Valley Haven | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Visiting Nurse & Hospice Care | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| (Insert text from Other) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

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CCI Fall 2017 Community Caregiving Initiative of Santa Barbara County Partner Organization Survey

Desired amount of referrals to CCI partners and other organizations serving caregiver

* 11. Ideally, how many referrals to other CCI partners and other organizations serving caregivers would you like to make?

| | Fewer than we make now | About the same number as we make now | A little more than we make now | A lot more than we make now |
|---|------------------------|--------------------------------------|--------------------------------|-----------------------------|
| Adult and Aging Network | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Alzheimer's Association | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| ArtisD University | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Area Agency on Aging | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Atlas of Caregiving | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Coast Caregiver Resource Center | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Community Action Commission | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Community Partners in Caring | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Cottage Rehabilitation Hospital | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Dick DeWaes Community and Senior Center | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Family Service Agency | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Friendship Center | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Goleta Valley Cottage Hospital | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Life Steps Foundation - Santa Maria Wisdom Center | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Lompoc Skilled Nursing & Rehabilitation | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Lompoc Valley Community Healthcare Organization | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

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| | Fewer than we make now | About the same number as we make now | A little more than we make now | A lot more than we make now |
|---|------------------------|--------------------------------------|--------------------------------|-----------------------------|
| Lompoc Valley Medical Center/Lompoc Family Caregiver Support Center | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Marian Regional Medical Center | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Partners in Caring Foundation | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Sansum Clinic | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Santa Barbara Cottage Hospital | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Santa Barbara County Coalition in Support of Promotores de Salud | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Santa Barbara County Adult Protective Services | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Santa Barbara County Public Health Department | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Santa Barbara Parkinson's Foundation | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Valley Haven | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Visiting Nurse & Hospice Care | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| (Insert text from Other) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

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CCI Fall 2017 Community Caregiving Initiative of Santa Barbara County Partner Organization Survey

Desired amount of referrals from CCI partners and other organizations serving caregivers

* 12. Ideally, how many referrals from CCI partners and other organizations serving caregivers would you like to receive?

| | Fewer than we receive now | About the same as we receive now | A little more than we receive now | A lot more than we receive now |
|--|---------------------------|----------------------------------|-----------------------------------|--------------------------------|
| | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

13. Is there anything you want to tell us about your desired levels of interaction with other agencies?

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CCI Fall 2017 Community Caregiving Initiative of Santa Barbara County Partner Organization Survey

Please share your opinions and experiences

14. Can you please share a story that captures how your organization is making a positive difference in the life of a caregiver or a person they care for?

15. What are some things you notice (including things you've heard, observations, evidence you've seen, or data you collect) that help you know you are making a positive difference in the lives of caregivers or those they care for?

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CCI Fall 2017 Community Caregiving Initiative of Santa Barbara County Partner Organization Survey

About your agency

Your responses to the remainder of the survey questions will be kept confidential. Only summaries of these questions will be reported, and none will be linked to any specific organization.

The remaining questions ask about your organization and the Community Caregiving Initiative in Santa Barbara County.

As a reminder, the term "caregiver" always refers to people whose involvement is determined by a personal relationship rather than because of getting paid.

Please indicate how much you disagree or agree with the following statements.

* 16. Our staff understand that caregivers often need a range of social, medical, legal and financial supports.

Strongly disagree
 Disagree
 Agree
 Strongly agree
 Not applicable

* 17. Our staff work to address a range of caregiver needs, including social, medical, legal and financial supports.

Strongly disagree
 Disagree
 Agree
 Strongly agree
 Not applicable

24

* 18. Our staff view caregivers as integral to decision-making about who they care for.

Strongly disagree
 Disagree
 Agree
 Strongly agree
 Not applicable

* 19. Our staff routinely include caregivers in decision making and care planning, by including them in practices such as completing intake forms and conducting screenings.

Strongly disagree
 Disagree
 Agree
 Strongly agree
 Not applicable

* 20. Our organizational practices increase awareness and appreciation among our clients of the important contributions of caregivers.

Strongly disagree
 Disagree
 Agree
 Strongly agree
 Not applicable

* 21. Our staff are knowledgeable about caregiver services and supports available at other organizations serving caregivers.

Strongly disagree
 Disagree
 Agree
 Strongly agree
 Not applicable

25

* 22. Our staff know the appropriate way to make caregiver referrals to other organizations serving caregivers.

Strongly disagree
 Disagree
 Agree
 Strongly agree
 Not applicable

* 23. Our staff follow-up on caregiver referrals to other organizations to make sure services have been received.

Strongly disagree
 Disagree
 Agree
 Strongly agree
 Not applicable

* 24. Our staff provide caregivers with efficient referrals to other organizations serving caregivers.

Strongly disagree
 Disagree
 Agree
 Strongly agree
 Not applicable

* 25. Our staff provide caregivers with warm referrals to other organizations serving caregivers.

Strongly disagree
 Disagree
 Agree
 Strongly agree
 Not applicable

26

CCI Fall 2017 Community Caregiving Initiative of Santa Barbara County Partner Organization Survey

Working with other organizations

The next set of questions ask about activities in your organization over the past 6 months

When asked about "other organizations", think about organizations in the CCI.

* 26. Our staff worked to make systems for across-organization communication more effective.

No
 Yes
 Not applicable

If you answered "yes", please provide an example of how your staff has done this. If you answered "no", tell more about why not.

* 27. Our staff worked to increase their awareness of new caregiver supports offered by other organizations.

No
 Yes
 Not applicable

If you answered "yes", please provide an example of how your staff has done this. If you answered "no", tell more about why not.

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* 28. Our staff worked to develop inter-agency agreements to encourage communication about caregivers' needs between organizations.

No
 Yes
 Not applicable

If you answered "yes", please provide an example of how your staff has done this. If you answered "no", tell more about why not.

* 29. Our staff participated in relevant, shared training opportunities offered by other organizations.

No
 Yes
 Not applicable

If you answered "yes", please provide an example of how your staff has done this. If you answered "no", tell more about why not.

28

* 30. Our staff supported the development and use of a data management and referral system that shares client data across organizations.

For example, a system that helps with referrals to other agencies ("warm handoffs") and allows tracking of other services clients have received.

No
 Yes
 Not applicable

If you answered "yes", please provide an example of how your staff has done this. If you answered "no", tell more about why not.

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 Fall 2017 Community Caregiving Initiative of Santa Barbara County Partner Organization Survey

Beliefs about CCI

* 31. We believe the CCI, if successful, will help our organization better serve caregivers.

Strongly disagree
 Disagree
 Agree
 Strongly agree
 Not applicable

* 32. We believe the CCI, if successful, will improve the experiences of caregivers in Santa Barbara County.

Strongly disagree
 Disagree
 Agree
 Strongly agree
 Not applicable

* 33. We have actively worked to make the CCI a success, to the extent possible given our available resources.

Strongly disagree
 Disagree
 Agree
 Strongly agree
 Not applicable

30

* 34. We are strongly committed to the success of the CCI.

Strongly disagree
 Disagree
 Agree
 Strongly agree
 Not applicable

31

 Fall 2017 Community Caregiving Initiative of Santa Barbara County Partner Organization Survey

Effects of CCI activities

35. How much do you think the CCI has improved the effectiveness of the following?

| | Not at all | A little | A moderate amount | A lot |
|----------------------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Network communication | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Network collaboration | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Referrals among network partners | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Caregiver supports | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

36. How much do you think the CCI has improved caregivers' ability to:

| | Not at all | A little | A moderate amount | A lot |
|--|-----------------------|-----------------------|-----------------------|-----------------------|
| Receive needed services and support for themselves | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Take care of themselves and their own needs | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Improve their personal well-being | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Navigate the health care system | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Advocate for appropriate care for who they are caring for | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Provide the best possible care for who they are caring for | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Improve the well-being of who they are caring for | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

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 Fall 2017 Community Caregiving Initiative of Santa Barbara County Partner Organization Survey

Additional thoughts

37. Is there anything else you would like to add or share regarding the CCI?

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 Fall 2017 Community Caregiving Initiative of Santa Barbara County Partner Organization Survey

You're Done!

Thank you so much for your participation!

The results from this survey will be shared in December, 2017. We look forward to sharing the results with you then!

38. For your participation, the individual who submits their organization's survey by the deadline will receive a \$25 Starbucks or Amazon gift card.

Please select which gift card you would like to receive.

Starbucks
 Amazon

39. Please enter the email address you would like use to receive the gift card.

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APPENDIX G: FORMATIVE KEY-INFORMANT INTERVIEW QUESTIONS

1. When I think about the CCI broadly, I feel ___ and ____.
2. When I think about my organization's involvement in the CCI, I feel ____ and ____.
3. Can you help me understand why you chose to describe the CCI and your involvement in it that way? Tell me more about why you chose the words you did.
4. What would you say is the purpose of the CCI?
5. We'd like to understand how you define the term "health care system."
6. How aware do you think caregivers are of the role they play in the health care system? Has this awareness changed over the past couple of years? If yes, what do you feel has led to this shift?
7. What barriers do you think caregivers experience when navigating the care system? What mechanisms do you think are in place to help caregivers navigate systems? How could these mechanisms be expanded or improved upon? In what other ways can services and supports for caregivers and their loved ones in SB County be improved to better meet caregivers' needs?
8. In your opinion, what is the role of the CCI in improving services to better meet caregivers' and their loved one's needs?
9. What has/is worked/working well for you and your agency? From your agencies' perspective, what are the benefits of involvement with the CCI?
10. In what ways, if any, has the CCI changed the way you communicate, collaborate and make referrals to other partners and agencies serving caregivers and their loved ones? In your opinion, what is the role of the CCI in helping partners interact (communicate, collaborate and make referrals)? What has the CCI done well that has supported effective interaction?
11. Think about your and your agency's involvement in the CCI. What do you think some of the challenges have been for the CCI?
12. What advice do you have for other communities trying to do work similar to that of the CCI?
13. Tell me about the support you and your agency has received from the SBF. Describe the support for me. What has been helpful? Has any of the support offered failed to be helpful? Tell me a story to help me understand how this support has helped or not been helpful.
14. Have you or your agency received any support, outside of financial support, from the SBF related to the Initiative? Describe the support for me. What has been helpful? Has any of the support offered failed to be helpful? Are there ways in which the SBF could better support you/your agency in its efforts to contribute to the mission of the CCI?
15. What information has been most helpful to you and your agency for program planning and implementation?
16. What information would be most helpful to you for these purposes?
17. What could the CCI do to improve its support of effective interaction among partners?
18. Are there ways in which the CCI could be improved to have greater impact? Tell us about 3 of your top recommendations.
19. Are there ways in which the SBF could better support you/your agency in its efforts to contribute to the mission of the CCI? Tell us about 3 of your top recommendations.

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 involved in developing the rubric and metrics for the work of the CCI was paramount for identifying the desired impact. Deep gratitude goes out to the hundreds of 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 much 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 report successful. A special thank you to staff from the Coast Caregiver Resource Center, Family Service Agency, and Santa Barbara County Coalition of Promotores de Salud who piloted the initial versions of the caregiver survey and assisted in the Spanish translation of the caregiver survey. And, much appreciation goes to Strategic Development Associates, who provided organization, oversight, and thoughtful perspective as the evaluation process unfolded. Finally, the scope of this work owes largely to the investment of AARP and their willingness to learn with the Santa Barbara County Community Caregiving Initiative about how to better serve family caregivers in a local context.

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