Alameda County Care Alliance (ACCA)
Advanced Illness Care Program

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Family Caregiving for People with Cancer and other Serious Illness: A Workshop
May 16-17, 2022

Agenda

- ACCA History
- Program Overview
- Outcomes for Caregivers
- Care Navigator and Caregiver Experiences
- Impact of COVID-19
- Strategies for Community Engagement

Alameda County Care Alliance: Addressing Disparities, Advancing Equity

Faith Community

Health System

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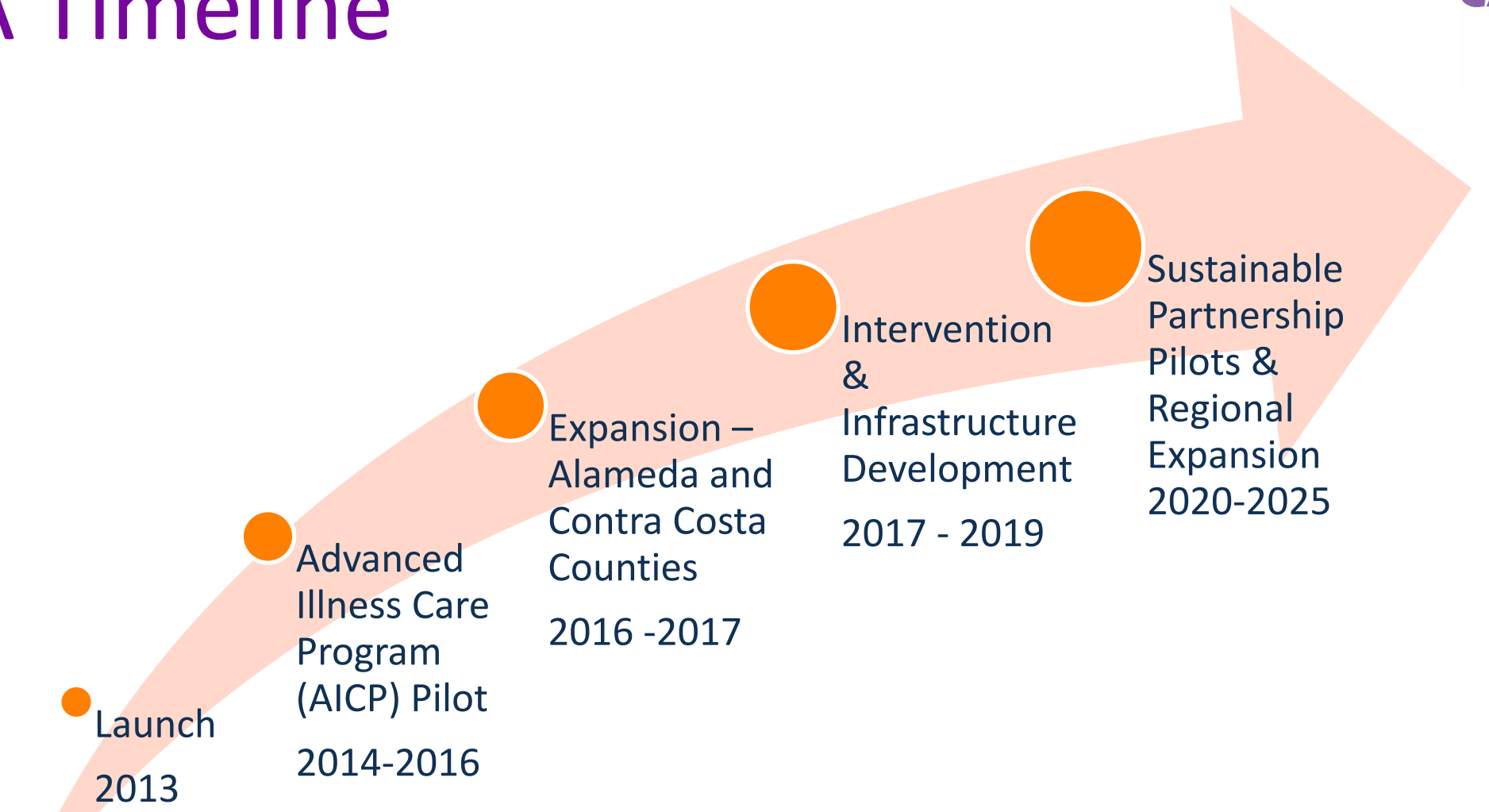
ACCA Timeline



Advanced Illness Care Program (AICP)™ Five Cornerstones

Spiritual Needs

Prayer, meditation, and faith community support

Health Needs

provider communication, physical and emotional support

Advance Care Planning Needs

Understanding, choosing and documenting advance care choices

Social Needs

Transportation, meals, housing, socialization, financial/legal

Caregiving Needs

Respite care, support groups, support for caregivers

- ***5-12 meetings between the Care Navigator and participant (PNC or caregiver) over approximately 6 months***

Participant Snapshot

- ✓ Caregivers are older adults; mean age 65 years (range 21-88)
- ✓ 81% African American
- ✓ 61% have annual household income <$50k; 39% report $50-$100,000
- ✓ Mean medical conditions = 1.5
- ✓ 55% have completed advance directives at the end of the program

Caregiving Cornerstone

- Support for caregivers
- Address caregiving needs of participants with serious illness
- 53% of all visits

Resources

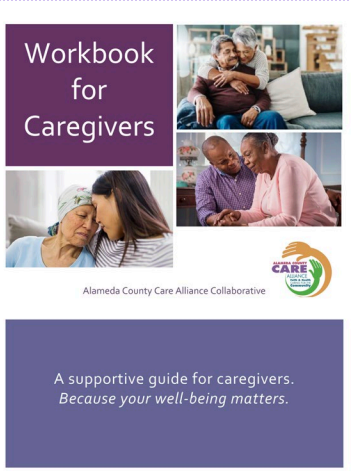
- In Home Support Services (52% of visits); respite (43%); financial assistance applications (16%)
- Mean = 3.5 social referrals

Tools

- Goal setting (100%)
- 8 Ways to Feel Better (63%)

Workbook for Caregivers (44%)

- Improve self-care/well-being
- Identify CR needs
- Identify others in network who can help



"Prior to my mother's death she [care navigator] provided comfort. She gave me phone calls. She followed up. She plugged me in with resources. . . . prepared me emotionally by [describing] me the process that my mother may have to go through and the decisions I might have to make" - Caregiver

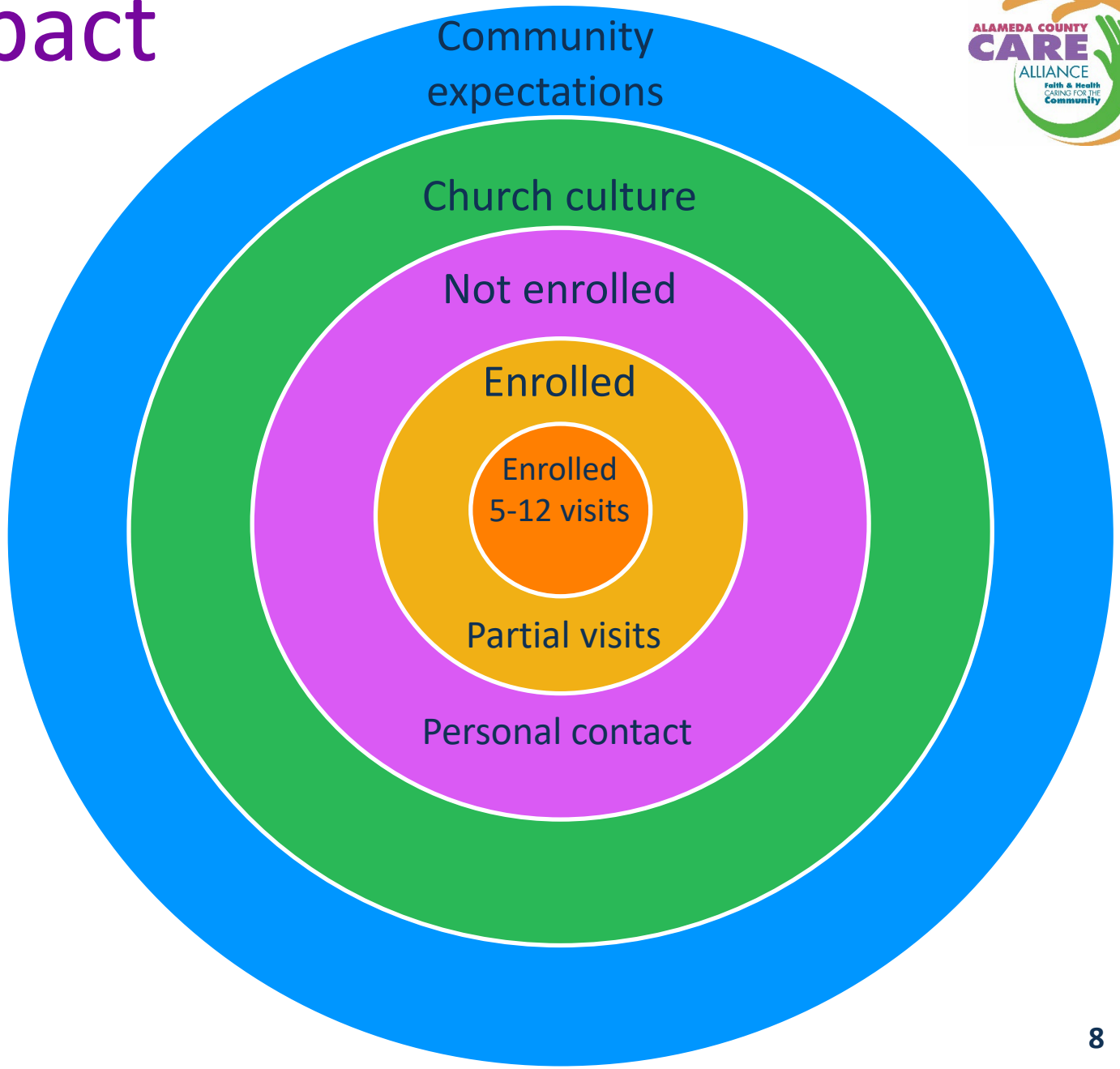
ACCA Program Impact

Since 2016

- > **1,500** participants
- **>16,500** individuals "touched"

2021-2022

- **314** participants
- **2,052** individuals "touched"

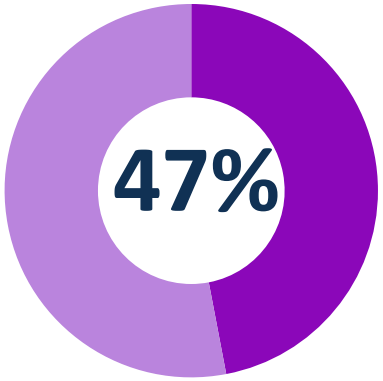


Congregation Assessment Survey

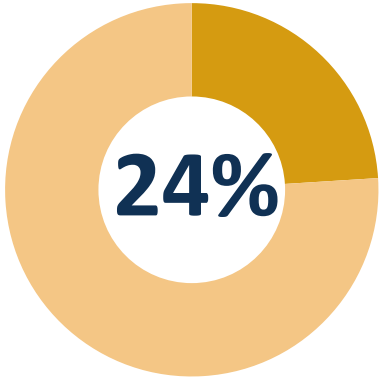
15% caregivers for someone with advanced illness

43% provide care 7 days a week

13% provide care without a break

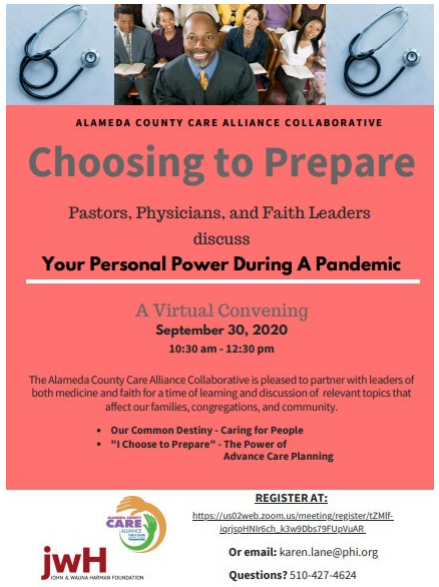


Completed an Advance Directive



Completed a POLST Form

Community Events



- Annual Caregiver Recognition Celebration
- Caregiver Recognition Letters
- I Choose to Prepare
- Choosing to Prepare Pastor Training with Extremis Documentary Discussion Guide
- Pastor Physician Dinners

Care Navigator Experiences

Care Navigator Role

- Meet participants 5-12 times; over ~ 6-months
- Encourage participant story-telling
- Identify participant needs and goals
- Provide trusted referrals/resources
- Relationship building
- Empower participants with tools/training

Care Navigator Surveys

- ✓ “Almost always” or “Always” able to:
  - establish trusting relationships with participants
  - meet participant needs
- ✓ High self-efficacy
- ✓ Low work stress
- ✓ High program satisfaction

Care Navigator Challenges

- ✓ Building trusting relationships with participants care can be difficult
  - More challenging with patients referred by health system and community partners than by churches
- ✓ Some individuals reluctant to sign consent forms

Spiritual Cornerstone as "Bridge to Trusting Relationships"

Care navigators describe spiritual connection with participants as a "bridge" to everything else accomplished in their role including establishing trust, serving, empowering, and offering resources and referrals

Caregiver Experiences

Advance Care Planning: *"(Now) we can go in there and already have a plan. We don't have to wait for the doctor to tell us the plan. . . You don't have to just listen to what the doctor says, you have a say."*

Spiritual Support: *"The Pastor came over at the end and he prayed with her; he prayed with all of us….. You can rely on the Lord for strength because you're going to break. Eventually you're going to break."*

(The program has) been a tremendous blessing . . . to those who are in need."

Health Support/Empowerment: *"My Care Navigator (CN) encourages [my Person needing care (PNC)] to get help from medical sources. My [PNC] doesn't like to go to the doctor, so [CN] is real motivating . . . in getting her to believe or to accept medical help."*

Lessons Learned

- Build **trust** for effective community relationships
  - Be fully present and open; trust is essential
  - Foster two-way dialogue (e.g., pastor-physician dinners)
- Build **long-term partnerships**
  - Strong leadership and champions are needed—from both community and health care system
  - Integration within organizations is key for long-term partnerships

Thank You ACCA Partners!

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