CHAMPIONS IN CARE FORUM

Driving Caregiver Support in Healthcare Delivery

NATIONAL ALLIANCE FOR CAREGIVING

C+TAC
COALITION TO TRANSFORM ADVANCED CARE

About Us

Established in 1996, the National Alliance for Caregiving (NAC) is a system change organization transforming how we value family caregivers through **research**, **advocacy**, and **narrative change**.

Our Network

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Priorities

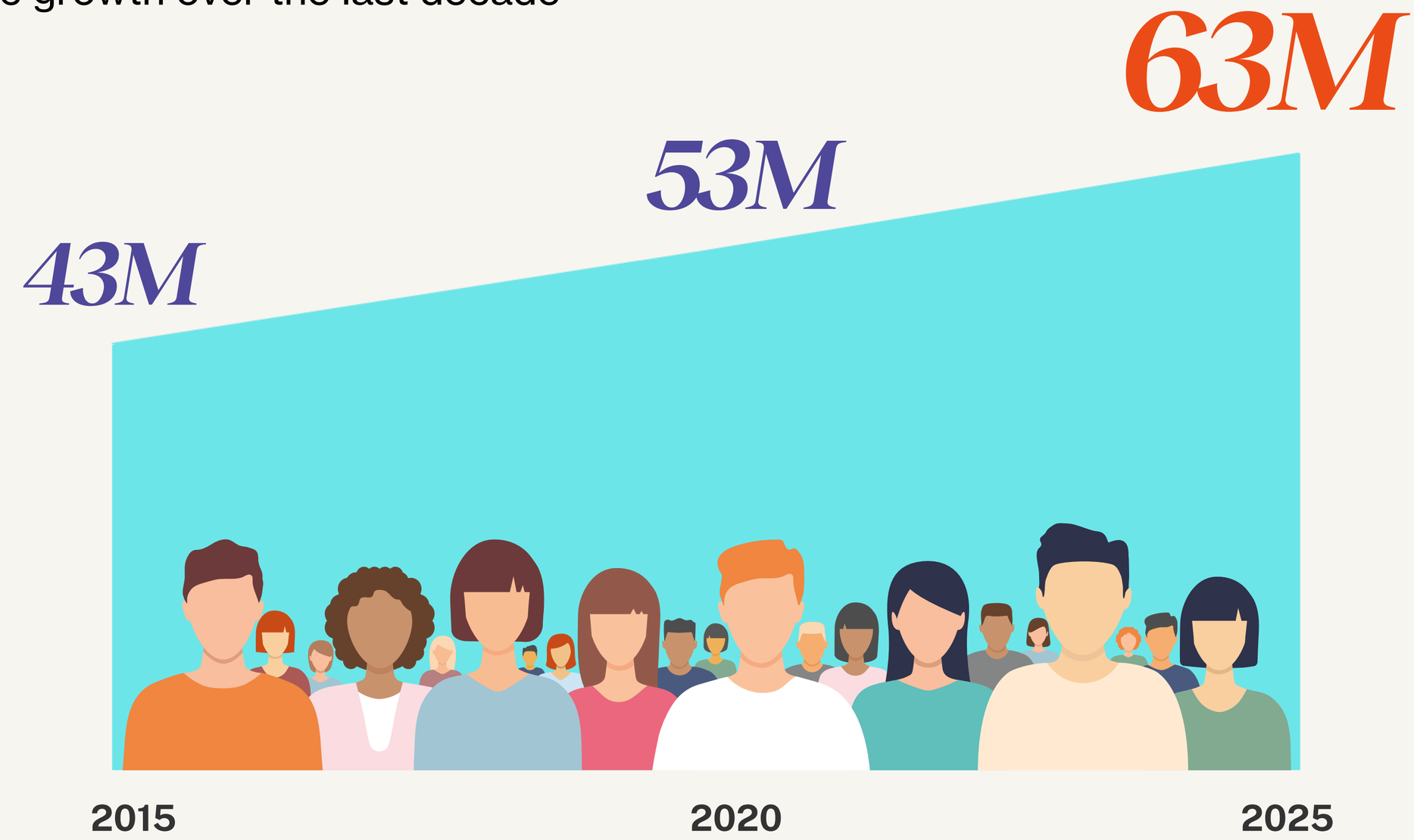
Champion Caregiver Health & Wellness

Drive Economic Inclusion

Foster Caregiver Friendly Communities

Prevalence of Caregiving

Dramatic growth over the last decade



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Cancer

Transplant

Complex Care Collaboratives

Catalyzing cross-sector partnerships to enhance recognition and support for family caregivers in complex care delivery

Systematically translating the lived experiences of family caregivers into practice and policy change

Caregiver Voice

Portraits of Caregiving

Spillover Effects

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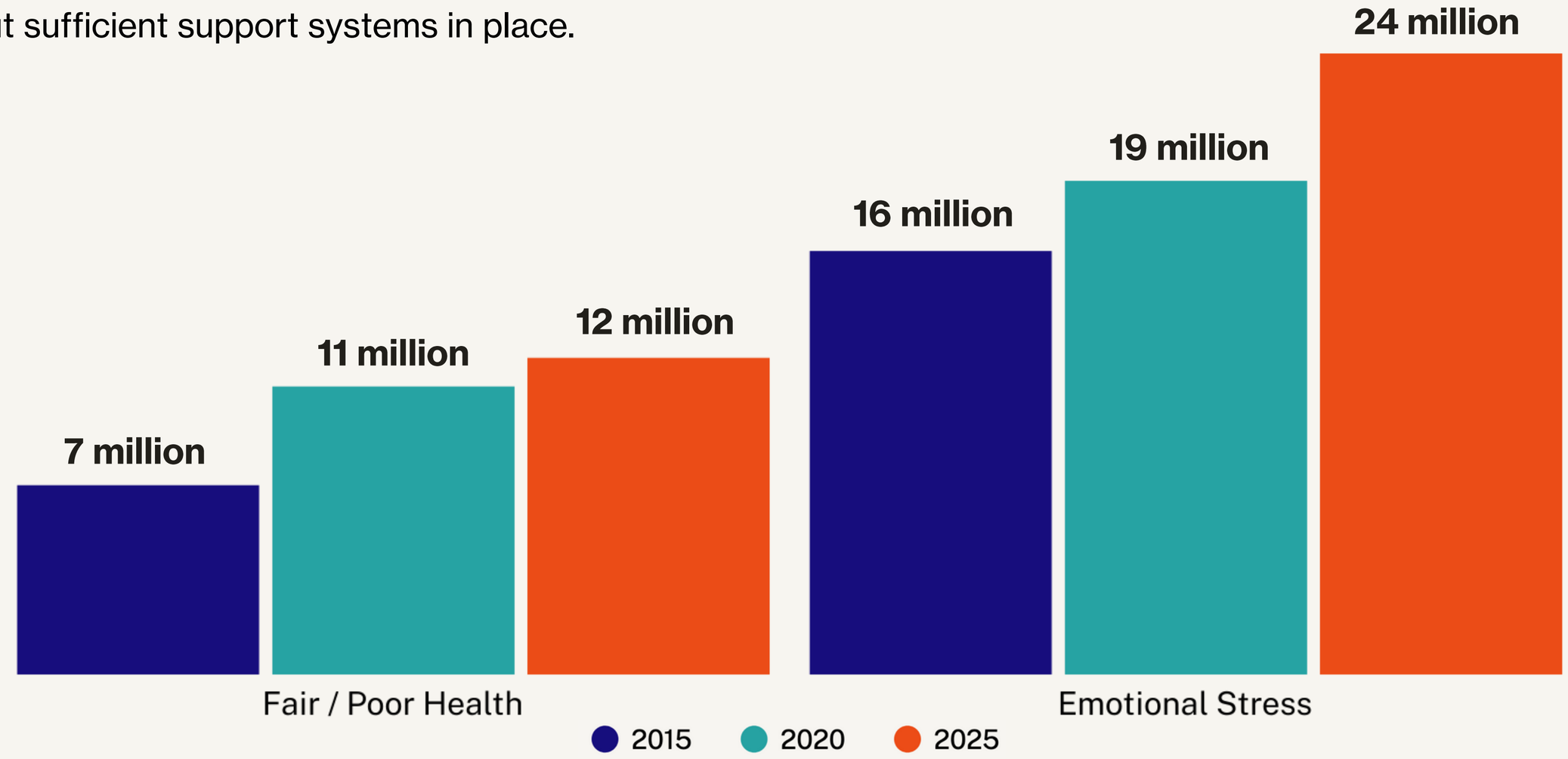
Family Caregiver Health & Wellness

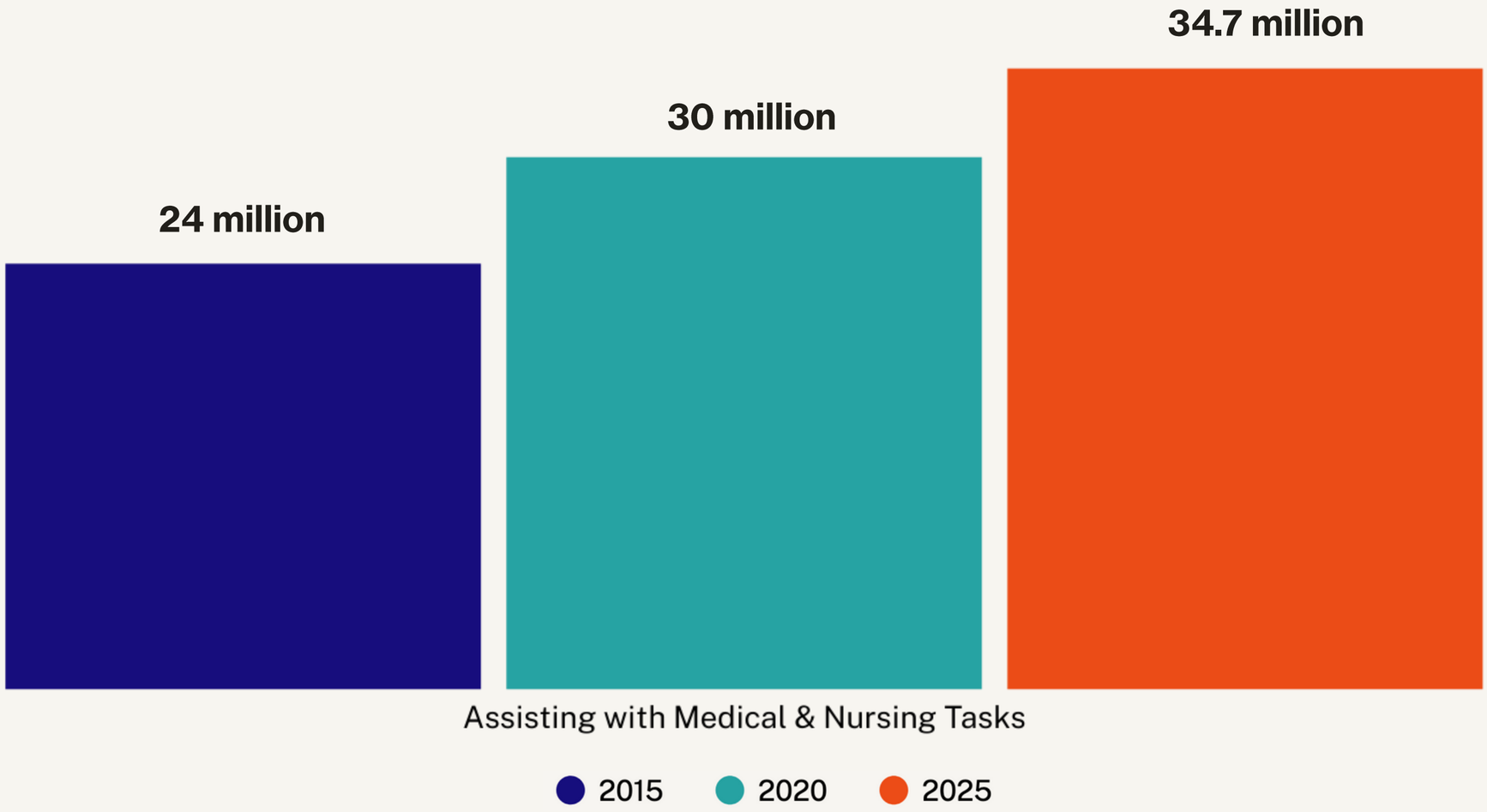
Family caregivers face significant physical and emotional health challenges, often without sufficient support systems in place.



Source: NAC & AARP, Caregiving in the US, 2015-2025

Family Caregivers Navigating Complex Care

More and more, family caregivers are managing intricate medical and nursing responsibilities without adequate training and support.



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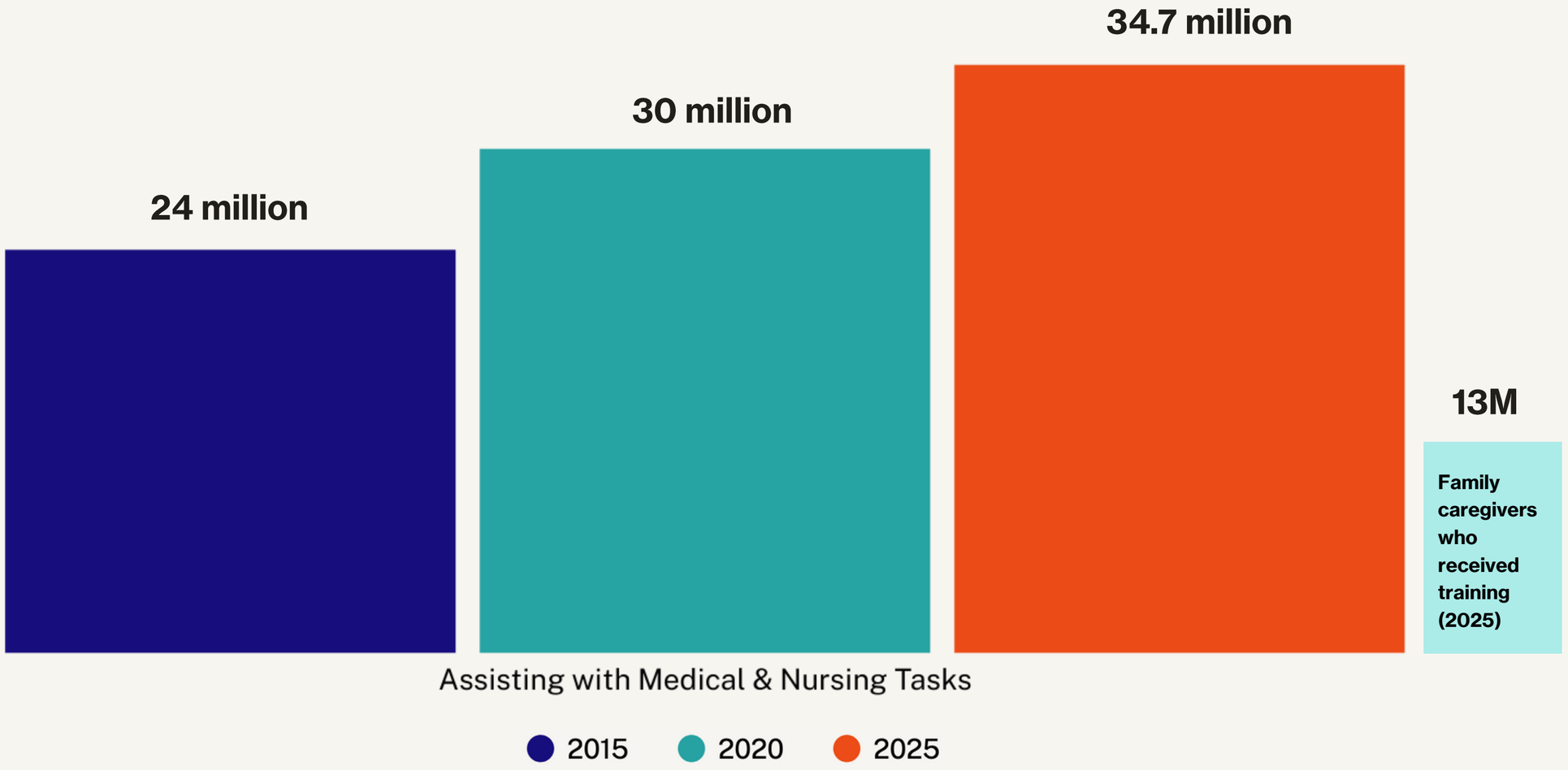


Source: NAC & AARP, Caregiving in the US, 2015-2025

Increasing Trend Towards Home-Based Care

An increasing number of family caregivers will be impacted by market and policy incentives to offer home-based care.

The Washington Post

Bringing hospital care to patients' homes

A movement to tend to sick patients in their own beds and familiar surroundings is growing.

February 25, 2025

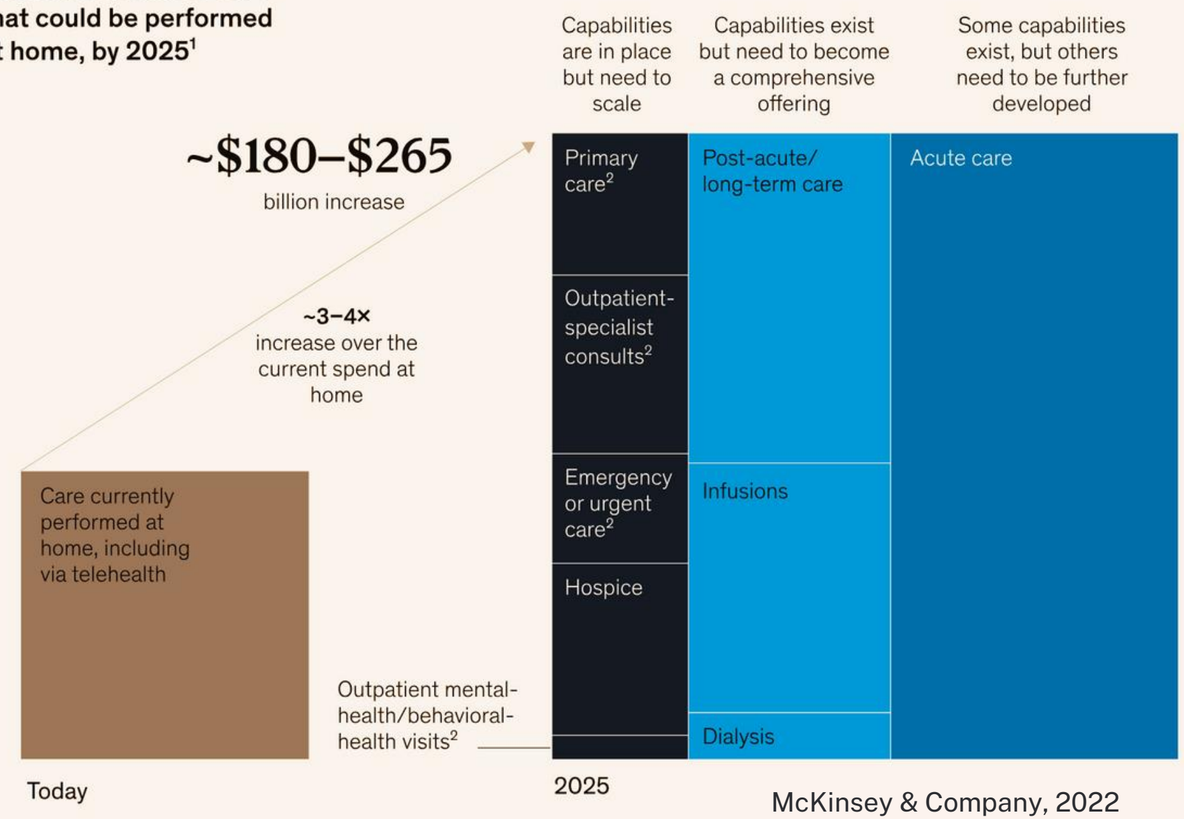
HOME SWEET HOME

Hospital-at-home needs to support family caregivers, advocate says

FOSTER STUBBS

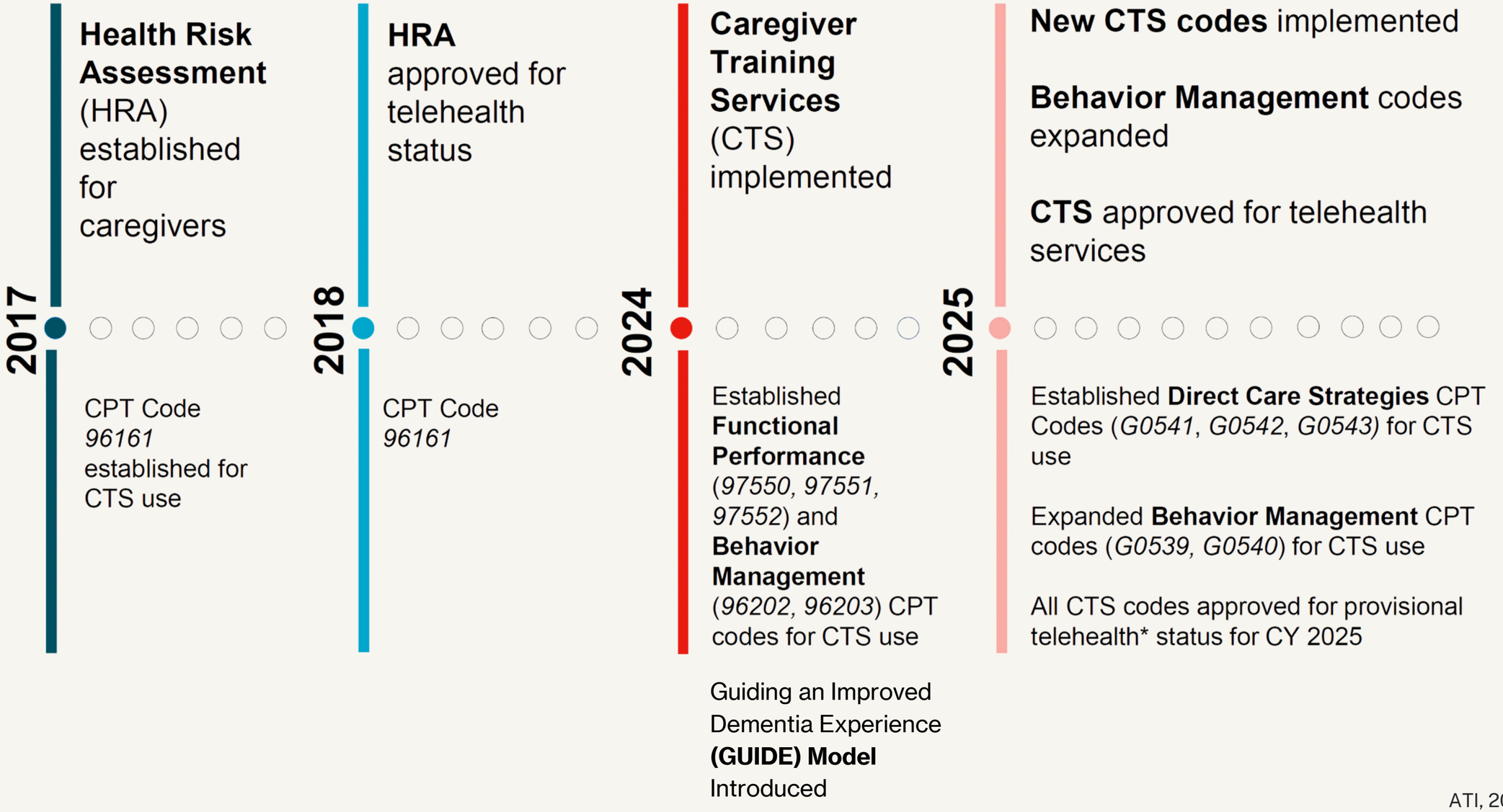
Photo credit: Halfpoint Images/Getty Images

Up to $265 billion worth of care services currently being delivered in clinics, facilities, and physicians' offices could shift to the home by 2025.



McKinsey & Company, 2022

Increasing Regulatory Recognition of Family Caregiver Support



ATI, 2025

"Nothing fulfills our lives more than caring for our loved ones but for us to sustain that care, to keep them out of the hospital system, we need to sustain ourselves."

Parvathy Krishnan
Family Caregiver

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NAC's Transplant Caregiving Collaborative

Melina Pineyro, MPH

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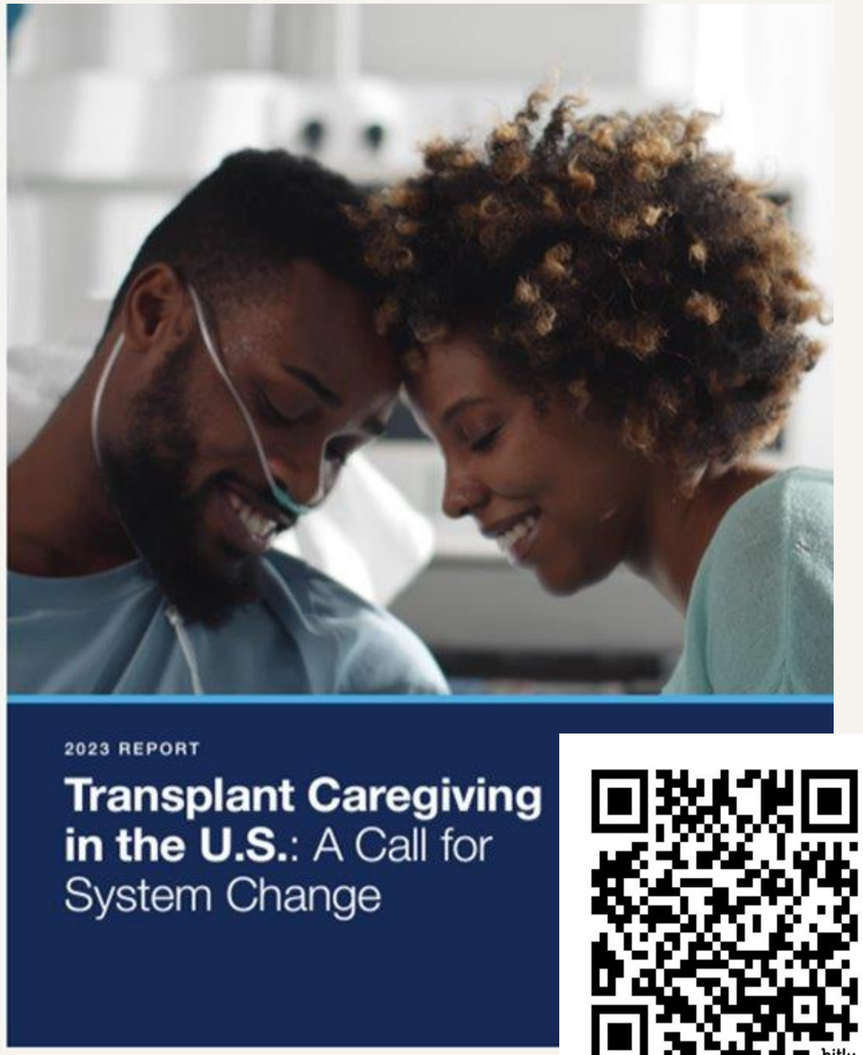
Experiences Of Transplant Caregivers

- Family caregivers **play a vital role** in transplant care referral, evaluation, waitlist, and post-surgery
- **Demanding and stressful role** with high levels of emotional and financial strain
- **Lack of system-wide support** leads to feelings of isolation and overwhelm
- **Unequal burden:** The burden of transplant caregiving is inequitable, with caregivers from socioeconomically disadvantaged and diverse racial and ethnic backgrounds facing exacerbated challenges



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Availability Of Family Caregiver Programs

- **Inadequate Assessment of Caregiver Support Needs**
  - Over 40% of transplant centers lacked written procedures for assessing caregiver support needs or were unaware of such documentation processes.

- **Gaps in Availability and Delivery of Caregiver Support**
  - Most transplant centers offered between 2-4 types of family caregiver programs and 30% reported none.

- **Lack Standardized Practices for Caregiver Education and Training:**
  - 58% of transplant centers offer some form of caregiver-specific education

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THE FAMILY CAREGIVER GAP

Disparities and Missed Opportunities in Support Services Across U.S. Transplant Centers

DOWNLOAD REPORT

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Delivery of Caregiver Support Programs

- **Heavy reliance on referrals:**
  - Critical services are frequently outsourced
    - Financial counseling: 66-70% referred
    - Distress screening: 52-70% referred
    - Medical education: 57-70% referred

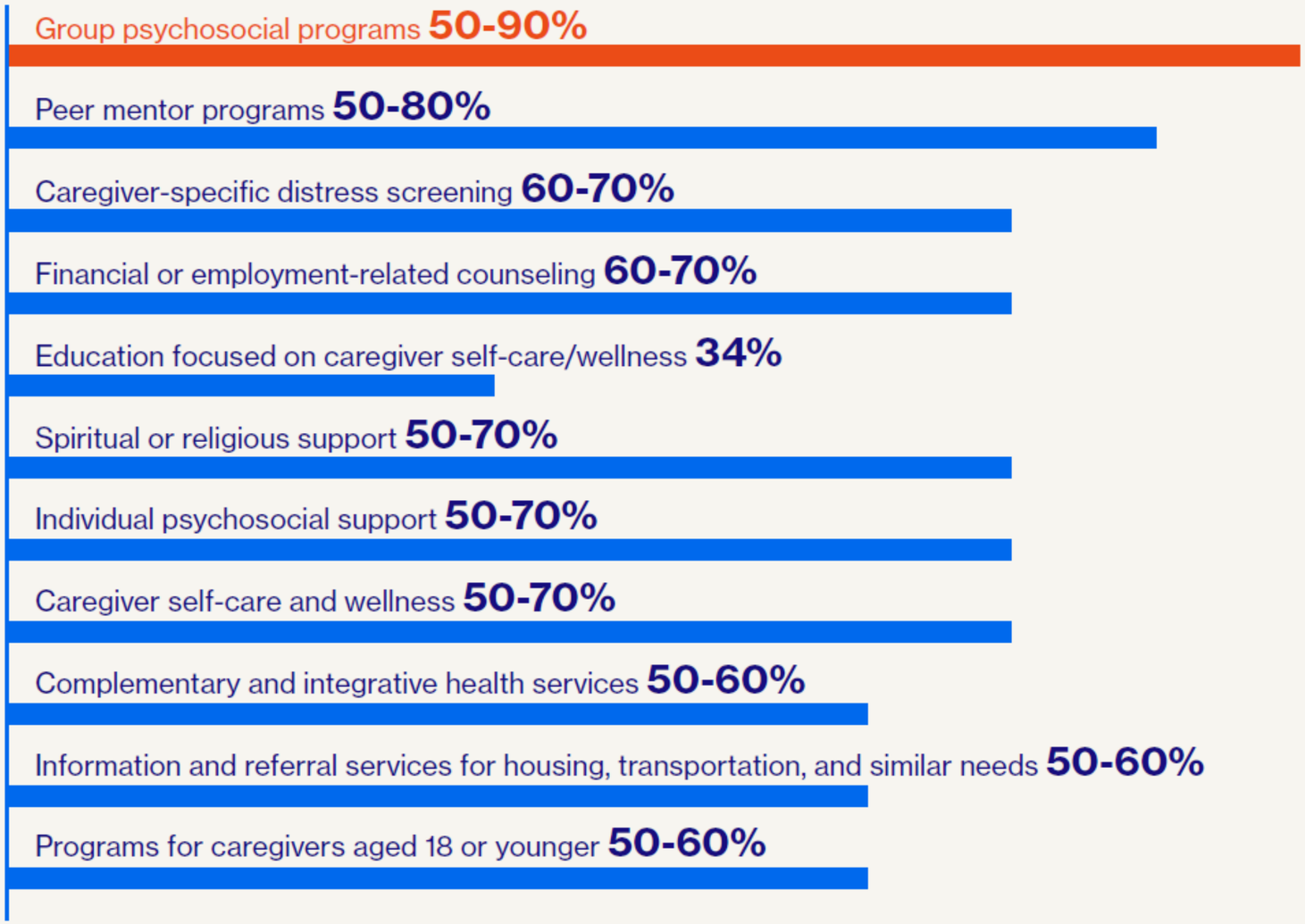
- **"All or nothing" access patterns:**
  - Significant disparities exist between centers, with some caregivers receiving comprehensive support while others have limited or no access to services.

TABLE 2. PROGRAM DELIVERY MODE

Program	Onsite		Referred within the system		Referred to a third party	
Group Psychosocial	31	(56%)	31	(56%)	33	(60%)
Individual Psychosocial	27	(54%)	39	(78%)	36	(72%)
Integrative Health	17	(34%)	38	(76%)	35	(70%)
Spiritual/Religious Support	22	(46%)	36	(75%)	34	(71%)
Peer Mentor	22	(45%)	29	(59%)	33	(67%)
Self-Care/Wellness Education	19	(40%)	37	(77%)	37	(77%)
Training or Education: Medical/ Nursing	22	(48%)	26	(57%)	32	(70%)
Distress Screening	19	(41%)	24	(52%)	32	(70%)
Financial or Employment-related Counseling	20	(45%)	31	(70%)	29	(66%)
Information/Referral Services	18	(45%)	28	(70%)	29	(73%)
Youth Caregiver Programs	8	(32%)	21	(84%)	18	(72%)

Utilization of Caregiver Support Programs

FIGURE 2. CAREGIVER SUPPORT SERVICE UTILIZATION



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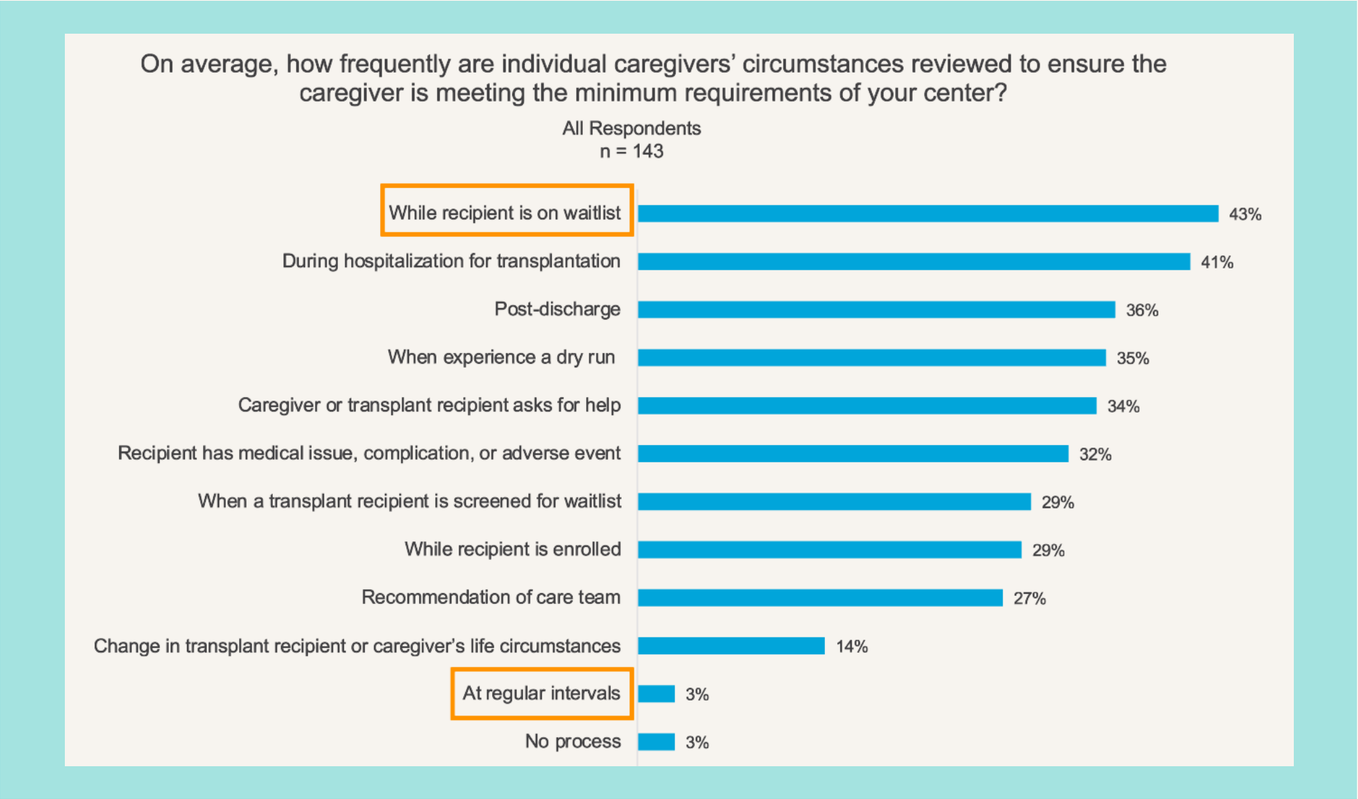
Drivers of Caregiver Support Programs

- **Reactive, not proactive approach:**
  - Only 3% of centers conduct regular reviews of family caregiver support needs, with most assessments triggered by specific milestones
    - Waitlist: 49%
    - Dry Run: 43%
    - Crisis: 38%
- **Self-advocacy drives support access:**
  - The most utilized services (peer mentoring, psychosocial support) are primarily accessed when family caregivers ask for help themselves (47-57% of centers), placing the burden on already stressed caregivers.



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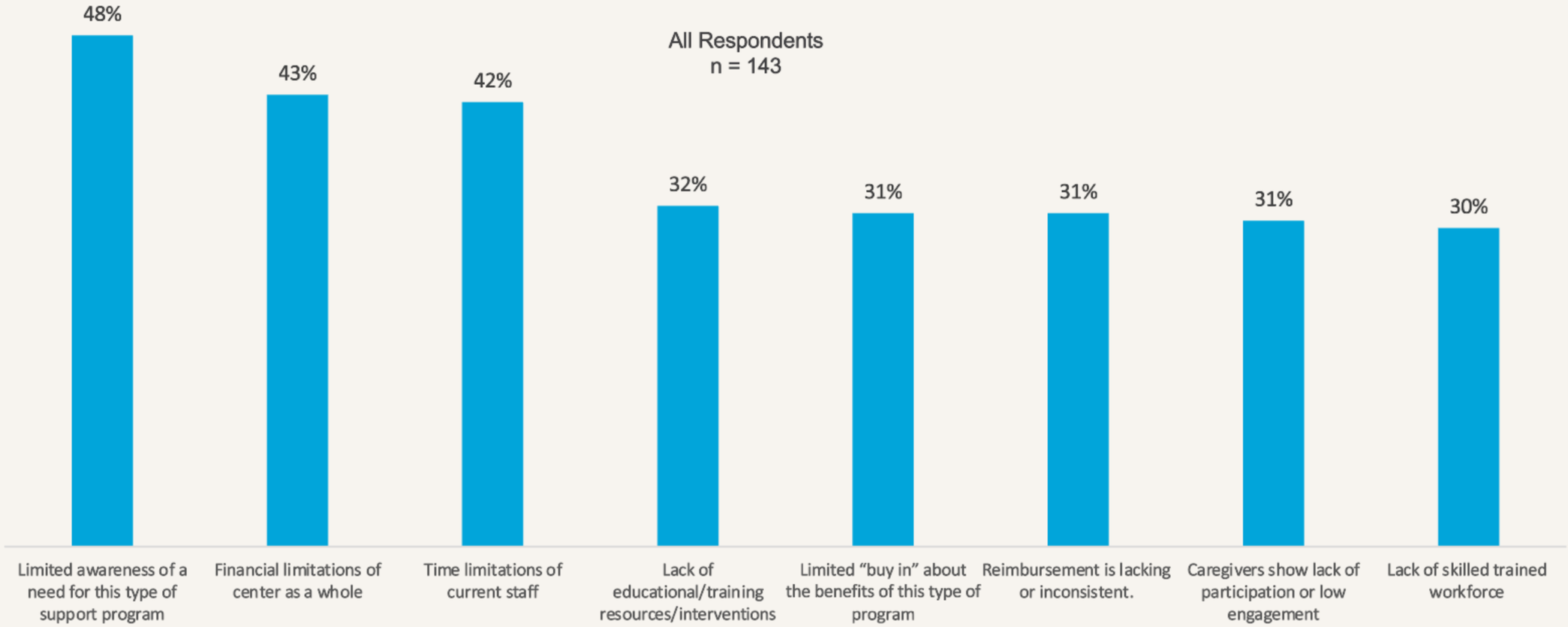
Barriers to Caregiver Support Programs



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Disparities and Gaps in Caregiver Support Programs

Racial disparities in service availability:

- Centers serving mostly Black/African American populations offer significantly fewer support programs across all categories
  - 21-28% compared to ~33% at centers overall.

Income disparities:

- Centers serving exclusively low-income populations are least likely to offer financial counseling
  - 22% vs. 31% overall

Youth caregivers overlooked:

- Only 18% of centers offer youth-specific programs
- 11% at centers serving low-income populations

"The hardest part for me is that you really do become a (nurse) tech in a way. He had a port, and I had to deal with the dosage of the medication, and it was not easy."

Nancy, Stem Cell Transplant Caregiver

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Not Just Visitors:
Integrating Caregivers in Care Delivery and Design

C+TAC

decipher
HEALTH STRATEGIES

Coalition to Transform Advanced Care (C-TAC)

The Coalition to Transform Advanced Care (C-TAC) is a national, bipartisan alliance of 200+ organizations working to improve care for people with serious illness and their families. C-TAC partners across health systems, policy, and communities to advance person-centered care through advocacy, delivery reform, public engagement, and collaboration. Its initiatives integrate family caregivers, promote culturally appropriate care, and support innovation to improve quality of life.

Decipher Health Strategies

Decipher Health Strategies is a healthcare advisory firm specializing in policy analysis, strategic planning, and payment and provider delivery transformation. With experience in government, non-profits, and provider organizations, Decipher Health helps clients like C-TAC turn complex challenges into clear priorities and actionable goals. The team partners with organizations to deliver measurable results that strengthen performance and create lasting impact.

Forthcoming Report:

Not Just Visitors:
Integrating Family Caregivers in Care Delivery and Design

C-TAC and NAC are grateful for the support of the Elea Institute to prepare this report.

Healthcare Payment and Model Structures

Fee-for-Service (FFS)

Transactional health care payments

- Medicare Physician Fee Schedule
- Part B Coding

FFS: Specialty Care Models

Sub-populations or those with a specific clinical experience; may be exclusively focused on populations with serious illness

- Kidney Care Choices
- Oncology Care Model
- Transforming Episode Accountability Model (TEAM)

FFS: Accountable Care Organizations

Relatively broad population, sub-populations with serious illness care needs

- Medicare Shared Savings Program
- ACO REACH

Medicare Advantage

Plan based approach

- Special Supplemental Benefits for the Chronically Ill (SSBCI)

Incorporating Caregivers Into Models

Identification

Skill Building

Program Design

Quality

Example: Kidney Care Choices (KCC)

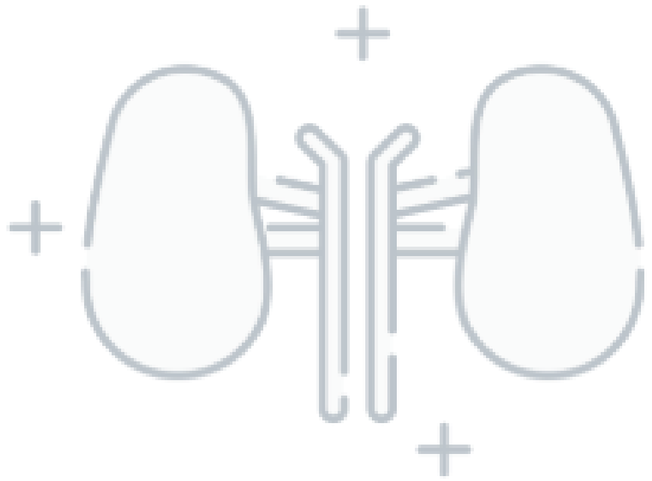
What: CMS Innovation Model for Medicare Fee-for-Service patients with late-stage CKD (4–5) and ESRD

Who: Nephrology practices, transplant providers, dialysis facilities, and Kidney Contracting Entities (KCEs) with care teams of physicians, nurses, dietitians, social workers, and coordinators

Focus: Delay dialysis, boost transplants, promote home dialysis, and improve care coordination

Payment: Adjusted FFS plus incentives tied to quality, cost savings, and transplant rates

Timeline: Launched 2022, runs through 2026



Example: KCC Design Related to Caregivers

Design Feature	KCC Approach	Considerations
 Identification	Entities required to share a plan for engaging caregivers in application, but no other explicit requirements for identifying family caregivers in the model.	Require structured care planning that includes caregiving.
 Skill Building	Entities required to specify decision support tools that caregivers could use, but no other specified training programs identified.	Incorporate structured education and support for caregivers.
 Program Design	Applicants required to outline a plan for open communication with caregivers in application, but no additional direction on how they should be included.	Similar to GUIDE, identify dyads (beneficiary and caregiver) and assign them to supports, make respite services available. Include reimbursable caregiver training as a core benefit and support non-monetary incentives for caregivers.
 Quality	Metrics are focused on provider performance and patient outcomes; no measures related to caregiver burden or engagement.	Assess impact of caregiver support and engagement on KCC beneficiary outcomes.

Beyond the Patient: Centering Caregivers in Transplant System Reform

Yadira Montoya, MSPH

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Understanding the OPTN Modernization Initiative

- **Ongoing legislative and executive effort to improve the organ transplant system in the U.S**
  - OPTN was created in 1984, modified by legislation in 2023, and continues to evolve
  - Major issues include modernizing IT infrastructure, improving competition among OPTN contractors, reducing conflicts of interest in leadership, and addressing patient concerns about safety, waste, and delays

- **Modernization initiatives are happening against the background of heated national conversations about issues with the organ transplant system**
  - Lack of communication and transparency to patients and families
  - Conflicts of interest
  - Lost organs in transit, wasted organ donors

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Challenges and Needs Reported to OPTN by Patients & Families

Education

- Comprehensive education on transplantation, centralized support resources, and standardized communication for patients and their caregivers

Transparency

- Lack of transparent communication from transplant centers about the eligibility criteria, evaluation process, and inactive waitlisting
- Lack of communication of the impact of modernization on the transplant system

Financial Support

- Need for financial support, including assistance with government aid and support for non-medical expenses
- Assessing impact of financial considerations on decision-making

Mental Health Support

- Mental health support necessary throughout the transplant journey, addressing depression, guilt, anxiety, and emotional challenges

Post-Transplant Coordination

- Feeling surprised by recovery challenges
- Diverse experiences with post-transplant complications, noting the importance of ongoing care and communication with the transplant team

Organ Offer Process

- Feeling unprepared for the organ offer process, particularly understanding if the organ was a good choice for them
- Lack of understanding to on making an acceptance

Patient Advocacy

- Patient self-advocacy for a positive transplant experience (without their self-advocacy for evaluations, decision-making, self-education, and push for center support, many noted they would not have received a transplant)

Support System

- Pivotal role of support systems and navigators in the transplant journey

Source: Dr. Suma Nair, HRSA, Champions in Care: Uplifting Caregivers in Transplant Care

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NAC: Six Priority Areas for OPTN Modernization

NAC Recommendation	Alignment to OPTN National Dialogue
Implement a standardized screening process during the transplant waitlist/referral period to reduce bias and health inequities and to identify caregivers who need additional support at the onset of transplant care.	• Improve patient and family communication regarding waitlists, decisions, and availability • Improve evaluation process to determine eligibility for organ donation to include caregivers, including potentially creating new CPT codes (such as a CPT code for initial evaluation for kidney transplant, etc.)
Standardize processes to collect and store caregiver data across transplant centers to assess and document caregiver needs, which can improve care coordination, continuity of care, and inform outcomes-based caregiver research.	• Improve and invest in IT infrastructure for modernizing organ donation systems • Identify the caregiver within the medical record and offer training as needed to support post-transplant care
Integrate dedicated caregiver coordinators within transplant teams to identify, address, and support caregivers and their needs along the transplant journey.	• Ensure communications are transparent about the challenges facing transplant patients • Reassure donor families that organ donors will be treated with respect and dignity

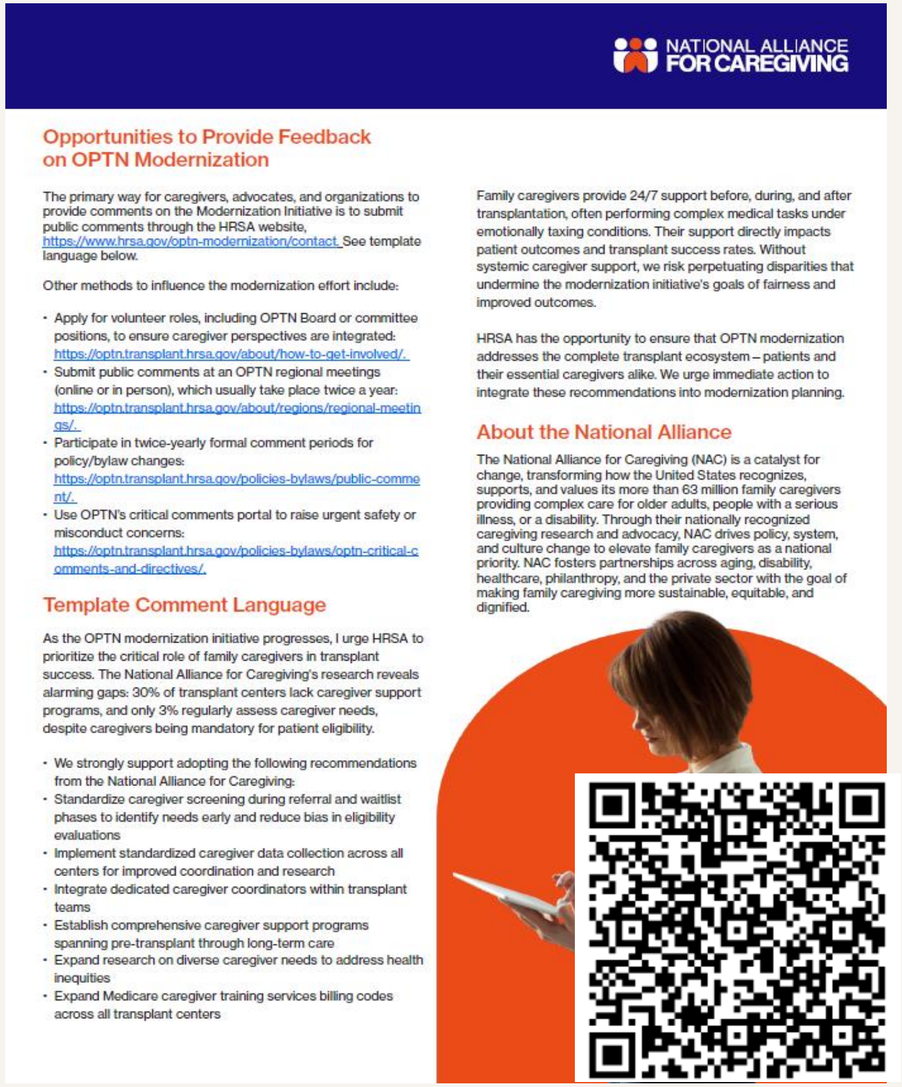
NAC: Six Priority Areas for OPTN Modernization

NAC Recommendation	Alignment to OPTN National Dialogue
Implement comprehensive, standardized caregiver support programs at transplant centers that are targeted, consistent, evidence-based, and provided continuously throughout the entire transplant journey – from pre-transplant evaluation through long-term post-transplant care – to ensure equitable and effective support for all caregivers.	• Improve data collection and quality metrics for organ transplant centers • Report quality data through existing government programs like Medicare, Medicaid and other providers
Conduct additional evidence-based research focusing on the diverse needs of transplant caregivers from various demographic and socioeconomic backgrounds to address existing health inequities in the transplant system.	• *Out of scope for the OPTN Modernization Initiative*
Promote the wide adoption of new Medicare Caregiver Training Services (CTS) billing codes across all types of transplant centers to enhance access to essential training and support services for family caregivers.	• Encourage alignment across agencies, including with the Medicare CTS codes and the RAISE Council

Support Family Caregivers: Get Involved in OPTN Modernization

- **Advocate for family caregivers:** Join NAC in raising awareness about the role and contributions of family caregivers in transplant care

- **Contribute your perspective:** Submit your public comment on the Modernization Initiative
  - HRSA's Contact Form: **https://www.hrsa.gov/optn-modernization/contact**
  - **Need a starting point.** Sample template comment language



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Opportunities to Provide Feedback on OPTN Modernization

The primary way for caregivers, advocates, and organizations to provide comments on the Modernization Initiative is to submit public comments through the HRSA website, https://www.hrsa.gov/optn-modernization/contact. See template language below.

Other methods to influence the modernization effort include:

- Apply for volunteer roles, including OPTN Board or committee positions, to ensure caregiver perspectives are integrated: https://optn.transplant.hrsa.gov/about/how-to-get-involved/.
- Submit public comments at an OPTN regional meetings (online or in person), which usually take place twice a year: https://optn.transplant.hrsa.gov/about/regions/regional-meetings/.
- Participate in twice-yearly formal comment periods for policy/bylaw changes: https://optn.transplant.hrsa.gov/policies-bylaws/public-comment/.
- Use OPTN's critical comments portal to raise urgent safety or misconduct concerns: https://optn.transplant.hrsa.gov/policies-bylaws/optn-critical-comments-and-directives/.

Template Comment Language

As the OPTN modernization initiative progresses, I urge HRSA to prioritize the critical role of family caregivers in transplant success. The National Alliance for Caregiving's research reveals alarming gaps: 30% of transplant centers lack caregiver support programs, and only 3% regularly assess caregiver needs, despite caregivers being mandatory for patient eligibility.

- We strongly support adopting the following recommendations from the National Alliance for Caregiving:
- Standardize caregiver screening during referral and waitlist phases to identify needs early and reduce bias in eligibility evaluations
- Implement standardized caregiver data collection across all centers for improved coordination and research
- Integrate dedicated caregiver coordinators within transplant teams
- Establish comprehensive caregiver support programs spanning pre-transplant through long-term care
- Expand research on diverse caregiver needs to address health inequities
- Expand Medicare caregiver training services billing codes across all transplant centers

Family caregivers provide 24/7 support before, during, and after transplantation, often performing complex medical tasks under emotionally taxing conditions. Their support directly impacts patient outcomes and transplant success rates. Without systemic caregiver support, we risk perpetuating disparities that undermine the modernization initiative's goals of fairness and improved outcomes.

HRSA has the opportunity to ensure that OPTN modernization addresses the complete transplant ecosystem – patients and their essential caregivers alike. We urge immediate action to integrate these recommendations into modernization planning.

About the National Alliance

The National Alliance for Caregiving (NAC) is a catalyst for change, transforming how the United States recognizes, supports, and values its more than 63 million family caregivers providing complex care for older adults, people with a serious illness, or a disability. Through their nationally recognized caregiving research and advocacy, NAC drives policy, system, and culture change to elevate family caregivers as a national priority. NAC fosters partnerships across aging, disability, healthcare, philanthropy, and the private sector with the goal of making family caregiving more sustainable, equitable, and dignified.

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Transplant Caregiving Collaborative Sponsors

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