

# THE POWER OF **PEER SUPPORT**

## FOR OLDER ADULTS AND THEIR CAREGIVERS

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**SDSU**

College of Health and Human Services  
Social Policy Institute



## Background

The SDSU Social Policy Institute (SPI) was instrumental in the creation of the Center for Excellence in Aging & Longevity (CEAL). As an integral part of SDSU's College of Health and Human Services, CEAL is at the forefront of initiatives to tackle the present and emerging challenges of healthy aging throughout the lifespan.

SPI is a non-profit affiliate of the School of Social Work at San Diego State University. SPI strives to be a dynamic catalyst for improving the community's well-being by bridging academia and community knowledge through training, technical assistance, program design, research, advocacy, and collaboration.

Together, SPI and CEAL are pioneering efforts to address the complex issues surrounding healthy aging across the lifespan. By leveraging their expertise in social policy and aging research, SPI and CEAL are actively engaged in developing innovative solutions to promote the well-being and quality of life for older adults. Through their collaborative efforts, they are advancing knowledge, informing policy, and implementing programs that aim to enhance the aging experience for individuals and communities alike.

Their partnership exemplifies the power of interdisciplinary collaboration in addressing pressing social challenges and underscores the importance of integrating research, education, and practice to create meaningful impact.

# Introduction

In May 2023, the San Diego State University Center for Excellence in Aging & Longevity (CEAL) launched the San Diego Caregiver Connections (SDCC) initiative to strengthen, diversify, and expand caregivers. This comprehensive program is focused on enhancing the lives of caregivers by increasing knowledge and skills for both paid and family caregivers. This initiative offers a wide range of resources, including over 80 hours of training (at no cost to the participant), peer support, and opportunities for career advancement.

SDCC is an innovative, cost-effective model, grounded in a commitment to inclusivity by actively reaching out to diverse, low-income, multilingual, and under-resourced communities. Caregivers often encounter various challenges, such as limited access to training resources, language options, technology, soft skills, and educational opportunities. However, one of the most significant obstacles they face is the absence of a robust network of peers who share similar experience. This network is vital for providing emotional support, valuable advice based on lessons learned, problem-solving skills, and access to essential resources.

*The peer support group is my safe place to vent, cry, and genuinely create bonds with people who truly get what I'm going through. I'm not alone and it's been a lifeline.*

**-Martha R., 44 year old caregiver**

# The Impact

As the U.S. Census projects a doubling of the older adult population to 80 million by the year 2040, the demand for unpaid family caregiving intensifies, with over 41 million Americans providing support to adults over the age of 50.<sup>1,2</sup> Unpaid caregivers make a significant contribution, delivering 36 billion hours of care per year to older adults in the United States, worth an estimated value of \$600 billion.<sup>3</sup> Among these caregivers, a substantial 75% are women who dedicate an average of nearly 40 hours per week to provide essential care to aging family members in need.<sup>4</sup> It's noteworthy that a significant portion of these caregivers are simultaneously employed and/or engaged in the responsibilities of raising children. An astonishing 61% of family caregivers navigate the balance between employment and caregiving responsibilities.<sup>2</sup> These statistics underscore the multifaceted roles and stressors that caregivers face.

Research indicates there are disparities in the rates of disability and the need for care across different racial and ethnic groups. Studies have shown that Blacks and Hispanics, on average, experience higher rates of disabilities that may require assistance compared to Whites.<sup>5</sup> Several factors contribute to these disparities, including social determinants of health, access to healthcare, socioeconomic status, and systemic inequalities. It is important to consider the intersectionality of race, ethnicity, and other social factors when examining disparities in caregiving.

[1] U.S. Census Bureau, Population Division. "Annual Estimates of the Resident Population for the United States, Regions, States, District of Columbia, and Puerto Rico: April 1, 2020 to July 1, 2021 (Nst-Est2021-Pop)." U.S. Census Bureau. (2021).

[2] National Alliance for Caregiving and AARP. "Caregiving in the U.S". (2000).

[3] AARP. "Valuing the Invaluable 2023". (2023).

[4] Institute on Aging. "How IOA Views Aging in America". (2016).

The prevalence of caregivers for individuals with Alzheimer's disease or dementia has notably increased, rising from 22% in 2019 to 26% today<sup>2</sup>. This shift emphasizes the growing demand for specialized care in response to the unique challenges posed by neurodegenerative conditions, and places caregivers at the forefront of providing crucial support and enhancing quality of life for this demographic.

A significant aspect of the caregiving experience is the emotional toll it takes on the provider of care, with 40% of caregivers reporting emotional stress.<sup>3</sup> Additionally, one in five caregivers face financial problems as a result of out-of-pocket expenses and reduced work hours required for caregiving.<sup>6</sup> These statistics emphasize the need for increased support systems to address the emotional and financial challenges that caregivers often encounter in their selfless commitment to the well-being of their loved ones.



[5] U.S. Department of Health and Human Services. "Diversity in Caregiving Needs and Networks by Race-Ethnicity in the Care Older Adults Receive". (2023).

[6] UCLA Center for Health Policy Research. "Who is caring for the caregivers? The financial, physical, and mental health costs of caregiving in California". (2021).

# The Importance of Peer Support

Peer support plays a crucial role in fostering emotional well-being and resilience, particularly in contexts where individuals face challenges such as caregiving responsibilities. The importance of peer support lies in its ability to create a sense of community, understanding, and shared experience among individuals navigating similar circumstances. In the realm of caregiver support programs, peer support can be a transformative element, providing caregivers with a space to connect, share insights, and gain strength from each other.

Drawing inspiration and the experience from other fields can enhance effectiveness of caregiver support programs. For example, evidence-based peer support models for behavioral health offer valuable insights into building supportive networks and implementing strategies for coping with unique challenges. The principles of empathy, active listening, and non-judgmental understanding found in behavioral health support groups can be seamlessly integrated into caregiver support initiatives.

Additionally, the exchange of ideas and practices across different peer support domains can lead to innovative solutions for common issues faced by caregivers. For example, lessons learned from disability peer support groups, where individuals often grapple with complex care needs, can inform the development of targeted resources and interventions within caregiver support programs. By embracing cross-disciplinary collaboration, caregiver support programs can benefit from a wealth of knowledge and strategies that have proven successful in related fields. This approach not only enriches the support and connection provided to caregivers, but also fosters a more comprehensive understanding of the diverse needs within the caregiving community.

# The Power of Connection

In the evolving landscape of caregiving, a substantial number of older adults are embracing the role of caregivers. Beyond providing practical assistance, the profound bond among these caregivers is rooted in shared experience and deep empathy. While offering vital support, they also seek solace and strength through connections with fellow caregivers facing similar challenges. The exchange of wisdom, shared stories, and mutual encouragement creates a resilient network that not only strengthens the caregiving community but also underscores the pivotal role of peer support for older adults.

## SHARED EXPERIENCE

Peer support groups provide a safe space for caregivers to share their experience and emotions without judgment. Being in the company of others who understand the challenges you face can be immensely comforting and validating.

## REDUCE ISOLATION

Isolation can lead to a decline in mental and physical health. Peer support combats this isolation by fostering a sense of belonging. It helps caregivers build a supportive network that understands and empathizes.

## PRACTICAL ADVICE

Caregivers often encounter complex situations and decisions. Peer support provides practical advice and solutions. Others may have faced similar challenges and can offer guidance and strategies.

## EDUCATION AND REFERRALS

Peer support is an opportunity to learn. Caregivers can exchange knowledge about medical conditions, caregiving techniques, and referrals. This wisdom helps caregivers become more effective.

## RESPIRE AND SELF-CARE

Peer support plays a vital role in encouraging caregivers to prioritize self-care. This includes learning to recognize the necessity of taking breaks and seeking respite care to recharge and attend to their own needs.

# Framework for Caregiver Support

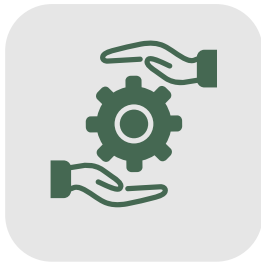
The **San Diego Caregiver Connections Framework for Caregiver Peer Support** establishes a comprehensive approach to peer support, recognizing the pivotal role in fostering emotional well-being and resilience. At the core of this framework lies the acknowledgment that caregivers benefit immensely from a sense of community, understanding, and shared experience with others navigating similar challenges. This framework aims to integrate evidence-based practices into caregiver support programs.

Additionally, this framework encourages the cross-pollination of ideas and practices across various peer support domains, borrowing lessons from peer support groups to address the nuanced and complex care needs that caregivers often encounter. Embracing cross-disciplinary collaboration, our framework envisions a synergistic approach that enriches the support provided to caregivers and fosters a comprehensive understanding of the diverse needs within the caregiving community.

Purpose & Principals	Guidelines & Strategies	Community Building	Diversity & Inclusivity	Feedback & Evaluation
<p>Strive to create a purposeful space where caregivers can connect, exchange insights, and find solace in a supportive community.</p> <p>Recognize the reciprocal nature of peer support, we affirm that both giving and receiving support are equally valuable contributions.</p>	<p>Clear boundaries must be defined and training on handling sensitive topics, crisis situations, and respecting privacy is essential.</p> <p>Emphasize effective communication strategies, encouraging active listening, empathy, and open dialogue.</p>	<p>Foster a sense of community through organized meetings, held in-person or virtually, for caregivers to connect and share resources.</p> <p>Smaller support groups based on shared experience, challenges, or caregiving contexts are actively encouraged.</p>	<p>Emphasize the importance of a diverse and inclusive caregiver peer support community.</p> <p>Incorporate elements including cultural sensitivity, language accessibility, intersectionality, representation, and partnerships with diverse organizations.</p>	<p>Encourage caregivers to provide input on their experience and satisfaction to foster suggestions for improvement.</p> <p>Regularly evaluate the framework and remain open to adaptation based on feedback, changing needs, and evolving best practices.</p>



**This framework incorporates best practices and essential components of caregiver peer support programs including:**



**Recognizing Your Role**

Embrace your identity as a peer supporter rather than assuming the roles of a therapist, counselor, or medical expert. Your strength lies in offering respect, empathy, encouragement, and information. Focus on listening, validating and empowering, avoiding the urge to solve their problems, dispense advice, or pass judgment. Cultivate a safe and respectful space where individuals can freely express themselves.



**Effective Communication**

Strong communication skills are key. Practice active listening by attentively absorbing their words without interruption or judgment. Encourage open dialogue with thought-provoking questions and summarize key points to affirm your understanding.



**Setting Clear Boundaries**

Foster a mutual relationship by respecting the autonomy, privacy, and choices of the person you're supporting. While prioritizing their well-being, establish boundaries regarding the frequency, duration, and mode of communication. Agree on topics to avoid, potential triggers, and crisis management strategies. This ensures a balanced exchange and guards against burnout.



**Shared Experience**

Harness the power of your own experience to inspire and instill hope. Seek permission before sharing, and keep your narratives brief and relevant. Maintain a positive and realistic tone, always tying your story back to the other person's situation. Instead of dictating lessons, inquire about their thoughts on your narrative or what insights they can derive from it.



### Resources and Referrals

Acknowledge that peer support complements, but does not replace, professional assistance. Recognize when additional services may be beneficial and provide relevant, reliable, and accessible resources and referrals. Direct them to community resources.



### Structured Training

Implement comprehensive training programs with modules on active listening, effective communication, and understanding the diverse challenges faced by caregivers. Utilize existing training such as *Caring for You*, *Caring for Me Education* and *Support for Family and Professional Caregivers* from the Rosalynn Carter Institute for Caregiving.



### Integration of Technology

Use technology to facilitate virtual meetings, reach a broader audience, and ensure accessibility for caregivers who face mobility or geographical constraints.



### Collaboration with Professional Providers

Collaborate with professionals to provide caregivers with a holistic range of support services, combining the benefits of peer support with expert guidance when necessary.



### Promotion of Self-Care Practices

Encourage and incorporate discussions on self-care, emphasizing the importance of caregivers taking care of their own well-being to prevent burnout and enhance their capacity to provide effective care.



**Going forward, CEAL and SDCC will focus on the following strategies to strengthen caregiver peer support programs:**

### **Advocate**

Promote the value of caregiver peer support programs to elected officials and request funding that demonstrates a commitment to the well-being of older adult caregivers.

### **Integrate**

Integrate caregiver peer support programs within broader healthcare systems, fostering collaboration between community organizations and healthcare providers to create a comprehensive support structure for caregivers and care recipients that can potentially reduce long term care costs.

### **Training and Certification**

Establish standardized training and certification requirements similar to other fields for individuals serving as peer support specialists.

### **Research and Evaluation**

Encourage research on caregiver peer support programs to evaluate impact and identify areas of improvement to contribute to evidence-based practices and estimate the financial impact.

### **Public Awareness**

Support public awareness campaigns to educate caregivers about the availability and benefits of peer support programs, especially family caregivers who do not view themselves in a formal caregiving role.

### **Collaborate with Employers**

Encourage collaboration between employers and caregiver peer support programs to develop policies that recognize the importance of supporting caregivers in the workforce.

## Conclusion

At the heart of SDCC's innovative model lies a deep recognition of the pivotal role of peer support, underscored by a commitment to inclusivity and engagement with diverse communities. Within this framework, peer support emerges as a transformative force, fostering a profound sense of belonging and empathy among caregivers. Drawing from diverse disciplines, such as behavioral health and peer support groups, enriches the support provided, ensuring a holistic approach tailored to multifaceted needs and promoting resilience within the caregiving community.

The San Diego Caregiver Connections Framework for Caregiver Peer Support embodies a comprehensive approach, emphasizing community, understanding, and shared experiences. By integrating evidence-based practices and encouraging cross-disciplinary collaboration, the framework addresses the complex care needs of recipients.

Best practices in caregiver peer support emphasize role recognition, setting clear boundaries, effective communication, and shared experiences. Prioritizing resources and referrals ensures caregivers receive holistic support to deliver quality care. Strategies to enhance caregiver peer support programs include advocating for funding, integrating programs with healthcare systems, establishing training standards, promoting research, raising public awareness, and fostering collaboration with employers.

In conclusion, SDCC's multifaceted approach, grounded in empathy and collaboration, sets a benchmark for comprehensive caregiver support. By championing the principles outlined in this initiative, we envision a future where caregivers are not only recognized and supported but also empowered to navigate their caregiving journeys with dignity, resilience, and strength.

***“There are only four kinds of people in the world - those who have been caregivers, those who are caregivers, those who will be caregivers and those who will need caregivers.”***

**-Former First Lady Rosalynn Carter**