Person- and Family-Centered, Trauma-Informed Approaches to Service Delivery for Family Caregivers

Introduction

An estimated 53 million Americans provide care for an older adult or someone living with illness or disability.[1] Family caregivers provide a wide range of services, such as transportation, food preparation, housekeeping and personal care, enabling care recipients to live at home or in the setting of their choice with dignity and independence. Without supportive services, nearly 62 percent of caregivers have suggested that the individual they care for would be living in a nursing home.[2] Additionally, there are at least 2.4 million children being raised by grandparents or other relative caregivers, serving as a safety net and providing care when children's parents are unable.[3]

This Action Guide is part of a series to help Aging Network organizations develop innovative caregiver services and supports that meet the needs of a growing population of caregivers.

> A ***family caregiver*** is an adult family member or other individual who has a significant relationship with, and who provides a broad range of assistance to, an individual with a chronic or other health condition, disability or functional limitation. This includes any grandparent or relative adult who has primary responsibility for grandchildren or other children who cannot remain with their parents.[4]

Challenges for Family Caregivers Caring for Older Adults Who Have Experienced Trauma

As many as 90 percent of older Americans will experience a traumatic event in their lifetime, with exposure to multiple traumatic events being the norm.[5] Caregivers may be caring for a survivor of trauma while also managing the effects of trauma they have experienced themselves.

Trauma refers to experiences that cause intense physical and psychological stress reactions. Trauma results from an event, series of events or set of circumstances that is experienced by an individual as physically or emotionally harmful or threatening and that has lasting adverse effects on the individual's functioning and physical, social, emotional or spiritual well-being.[6]

Caring for an older adult with a history of trauma places unique burdens and challenges on family caregivers. These challenges include: 1) managing the sudden onset or recurrence of trauma-related behaviors and symptoms, 2) coping with the social isolation or loneliness brought about by traumatic experiences in their loved ones, 3) managing fears and anxieties about retraumatizing their loved ones and being constantly alert for

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potential trauma triggers and 4) managing distrust of health and social services providers and explaining trauma-related behaviors in their loved ones to aging professionals.

Person-Centered, Trauma-Informed Care

According to the Jewish Federations of North America's Center on Aging, Trauma and Holocaust Survivor Care, the Person-Centered, Trauma-Informed (PCTI) Approach is a holistic model of care that promotes the health and well-being of individuals by accounting for the role of trauma across the life course and by resisting re-traumatization, while also focusing on the strength, autonomy and dignity of the person receiving care. The PCTI Approach combines the principles of the person-centered (PC) approach with the principles of the trauma-informed (TI) approach, to better serve all populations and provide comprehensive care. The PCTI Approach is universal; it can be used by any person at any level of any organization, in any care setting and with any population.

There are a multitude of benefits to utilizing the PCTI Approach across service settings and interactions. The PCTI Approach enables professionals and volunteers to have a greater impact on a person's health and well-being by improving the quality of service delivery experiences of professionals, volunteers and people receiving care.[7] It also provides organizations, professionals and volunteers with increased knowledge about their work and the people they support; improves staff well-being; and reduces vicarious trauma, burnout and attrition among staff. When applied to aging services, these benefits promote resilience and a positive outlook on aging. Once the PCTI Approach is infused into an agency's culture and practice, the risks for re-traumatization, misdiagnosis, underutilization of services and staff burnout are reduced.[8]

Action Steps

1. Explore innovative PCTI examples and resources for caregivers.

Program Name: Caregiver Advisory Board and Caregiver Groups
Organization: Jewish Family Services of Central New Jersey (Elizabeth, NJ)
Program Description: The Caregiver Advisory Board is made up of Holocaust Survivors, older adults, psychologists and community professionals who have experience working with traumatized populations. The Caregiver Support Groups is infused with PCTI principles and calls on the advisory board and the voices of caregivers to direct support group implementation. Virtual monthly groups are rooted in respite for caregivers and include dinners, outings, art and cooking classes, and mindfulness and meditation activities. Jewish Family Services of Central New Jersey has hosted caregiving conferences featuring specialists in the field of caregiving.
Learn More: Jewish Community Center of Central New Jersey, Caregiver Support Groups

Program Name: Club 2G
Organization: The Boro Park Y (Brooklyn, NY)
Program Description: Boro Park, NY, is home to the densest Holocaust survivor population in the country. Club Nissim serves children of Holocaust Survivors and family caregivers in the Hasidic community. Enrichment groups for caregivers include lecture series, activities (e.g., yoga) and overnights/excursions (e.g., Philadelphia Flower Show). Each of the outings and programs are planned and implemented through a PCTI lens. For example, serving the Orthodox community requires establishing trust, safety and sensitivity to effectively serve an insular community. The Boro Park Y also trains its staff and home health care aides in PCTI.
Learn More: Club 2G at The Boro Park

Program Name: Yaran ("Friends") Iranian Peer Counseling HelpLine
Organization: Cross Cultural Connections Community Counseling Center (Sherman Oaks, CA)
Program Description: Cross Cultural Connections Community Counseling uses the PCTI principles to guide programming for multi-cultural communities. The HelpLine supports Iranian older adults and caregivers with connection to informational resources and referrals. They host weekly virtual support groups in Farsi and workshops to train Yaran (Persian) volunteers and therapists on how to best work with older adults and caregivers in their community. Lastly, CCE has a suite of programming for Russian-speaking older adults and their caregivers as well, including support and process groups.
Learn More: Yaran Iranian Peer Counseling HelpLine

Program Name: Trauma-Informed Reciprocal Peer Support Model
Organization: Give an Hour
Program Description: Give an Hour's (GAH) Trauma-Informed Peer Support is an evidence-informed and customizable peer support training program designed specifically for those affected by trauma. Peer support is the process of giving and receiving encouragement and assistance to achieve long-term resilience and recovery. Peer supporters offer emotional support; share knowledge; teach skills; provide practical assistance; and connect people with resources, opportunities and communities of support. GAH-trained peer supporters offer their unique lived experience to provide support focused on advocacy, education, mentoring and motivation for a group of peers who have experienced similar trauma.
Learn More: Give An Hour

2. Help prevent caregiver burnout and secondary traumatic stress by promoting self-care through the following activities.

- Provide education on trauma so they can recognize the signs of vicarious/secondary trauma.
- Provide connections to local resources on caregiver support initiatives.
- Encourage positive coping mechanisms, like regular exercise, getting enough sleep and other self-care activities.
- Help caregivers set realistic goals to empower their success.
- Stay up to date on new data/research and best practices and help advocate for public policy that benefits family caregivers.
- Referral sources for caregivers include:
    - Eldercare Locator: a public service of the Administration for Community Living connecting older adults and their families to services
    - Family Caregiver Alliance–Caring for Yourself
    - National Institute on Aging–Taking Care of Yourself

3. Encourage ongoing trauma training for staff and deepen your organization's capacity and commitment to provide PCTI care.

- Research issues of trauma, aging, service needs and PCTI care to help address barriers for service access and utilization.
- Continue learning to enhance PCTI knowledge and partnerships through options such as Jewish Federations of North America's (JFNA) free, online, asynchronous PCTI training course called Person-Centered, Trauma-Informed Essentials for Aging Services. Continuing Education Units are available for social workers.
- Raise awareness and understanding about aging with a history of trauma triggers, trauma prevalence and service needs of communities—and how PCTI care can help.

Conclusion

The PCTI Approach has emerged as a best practice in aging services, improving the social connection, health and well-being of older adults and their family caregivers. Based on these results and the prevalence of trauma among

the United States population, PCTI care has the potential to improve services for all older adults and their family caregivers. The principles of PCTI care can be integrated into all aspects of policy making, funding, service design and delivery and organizational operations. By infusing principles of PCTI into medical and social services, all older adults with a history of trauma and their family caregivers can get the care they need and deserve.

Additional Resources

- AARP–How Caregiving Can Liberate Caregivers From Past Trauma
- ACL–National Family Caregiver Support Program
- ACL–National Strategy to Support Family Caregivers
- Best Programs for Caregiving
- Building Better Caregivers
- Care Is Fundamental: How Funders Can Accelerate Vital Progress on Caregiving
- Family Caregiver Alliance
- Jewish Federations of North America (JFNA)–Aging With a History of Trauma: Strategies to Provide Person-Centered, Trauma-Informed Care to Diverse Older Adults and Family Caregivers
- JFNA Center on Aging, Trauma, and Holocaust Survivor Care
- The John A. Hartford Foundation–Age-Friendly Health Systems
- National Academy for State Health Policy–Supporting Family Caregivers: A Roadmap for States
- National Clearinghouse on Abuse in Later Life–Power and Control and the Role of Caregiver Stress
- Nonviolent Communication Training (NVC Academy)
- Powerful Tools for Caregivers
- PTSD in Late Life–Resources for Caregivers
- RUSH University Medical Center–Caring for Caregivers Program (C4C)
- Scripps Gerontology Center–Enhancing Caring Communities Toolkit
- The National Center to Reframe Aging
- Veterans Affairs–Caregiver Support Line (CSL)
- Zen Caregiving Project

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