

**Supporting Family Caregivers of Older Adults with a History of Trauma:
Implementation Recommendations for the National Family Caregiving Strategy**
November 16, 2021

The Jewish Federations of North America (JFNA) Institute on Aging and Trauma is pleased to submit the following recommendations on person-centered, trauma-informed (PCTI) care for family caregivers of older adults with a history of trauma for implementation in the National Family Caregiving Strategy. JFNA applauds the leadership and vision of the Administration for Community Living (ACL) and RAISE Family Caregiving Advisory Council for their work on the National Strategy and their recent report to Congress, and is excited about the ground-breaking steps they have taken to support the nation's vital but highly vulnerable caregiving population. While our recommendations apply specifically to family caregivers of older adults with a history of trauma, they are applicable to family caregivers of all older adults given the widespread experience of trauma among the nation's older population. They are, in other words, 'universal precautions' that can benefit family caregivers of all older adults, whether their care recipients have a known history of trauma or not.

The recommendations were developed in consultation with the JFNA Work Group on Aging and Trauma, comprised of agencies representing African American, Black American, Latin American, Asian American, Native American, and LGBTQ American populations, veterans, refugees, and experts from various disciplines including trauma and person-centered care. The recommendations are grounded in JFNA's experience spearheading innovations in PCTI care for Holocaust survivors, older adults with a history of trauma, and their family caregivers through grants from ACL. PCTI care, a term coined by ACL, defined by JFNA, and codified in the recent reauthorization of the Older Americans Act, is a holistic approach to service provision that promotes the health and well-being of trauma survivors by infusing knowledge about trauma into agency programs, policies, and procedures. The recommendations offer PCTI-based strategies that can increase the use of family caregiver support services and promote better outcomes for family caregivers and the older adults they care for. They are based on the following principles:

- The hallmarks of trauma include the loss of a sense of power, safety, and control, the same hallmarks often experienced by family caregivers confronted with illness, loss of function, and/or declining physical, mental, emotional, and/or cognitive health in their loved ones. Family caregivers, then, are at high risk for being traumatized by the experience of caregiving, and/or for being re-traumatized by the experience if they have previous traumatic experience themselves.
- Trauma cuts across a wide swath of the American population, with almost no one being immune to having experienced a traumatic event such as a disaster, accident, crime, illness, sexual assault, war, terrorism, or other potentially life-threatening or life-changing event. But because trauma can be experienced by individuals as well as by communities and populations as a whole, and can carry over across generations, members of racial, ethnic, sexual minority, and other diverse and under-served communities are at particularly high risk for trauma exposure. Family caregiver

support programs for diverse populations need to incorporate awareness of this risk into their programs and infuse the principles of person-centered, trauma-informed care accordingly.

- The term ‘family caregiver,’ like the term ‘family’ itself, is a broad, multi-faceted, culturally, ethnically, historically, and personally defined term that includes family members, friends, partners, and anyone who has a significant relationship with a care recipient and is helping to provide care and support to that person. Health and social service providers should welcome anyone acting in the caregiving role in support of an older adult’s health and well-being as a valued member of the care team.

The recommendations are summarized in three categories developed by the RAISE Family Caregiving Advisory Council: awareness and outreach for family caregivers, engagement of family caregivers in healthcare and long-term services and supports, and services and supports for family caregivers. We are grateful for the opportunity to submit these recommendations and look forward to supporting ACL and the RAISE Family Caregiving Advisory Council on the implementation of the National Family Caregiving Strategy.

Background: Trauma, Older Adults, and Family Caregivers

In the United States today, one in six Americans – or about 42 million American adults - is caring for someone 50 or older (AARP/NAC, 2020). In 2017, the cumulative economic value of the unpaid care provided by family caregivers was estimated at \$470 billion, three times as much as total Medicaid spending on long-term services and supports (Reinhard et al., 2019).

While family caregivers often find their efforts to be fulfilling and rewarding, they also face numerous challenges. Twenty-one percent say their role as a caregiver has made their own health worse; 42% have experienced a financial impact due to caregiving; and 36% consider their caregiving situation to be highly emotionally stressful (AARP/NAC, 2020). Caregiving can also leave caregivers feeling socially isolated (RAISE Family Caregiving Advisory Council, 2021), an outcome that can have negative health impacts of its own.

But there is another challenge, a hidden one that gets far less attention, and that is the issue of trauma. Almost 90 percent of American adults have been exposed to a traumatic event (Kilpatrick et al., 2013). In any one year in the United States, more than 10 million women and men are physically abused by an intimate partner (National Coalition Against Domestic Violence). In 2017 alone, more than 25 million Americans were affected by disasters (FEMA). Posttraumatic stress disorder (PTSD) has been described as chronic in African Americans (Perez-Benitez et al., 2014) and as one of the most serious mental health problems faced by American Indian/Alaska Native (AI/AN) populations (Bassett et al., 2014). Pereira and Ornelas (2013) found that 34% of Latino immigrant parents and 29% of Latino immigrant adolescents experienced trauma. And all of this was before the COVID-19 pandemic that has killed over 700,000 Americans and left families and communities reeling from the trauma of lost jobs, lost connections, and lost loved ones.

While we don’t yet know the long-term impacts of the COVID-19 crisis, we do know that the impacts of trauma can last for years and even emerge decades after a traumatic event. Trauma and posttraumatic stress disorder are associated with an increased risk for cardiovascular and lung disease; gastrointestinal disorders; musculoskeletal disorders; and endocrine disorders (D’Andrea et al., 2011; DeOliviera-Solis et al., 2017; Jankowski, 2016; Kelsch and Kelsch, 2014; McFarlane, 2010; Rouxel et al., 2017; Wyatt et al., 2002). We also

know that changes often associated with aging, such as retirement, health problems, and the loss of friends and loved ones, can re-activate traumatic stress in older adults who had previously been coping well (Davison et al., 2016; Kaiser et al., 2017; Ladson and Bienenfeld, 2007; Paratz and Katz, 2011). Trauma and PTSD are risk factors for dementia (Mohlenoff et al, 2017; Yaffe et al., 2010), and dementia can lead to the re-emergence of PTSD symptoms.

These trends paint a daunting picture not just for older adults, but for the family members who care for and support them. Nightmares, irritability, sudden outbursts of anger, anxiety, depression, hypervigilance, and difficulties maintaining relationships can all occur in the aftermath of a traumatic event, immediately or years afterwards, and can be distressing for family caregivers and difficult to manage. Family caregivers of veterans with PTSD, for example, can feel like they live “in an atmosphere of constant chaos...” (U.S. Dept of Veterans Affairs). Halmasy (2016) writes of family members of first responders that they often feel helpless while their loved ones experience “depression, hypervigilance, nightmares, and irritability levels that are almost unbearable.” To manage these symptoms and behaviors, family caregivers may become hypervigilant themselves, constantly on alert for sounds, smells, and other stimuli that have the potential to remind their loved ones of previous traumatic events and thereby increase their distress, anxiety, or agitation. For some family caregivers the answer to avoiding such ‘trauma triggers’ in their loved ones can become not going out at all, escalating the risk family caregivers already face for social isolation.

Some trauma triggers can’t be avoided, however, adding even more burden to caregivers. Some Holocaust survivors, for example, hoard food as a result of the deprivation and starvation they experienced during the Holocaust. For these survivors, common caregiving activities around food, such as cleaning out expired food, can be re-traumatizing. The distress, anger, confusion, or panic that can result from such re-traumatization in their loved ones can be particularly disturbing to family caregivers.

People with a history of trauma can also develop difficulties with intimacy and with trusting others, including family members. This lack of trust can make caregiving relationships difficult and add additional emotional and psychological burdens to family caregiving relationships and tasks. And given that as many as 90% of American adults have experienced a traumatic event, many family caregivers *themselves* have a history of trauma, sometimes even at the hands of the person they are caring for. The already complicated and emotionally charged atmosphere of caregiving can be further exacerbated by any such pre-existing family relationships.

At the same time, people with a history of trauma can also develop a distrust of health and social service systems. Fear of being judged, stigma, not wanting to tell their ‘trauma stories’ again and again, previous traumatic experiences in medical care settings along with fears of being re-traumatized, and self-blame can all lead older adults with a history of trauma to avoid health and long-term care settings. Family caregivers in these situations can find themselves in the difficult situation of having to explain trauma-related symptoms and behaviors to medical providers in an attempt to ease the stress of receiving medical care in their loved ones. Distrust and fear of being re-traumatized by and in medical care settings can also result in family caregivers taking on medical care tasks themselves, which can be highly stressful and both physically and emotionally demanding.

Family caregivers of older adults with a history of trauma are also likely to face the challenges of caring for someone with dementia, as research continues to document trauma as a risk factor for dementia. Compared with caregivers of people without dementia, twice as many

caregivers of those with dementia indicate substantial emotional, financial, and physical difficulties, and evidence suggests that the stress of providing dementia care increases caregivers susceptibility to disease and health complications (Alzheimer's Association, 2021). When persons with dementia also have depression and behavioral disturbances, their caregivers face a higher risk of emergency department visits and hospitalization compared with caregivers of person with dementia alone. (Alzheimer's Association, 2021). As we have documented, individuals with a history of trauma are at high risk for experiencing both of these complications.

In sum, caring for an older adult with a history of trauma places a number of unique burdens and challenges on family caregivers. These challenges include:

- Managing the sudden onset of trauma-related behaviors and symptoms
- Coping with the re-emergence and/or exacerbation of trauma-related emotions and behaviors due to normal changes of aging
- Dealing with expectations of betrayal in relationships, withdrawal, and fears of intimacy in their loved ones
- Coping with the social isolation brought about by traumatic experiences in their loved ones
- Managing fears and anxieties about re-traumatizing their loved ones and being constantly alert for potential trauma triggers
- Managing distrust in their loved ones of health and social services providers and explaining trauma-related behaviors in their loved to those providers
- Managing multiple trauma-related physical, emotional, and mental health conditions in their loved ones simultaneously
- Managing their own traumatic experiences and issues while dealing with them in their loved ones

JFNA's Institute on Aging and Trauma designed the following recommendations to help the nation support family caregivers of older adults with a history of trauma by helping them overcome these challenges. The recommendations incorporate our experience evaluating and disseminating innovations in PCTI care and are infused with the principles of trauma-informed care espoused by SAHMSA (2014) that include safety; trustworthiness and transparency; peer support and self-help; collaboration and mutuality; empowerment, voice, and choice; and cultural, historical, and gender issues. As noted previously, while the recommendations apply specifically to family caregivers of older adults with a history of trauma, due to the prevalence of trauma and the risks it presents for re-traumatization, they can benefit all family caregivers, regardless of whether the older adults they are caring for have a known history of trauma or not.

JFNA Recommendations for the National Family Caregiving Strategy:

A. Awareness and Outreach for Family Caregivers

Recommendations:

1. Develop and distribute outreach messages that acknowledge that, while family caregiving can be rewarding, it can also be challenging, and that services and supports are available to help with those challenges, whatever they may be and whatever family issues and personal histories they may have surfaced.

2. Outreach messages should be brief and easy to understand, available in different formats (caregiver videos, written brochures, etc.), easily accessible, include resources for follow-up, and take into consideration the traditions, values, and understandings different peoples and cultures bring to the notions of family and family caregiving.
3. All language, pictures, graphics, videos, and other communications included in outreach materials should be person centered and trauma-informed, i.e., they should promote a sense of safety, trust, and empowerment, take into consideration the language preferences, cultural values, gender dynamics, and historical circumstances of the audiences they are developed for, and be created and distributed in partnership with those family caregivers.

B. Engagement of Family Caregivers in Healthcare and Long-Term Services and Supports.

Recommendations:

1. Raise awareness that women and members of racial, ethnic, and sexual minority communities have a high likelihood of having experienced trauma as well as a history of being disempowered by traditional health care settings, and may be reluctant to engage with or be easily re-traumatized in these settings. Take steps to promote the safety and empowerment of these caregiving populations in all these settings.
2. Train family caregivers on caregiving tasks to increase their comfort and ability at these tasks, ask if trauma histories in their loved one may interfere with these tasks and how any triggers or anxieties about re-traumatizing during caregiving tasks can be reduced.
3. Train health, social service, and long-term care staff and volunteers on the principles of person-centered, trauma-informed care, including awareness of the prevalence and impact of trauma in the lives of older adults and on how changes associated with aging such as retirement and declining health can trigger the emergence of trauma-related symptoms.
4. Promote trust in health, social services, and long-term care settings by asking about, listening to, and, if appropriate, providing resources to family caregivers to help them with their caregiving tasks and with any physical, emotional, financial, and psychological challenges they may be experiencing. Help family caregivers understand that they are not alone in experiencing these difficulties, that sometimes difficulties can be compounded by challenges experienced by their loved ones in the past, and that resources are available to help.
5. Understand that behaviors that may be perceived as 'non-compliance' by health care and long-term care staff may in fact be attempts to cope with fear, stigma, and feelings of being out of control, and provide a safe space to help individuals and their family members feel more in control of their situations.
6. Help family caregivers maintain a sense of control over their lives while engaged in caregiving, including informing them of all care options, asking their feedback and suggestions on which options may be most beneficial to them and to their loved ones, and getting their consent on care decisions whenever possible and appropriate.

7. Create environments that promote a sense of safety by limiting potential trauma triggers such as loud alarms, unexplained medical procedures or screenings, and anything that promotes a sense of lack of control in family caregivers or their loved ones. Understand that trauma triggers can be the result of cultural, historic, and individual factors and include this understanding in all service and support settings. Create a sense of safety and calm using neutral warm lighting and culturally appropriate signs and decorations that are welcoming to both the care recipient and the family caregiver. Ensure that the history, background, and relationships of the care recipient and caregiver are understood and respected, and provide services in accordance with those understandings and in the preferred language whenever possible.
8. Promote collaboration and mutuality in health, social service, and long-term care settings by including family caregivers as partners in care teams while acknowledging that family histories, dynamics, and backgrounds may influence caregiving decisions and tasks. Note that all members of the care team need to feel empowered to the full extent of their physical, emotional, and cognitive capabilities to voice their thoughts, opinions, questions, and concerns, and to have those thoughts, opinions, questions, and concerns responded to in a timely manner suitable and appropriate to the care recipient and his or her family. Help family caregivers empower their loved ones with information and support so that care decisions can be made based on information that is understood by both the caregiver and care recipient. Improve the health literacy of family caregivers by connecting them and educating them on the care they are providing.
9. Explore the strengths, challenges, and circumstances of the caregiver, and his, her, or their willingness and ability to take on caregiving tasks that may be difficult, physically or emotionally challenging, or re-traumatizing to the care recipient. Train providers on how to sensitively assess for trauma and on how trauma may be influencing family caregivers and the completion of caregiving tasks. Train and dedicate a professional in health, social service, and long-term care settings to assess the needs, strengths, resources, individual, cultural, ethnic, and historical backgrounds of caregivers and on how to meet their needs based on this assessment and understanding.
10. Encourage participation, voice, and choice of family caregivers with their care recipients in all care transitions, including transfers of family members to different inpatient units, to different facilities (which can be particularly stressful), and transfers back home, and be sensitive and prepared to ameliorate any triggers, anxieties, or feelings of loss of control and re-traumatization that can occur during such care transitions. Provide family caregivers with sufficient and easily understandable information and resources about care transition options, and ensure that they have enough time to make the best choice about those options for themselves and their family members.
11. Develop a committee of family caregivers and ask for their continual feedback on caregiver services and supports and how they can be improved. Work with the committee and develop a 'caregiver bill of rights' to be posted throughout the agency.
12. Raise awareness about the relationship between trauma and dementia, and on how to implement person-centered, trauma-informed care to older adults with dementia and a history of trauma and their family caregivers. Develop outreach strategies and support programs that specifically take into account the relationship between trauma and dementia and the extra challenges faced by family caregivers who are caring for older adults with dementia and a history of trauma.

13. Educate professionals on the multiple, varied, and complex tasks family caregivers engage in every day and the value they bring to the health and long-term care system. Encourage providers to welcome family caregivers to learn more about the health conditions of their care recipients and encourage activities such as interactive forums that promote dialogue between health care professionals and family caregivers.

C. Services and Supports for Family Caregivers

Recommendations:

1. Provide resources and options to caregivers whenever possible on all aspects of caregiving, including the information they want to receive, in what format, and how often, and on different resources they can use to preserve their health and well-being while engaging in caregiving tasks. Reassure them that caregiver support services are designed for them and should not be perceived as 'something else they need to do' on top of their already long list of caregiving tasks.
2. Understand that different support services may be helpful at different points in each caregiver's 'caregiver trajectory,' for example, that information and referral may be helpful to a new caregiver while respite services may be helpful to a caregiver who has been caregiving for a longtime. Use assessments to help the caregiver choose which support services may be best for her or him at which point in time.
3. Offer referrals to services and supports that are provided in a person-centered, trauma-informed way, i.e., that take into consideration the role trauma may be having in the caregiving experience and that seek to avoid re-traumatizing caregiving clients.
4. Understand that certain services and supports designed to help older adult clients and their family caregivers such as home modifications and future planning can be perceived as emotionally intrusive and therefore re-traumatizing, and provide these services in a person-centered, trauma-informed way that minimizes trauma triggers and the risk of re-traumatization.
5. Ensure that respite and adult day care facilities promote a sense of safety for clients and family members and that potential trauma triggers such as loud noises and restrictions on movement are minimized.
6. Train providers of counseling and other caregiver support services on the principles of person-centered, trauma-informed care and on how to respond to family caregivers in need of trauma-specific services and supports.
7. Implement person-centered, trauma-informed services and supports shown to be effective at decreasing stress, anxiety, and burden among family caregivers and effective at improving their overall health and well-being. Promote and prioritize the development and evaluation of evidence-based innovations for family caregivers from diverse cultures, ethnicities, and historical circumstances.
8. Promote peer support among family caregivers by creating and advertising information about support groups (in-person and online), online forums, and other platforms where

family caregivers can share resources, challenges, success stories, and lessons learned with each other. Remind family caregivers that they are not alone, that they are part of a vast network of caregivers providing billions of hours of support across the country, and that peer networks are a great way to tap into the resilience, strength, and support of diverse caregivers from a wide variety of backgrounds, ethnicities, and identities.

Together, these recommendations represent a comprehensive, holistic set of strategies that acknowledge trauma as a powerful, often invisible influence in the lives of older adults and family caregivers. The recommendations align with the vision of ACL and the RAISE Family Caregiving Advisory Council by addressing trauma's influence and promoting the well-being of family caregivers facing the challenges caused by trauma. We look forward to working with ACL and the RAISE Family Caregiving Advisory Council on these recommendations and to helping to strengthen and support family caregivers in the vital contributions they make to the country every day.

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Additional Resources

Examples of short 'white board videos' from the U.S. Department of Veterans Affairs, National Center for PTSD: <https://www.ptsd.va.gov/appvid/video/index.asp>

Resources from the National Center on Advancing Person-Centered Practices and Systems:

- A Toolkit on Asset Mapping containing frequently asked questions, a glossary of terms, step-by-step instructions, facilitator tools, and example Asset Maps and Engagement Plans – to support human service agencies in their stakeholder engagement efforts: https://ncapps.acl.gov/docs/AssetMappingToolkit_200827_linked.pdf
- A Best Practice Guide for Engaging People Who Receive Services: <https://ncapps.acl.gov/docs/Participant%20Engagement%20Guide%20200904.pdf>
- A resource for engaging people who may be living with cognitive disabilities or challenges: Survivor Engagement: Lessons from The TAL-Group's Advocacy Journeys https://ncapps.acl.gov/docs/TBITARC_SurvivorEngagement_Final_May2020.pdf

An example of a form that could be adapted to include a trauma-informed lens from The National Consumer Voice and SAGE:

<https://www.lgbtagingcenter.org/resources/resource.cfm?r=916>

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