

First Principles: Cross-Cutting Considerations for Family Caregiver Support



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The Recognize, Assist, Include, Support, and Engage (RAISE) Act
Family Caregiving Advisory Council

&

The Advisory Council to Support Grandparents Raising Grandchildren



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Introduction

This document is a component of the 2022 National Strategy to Support Family Caregivers (**Strategy**), which was developed by the RAISE Act Family Caregiving Advisory Council and the Advisory Council to Support Grandparents Raising Grandchildren (SGRG) (collectively, the **Advisory Councils**). The Strategy empowers communities, agencies, and other stakeholder groups to select actions for implementation, based on community and family caregiver needs and preferences and in consideration of existing supports already in place, resource constraints, and other factors.

No two family caregiving situations are exactly the same. Because of the diversity of the people providing and receiving care and wide variations in the complexity, volume and duration of support needed by each person, and other variables (as illustrated in Figure 1), there is an almost limitless number of family caregiving configurations.

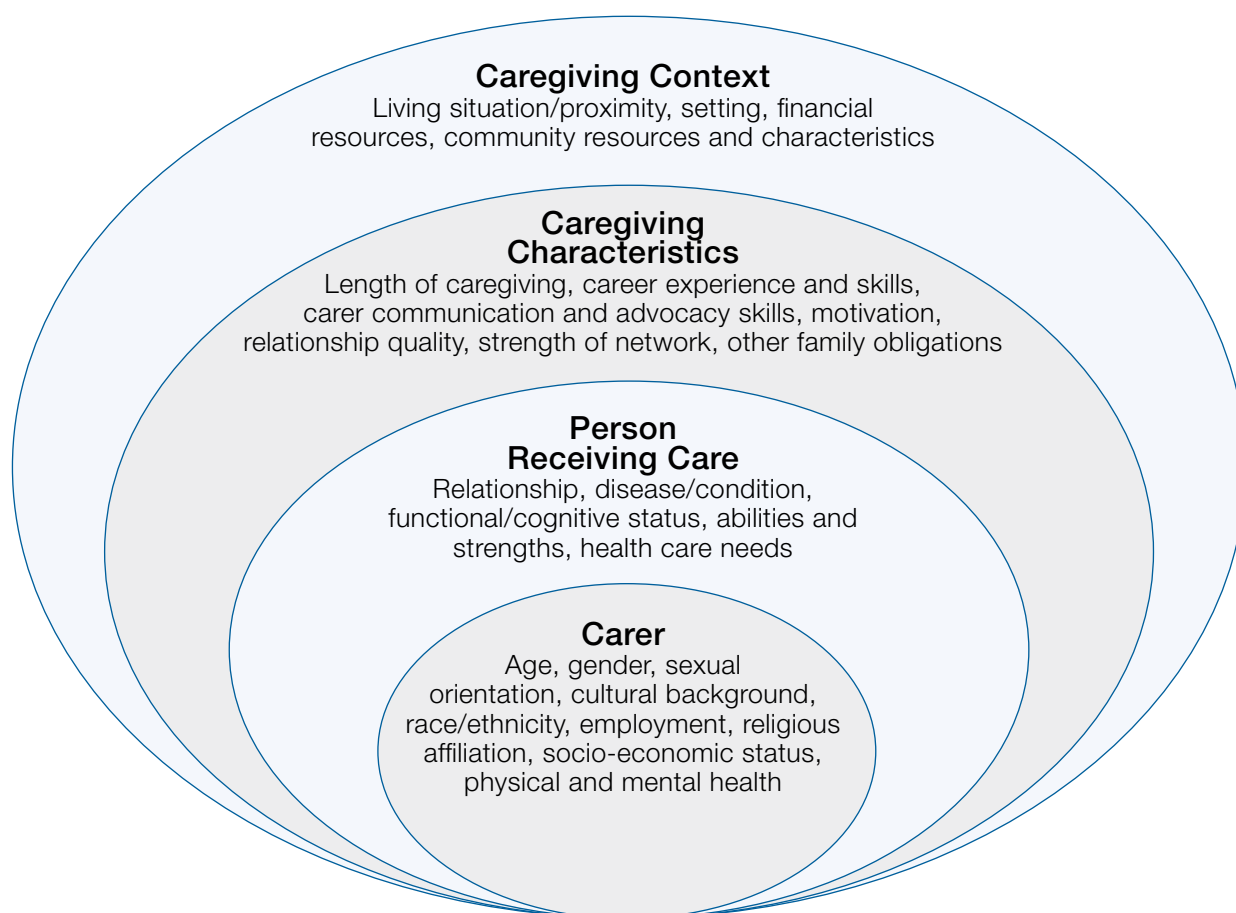


Figure 1. Family caregivers themselves are diverse and have heterogeneous needs that are shaped by a wide range of factors. Image Source: [The Gerontologist. 2020 Fe; 60 \(Supp 1\): S14-S28.](#)



Consequently, no two family caregivers will have exactly the same needs. However, the Advisory Councils identified four cross-cutting issues that influence the caregiving experience and how supports and services are accessed and used. While many other issues affect family caregivers, the Advisory Councils noted that the four issues below must be considered and addressed to achieve success in efforts to support family caregivers:

- [Person- and family-centered approaches](#): As the U.S. builds a system of coordinated and inter-related responses to the needs of family caregivers, it is important that family caregivers themselves—not the needs of systems or providers—remain the focal point of each encounter.
- [Trauma and its impact](#): The experience of trauma, in the lives of caregivers and the people they support—including decades-old traumas—has an impact on the caregiving journey in ways that must be proactively addressed.
- [Diversity, equity, inclusion and accessibility](#): While there are limited systems of support for family caregivers, the difficulties and impacts of caregiving are not equally distributed. Caregivers who represent unserved and underserved and/or marginalized communities frequently experience greater physical, emotional, and financial challenges associated with caregiving.
- [The direct care workforce](#): Even though the Strategy focuses on family caregiving, the well-being of the nation’s 4.6 million professional caregivers (also known as direct care workers, direct service workforce, direct service providers, etc.) directly influences the ability of family caregivers to provide long-term support (PHI, 2018). Only through the development of a robust, well-trained, and well-paid direct care workforce can we ensure family caregivers and those they support have access to reliable, trusted, and affordable paid supports and assistance when and where they need it.

This document includes essential practices to support each of the above considerations. These practices should be embedded in the planning for all services and supports for family caregivers.

Placing the Family and Person at the Center of All Interactions

Family- and person-centered approaches are those that treat people as individuals and allow for the investment of time in finding out what is important to them and relevant to their treatment and support. It is sometimes referred to informally as “individualized care” because this approach allows for clinicians to invest time in understanding “what matters most to people in their care and creating the conditions to enable these needs

to be met” (Kulkuski, et al., 2019). When it comes to family caregiving, that distinction matters because caregivers themselves are so often forgotten in clinical and social service settings where the focus is solely on the needs of the person receiving support. A person-centered approach that supports family caregivers also would consider the caregiver when developing the plan of care, and care plans would be built to balance the needs of both, with support from a facilitator as needed and desired. The facilitator might be a case manager, support coordinator, clinician, peer specialist, or another independent staff person who is specifically tasked with helping to facilitate a person-centered plan. The methods used to undertake person-centered planning may vary based on the unique structures of systems and the unique needs and preferences of the people they support. But in all circumstances, the relationship between the person and the facilitator is a mutually respectful partnership where the plan is co-created with the goal of helping the person and their family caregiver achieve their unique vision for a meaningful care plan and all activities focus on the person (and family) as a whole and are informed by culture and identity.

When the family caregiver knows that their unique voice is heard and valued and the preferences and needs of the individual they are supporting are valued, and they are confident in their skills and abilities to provide support, they can be more effective in their caregiving. This confidence will enable them to provide better quality support for longer. Key to ensuring this confidence is the availability of multi-faceted training for family caregivers on the range of issues and tasks they might be called upon to handle. Additionally, if family caregivers know where to find and access the support and services needed for the individuals for whom they are caring and when they can access assistance for their own needs, they can more effectively focus on addressing the needs of those they support. Further, having access to services and supports focusing on their unique needs, provided in a way they deem most appropriate, family, kin, and grandparent caregivers can realize greater benefit from formal services like respite, counseling, or skills training.

Learn More about Putting the Family and Person at the Center of All Planning

[Person-Centered Practice as Anchor and Beacon: Pandemic Wisdom from the NCAPPS Community](#). These videos are now featured as part of the NCAPPS Shorts collection. NCAPPS invited all participants to co-create a journal article exploring the themes that emerged from the videos. Twelve people - a mix of disabled and non-disabled NCAPPS staff and colleagues, came together to create the paper. The paper - and the process - was a very collaborative effort and is a reminder of the power of community and connection in advancing person-centered thinking, planning, and practice.



[Doing With, Not Doing For: What It Takes to Facilitate Person-Centered Planning.](#)

(January 2021) This webinar is a companion to the Five Competency Domains for Staff Who Facilitate Person-Centered Planning NCAPPS resource. The five competency domains are incredibly useful when seeking to hire or train facilitators in person-centered planning, developing quality standards, or helping people who access services, and their caregivers learn about what they should expect from the planning process.

Essential practices that must be embedded in all family caregiver support to ensure family- and person-centeredness

A fundamental tenet of person-centered support is that services provided to either family caregivers or the person they support should be responsive to the needs of the person receiving those services (i.e., the family caregiver and the person they support.) The needs addressed should be defined by the person, not the service provider. In 2020 the ACL-funded National Center on Advancing Person-Centered Practices and Systems (NCAPPS) released five [competency domains for professionals and volunteers who facilitate person centered planning](#). Person- and family-centered programs should:

- **Be strengths-based, culturally informed, whole person-focused:** An effective person-centered care plan is built upon the assumption that people grow, change, and can realize personally valued goals. It focuses on the universally valued goal of living a good life as defined by the individual and their family caregiver.
- **Cultivate connections inside the system and out:** Person-centered planning actively explores ways to connect the person and their family caregiver with both paid (professional) and unpaid (natural) supports. This requires nuanced understanding of both the individual's relevant health or disability issues, as well as knowledge of the formal and informal services and supports they and their caregiver has access to.
- **Prioritize rights, choice, and control:** Relationships and planning activities are based on respect and the assumption that people and their family caregivers are presumed competent and have the right to control decisions that impact their lives.
- **Drive partnership, teamwork, communication, and facilitation:** Planning interactions and meetings are facilitated in a respectful, professional manner and in accordance with person-centered principles and the preferences of both the family caregiver and the person receiving support.
- **Include documentation, implementation, and monitoring:** The person-centered plan is co-created and captured in writing in a manner that adheres to established expectations around person-centered plan documentation. The plan is valued as a "living document" that is revised as needed based on the person's preferences and evolving situation.



Addressing Trauma and its Impact on Families

The defining characteristic of trauma is a feeling of helplessness in the face of people or events that can cause lasting harm. According to the Jewish Federations of North America, as many as ninety percent of American adults have been exposed to a traumatic event at some point in their lives (Jewish Federations of North America, 2021). The effects of trauma change people's core assumptions about themselves, their families, and their places in the world. In short, they no longer feel safe, which has tremendous implications for caregiving, a task that involves trust.

Trauma can linger for decades and be transmitted across generations. Yet the topic receives little attention. Anyone can be at risk of trauma, but some populations are at greater risk. In November 2021, the Jewish Federations of North America published an issue brief developed to inform the development of this strategy. As the brief, [Supporting Family Caregivers of Older Adults with a History of Trauma: Implementation Recommendations for the National Family Caregiving Strategy](#), noted:

“Post-traumatic stress disorder (PTSD) has been described as chronic in African Americans and as one of the most serious mental health problems faced by American Indian/Alaska Native (AI/AN) populations... 34% of Latino immigrant parents and 29% of Latino immigrant adolescents experienced trauma.”

(Jewish Federations of North America, 2021)

These experiences intersect with caregiving in multiple ways. For example, trauma and PTSD are risk factors for dementia. On the other hand, a person who is living with dementia may experience a resurgence of difficult-to-manage symptoms that are a result of their trauma exposure. This can include nightmares, irritability, sudden outbursts of anger, anxiety, depression, and hypervigilance. These behavioral symptoms of PTSD can make the experience of family caregiving particularly challenging. When people have experienced trauma in medical settings, they may be reluctant to receive medical care. When caregivers themselves have experienced trauma, especially if they have experienced trauma at the hands of their care recipient, it can add further complexity to the family caregiving experience.

For kin and grandparent caregivers, exposure to trauma shapes the family caregiving journey in both similar and differing ways. Some children in kinship families and grandfamilies have been exposed to trauma. When children have a history of trauma, it can manifest in behaviors that are difficult to manage. Many people do not recognize these behaviors are related to trauma, and so kin and grandparent caregivers may find themselves repeatedly having to explain and describe the child's traumatic experiences. The challenges are compounded and amplified if the caregiver also has a history of trauma.



These are not easy situations to navigate. As a result, it is imperative that efforts to increase recognition and support for family, kin, and grandparent caregivers include a comprehensive, holistic set of strategies that acknowledge trauma as a powerful, yet invisible influence in the lives of family caregivers, kin and grandparent caregivers, and the people they support.

Essential practices to mitigate the impacts of trauma

According to the issue brief by the Jewish Federation of North America (2021), the following essential practices must be embedded in all caregiver support to mitigate the impacts of trauma:

- 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.
- Ensure that 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.
- 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.
- 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, kin, and grandparent caregivers or their loved ones.
- Explore the strengths, challenges, and circumstances of the caregiver and 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, kin, and grandparent caregivers and the completion of caregiving tasks.
- Understand that certain services and supports designed to help older adult clients and their family, kin, and grandparent 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.

- Promote peer support among family, kin, and grandparent caregivers by creating and advertising information about support groups (in-person and online), online forums, and other platforms where family, kin, and grandparent caregivers can share resources, challenges, success stories, and lessons learned (Jewish Federations of North America, 2021).

Advancing Equity, Accessibility, and Inclusion for Family Caregivers in Underserved Communities

Caregiving affects all families—but it does not affect every family equally. On April 28, 2021, at the request of the RAISE Advisory Council, the Older Adults Equity Collaborative (OAEC) provided [a briefing that included key actions to address social inequities that must be embedded into caregiver support efforts](#). The OAEC speakers represented the following organizations:

- [MHP Salud](#)
- [National Asian Pacific Center on Aging \(NAPCA\)](#)
- [National Indian Council on Aging \(NICOA\)](#)
- [National Center and Caucus on Black Aging \(NCBA\)](#)
- [SAGE - Advocacy & Services for LGBTQ+ Elders Center for Healthy Aging](#)
- [New York Academy of Medicine](#)

The speakers noted that implicit biases embedded in our laws and public policies, and in our public and private institutions, have often left segments of the population of caregivers—such as those who support individuals with disabilities and those who are members of underserved communities--without any recognition or support. For example, people with disabilities experience significant health care disparities as a result of lower rates of cancer screenings, less access to preventative care and health promotion efforts, and societal misconceptions about their needs and preferences (Diverse Elders Coalition, 2021). This adds challenges for the caregiver supporting a person with a disability. Those challenges are further compounded if the caregiver or care recipient is a member of an underserved community. Family caregivers of color, for example, often provide more intensive caregiving, for longer, and have outcomes that are worse than those experienced by White caregivers. For example, the Hispanic/Latinx older adult population is more likely to have more than one chronic condition and their family caregivers are more likely to assist with nursing and medical tasks than White caregivers. Disproportionate rates of dementia, anxiety, and depression have been noted in communities of color, increasing the intensity and number of hours of caregiving necessary. Forty-five percent of Latino and Hispanic caregivers provide 32+ hours of care per week, compared to 30% of White caregivers (Diverse Elders Coalition, 2021).



Cultural expectations. Culture affects caregiving in nuanced ways that have a broad impact on the caregiving experience. In some cultures, such as American Indian/Alaska Native communities, caring for elders is part of a sacred tradition. The individuals providing support may not think of themselves as caregivers or may be reluctant to ask for assistance. In Hispanic cultures, the concept of *familismo* is the value of putting family above oneself, which has implications for self-care, career, and housing choices. Communicating cultural expectations is further complicated by language differences. According to the Center for Medicare Advocacy, even though language access is a protected civil right, “health care providers from around the country have reported language difficulties and inadequate funding of language services to be major barriers to access to health care for limited English proficiency individuals and a serious threat to the quality of care they receive” (Center for Medicare Advocacy, 2015). It also affects family caregiving; in one study, seven out of ten Hispanic/Latinx family caregivers report difficulties with medications and coordinating care.

Heterogeneity within communities. No community is a monolith. Further, within a given community, the extent to which differing members of a family choose to embrace the norms of another culture also plays a role in shaping family caregiving. Some caregivers are immigrants who have been in the U.S. for a short period of time. Others have been in this country for multiple decades or even generations. The expectations and lived experiences of a first-generation American grandparent may differ considerably from the expectations and preferences of their third-generation caregiving grandchild. These differences can also lead to differing levels of confidence when interacting with the U.S. government and/or its programs and institutions.

Discrimination. Experiences of discrimination in the health care system are more common than previously recognized and deserve considerable attention. More than 20 percent of [survey respondents in a representative cross-sectional survey](#) reported having experienced discrimination in a health care setting. Racial and ethnic discrimination was the most common and nearly three quarters of the respondents was able to cite more than one experience of discrimination (Nong, Minakshi, Creary, Kardia, & Platt, 2020). Some LGBTQ+ older adults are also distrustful of service providers, making them less likely to seek assistance until they “[reach a point of crisis](#)” (SAGE, 2017). Many members of Indian tribes, Alaska Native villages, and the Native Hawaiian community express a distrust of the U.S. government and its institutions and policies due to previous experiences of discrimination and cultural erasure. Fear of discrimination of any kind has a real impact on whether caregivers in underserved populations will seek assistance from institutions and systems, either for themselves or for the people they support. That in turn can have an impact on the burden of care required (if medical needs are not addressed) and the caregivers’ own risk of burnout.



Nontraditional family structures. It has been said that “love makes a family,” but public policies do not consistently recognize non-traditional family structures. This has implications for LGBTQIA+ caregivers, who, as a result, often report higher levels of caregiving stress (SAGE, 2017). While biological family members play a primary role in the support of older adults in the general population, members of the LGBTQIA+ community who need caregiving support are more likely to rely on partners and friends, many of a similar age. Mutual caregiving, as it is known, has important implications for LGBTQ+ caregivers and the people they support because members of the [LGBTQIA+ community experience higher rates of many chronic diseases, including depression, cardiovascular disease, and obesity](#). Some members have a greater risk of alcohol use disorders. While caregivers are likely juggling their own issues and conditions as well as those of the person or persons they support, they may lack the access to health care information and supports and services, including financial protections, that biological relatives and spouses can take for granted (Fredriksen-Goldsen, Kim, Barkan, Muraco, & Hoy-Ellis, 2013).

A similar challenge faces caregivers in kinship families and grandfamilies; the health care, social services, and educational systems with which they must interact in their caregiving do not recognize or support their role as caregiver of the child. This leaves many kin and grandparent caregivers outside of the systems (education, child care, health care, etc.) designed to support parents and legal guardians of children.

Intersectionality: By 2030, nearly 3 in 10 older Americans will identify as a member of at least one diverse or underrepresented group (Diverse Elders Coalition, 2021). As the overall number of diverse older adults grows, there will also be a corresponding increase in the number of caregivers grappling within multiple intersection challenges. When caregivers experience multiple challenges, they are not merely additive, but rather have a compound effect that hampers a person’s ability to provide quality care over time. As people age, these issues are often further exacerbated. These challenges have only been intensified during the pandemic, worsening preexisting stressors, strains and both physical and mental health outcomes for diverse caregivers and their older loved ones. The impact of the pandemic has been particularly significant in the caregivers in communities of color. As a result, when it comes to addressing disparities, recommendations that suggest a universal approach should be avoided. Despite the ubiquity of caregiving, caregivers are not a monolith, and their needs must be addressed individually.

The National Resource Center on LGBTQ+ Aging offers [a series of facts](#) sheets with information on how age, race, sexuality, and disability intersect and steps that can be taken to strengthen supports for marginalized groups.



Spotlight on Underserved Caregiving Populations

- **American Indian/Alaska Native/Native caregivers** may not identify as such because honoring elders is so deeply embedded in their cultures. As a result, they may not seek assistance when they need it.
- **Asian American and Pacific Islander caregivers** represent over 50 unique ethnicities and 100 different languages, many of which have differing perspectives on caregiving.
- **Black and African American caregivers** provide more intensive care, over more time than White caregivers and contributing to greater negative financial consequences.
- **Children who provide care** to parents, grandparents, and siblings miss school and social/developmental opportunities, but there are few programs or resources that acknowledge the kind of caregiving they provide.
- **Hispanic/Latino caregivers** are more likely to be the sole caregivers for their loved ones placing them at risk of isolation and mental health strain.
- **Kin and grandparent caregivers** open their arms and homes to children who cannot stay with parents, yet, despite their age and limited resources, few have access to financial assistance.
- **LGBTQIA+ caregivers** are more likely to become caregivers at a younger age and across multiple situations (parents, siblings, partners, & friends), increasing their risks of long-term financial challenges, social isolation, and burnout.

Essential practices that must be embedded in all caregiver support to advance equity and inclusion for diverse populations of caregivers

- Include in all relevant legislation specific provisions that promote cultural and linguistic competence for all racial and ethnic groups, American Indian/Alaska Native, as well as for LGBTQIA+ caregivers, across physical and mental health, and well-being.
- Prioritize actions that protect caregivers (and the people they support) who experience multiple forms of discrimination and are particularly vulnerable to exploitation because of race, ethnicity, gender, gender identity, sexual orientation, religion, income level and national origin.

- Prioritize actions that specifically ensure compliance with current federal law requiring access to services for older adults, people with disabilities, and family caregivers with limited English proficiency.
- Advance provisions that support family caregivers regardless of immigration status or that of the person they support.
- Develop programming, research, and policy for caregivers in Indian Country in collaboration with tribes and tribal communities, including their internal review boards and tribal governments.
- Amend data collection, project assessments, and reporting requirements in legislation to ensure that all racial and ethnic groups, American Indians/Alaska Natives, as well as LGBTQIA+ older adults, are represented and provided the opportunity to participate in research.
- Collect data in a way that builds trust with caregivers by providing education about its purpose and use.
- Recruit, promote, and support a diverse, culturally competent health care and social services workforce that represents the culture of the community.
- Close service gaps by reviewing screening and intake for cultural competency.
- Ensure that all language, pictures, graphics, videos, and other communications included in outreach materials include and reference same sex couples and racially and ethnically diverse older adults, people with disabilities, and caregivers.

Elevating Direct Care Workers as Family Caregiving Partners

Family caregivers cannot support their loved ones alone. Just as family caregivers often step in when paid care is not available for a loved one, when family caregivers are not able to provide support or need additional support or respite, they may turn to professionals who assist older adults and disabled people of all ages with essential daily tasks across a range of settings. This workforce includes people identified by a range of different job titles including personal care attendants, home health aides, job coaches, direct support professionals, residential workers and others who provide similar supports. While titles, required skills, and responsibilities differ, all direct care workers should have access to quality jobs with adequate training and support, compensation, voice in their working environment, an opportunity for growth through a career ladder or lattice, and broad recognition of their value in the long-term supports system.



Meeting the needs of family caregivers is inextricably linked to the need to provide better pay, working conditions, and career pathways for people who provide caregiving support as a vocation. The current shortage of workers and frequent turnover not only compromises the ability of older adults and people with disabilities to live in the community, but it can also compromise their health and safety. The need for direct care workers, which already far exceeds supply, [is projected to grow significantly](#) in the next decade as the number of older adults and people with disabilities increase and as government spending shifts to prioritize home and community-based services. The recruitment, retention, and development of a competent workforce is critical to providing home and community-based services so that older adults and people with disabilities can live, work, and participate in the community.

Despite the criticality of these roles, direct care workers remain vulnerable to low wages and unstable working conditions. In 2020, DCWs providing HCBS were paid a median hourly wage of \$12.98 (PHI, 2021). Nearly half of these workers live in low-income households, and more than half rely on some form of public assistance. Significant gender, racial, and ethnic disparities exist in the direct care workforce: Nearly 90 percent of direct care workers are women, three in five are people of color, and a third are immigrants to the U.S (PHI, 2021).

Many direct care positions are part-time jobs, which means that while workers may put in long hours of care (sometimes cobbling together multiple clients from differing agencies or at multiple care facilities), they are rarely eligible for the compensation benefits that accompany full-time employment. This includes sick leave, paid holidays, and adequate education on important topics that could improve the quality of their work, such as dementia competency training. Nor are there many career advancement opportunities for direct care workers. When it comes to workplace safety, the situation is equally challenging. The rate of on-the-job injuries experienced by direct care workers is three times higher than that of the average U.S. worker. As a result of these challenges, turnover in this industry is high and it is hard to fill empty positions. The shortages that result from this can leave family caregivers vulnerable to coverage and care quality gaps when a worker doesn't show up for a shift or they find themselves having to train a replacement.

Developing a ready and well-qualified direct care workforce through better pay and working conditions, training, and improved career pathways, on the other hand, has the potential to reduce burnout among informal or family caregivers by increasing access to a range of support options. That in turn could allow caregivers to provide high-quality support for longer.



Learn More about Strengthening the Direct Care Workforce

- [Direct Support Professionals and the Disability Community](#)
- [Feeling Valued Because They Are Valued: A Vision for Professionalizing the Caregiving Workforce in the Field of Long-Term Services and Supports](#)
- [Investing in Direct Care Workforce Interventions to Improve the Quality of Services and Supports for Older Adults and People with Disabilities](#)
- [DSW Core Competency Project](#)
- [The CMS National Direct Service Workforce Resource Center](#)
- [Coverage of Direct Service Workforce Continuing Education and Training within Medicaid Policy and Rate Setting - A Toolkit](#)
- [Overviews of Workforce Challenges and Effective Improvement Strategies](#)
- [Strengthening the Entry-Level Health Care Workforce: Finding a Path](#)

Essential practices that must be embedded in all caregiver support to strengthen the direct care workforce

- Expand the pipeline of potential caregivers by recruiting nontraditional workers to the LTSS field and changing immigration policy so more caregivers will seek out jobs in the LTSS field.
- Enhance education and training, both initial and ongoing, so professional caregivers will feel well-prepared to carry out increasingly complex care tasks, and so home care organizations, nursing homes, assisted living communities, consumers and their families will have confidence in them.
- Provide access to career ladders that offer opportunities beyond the traditional nursing path, including careers in social work, therapy, and management positions that use their relationship skills.
- Increase compensation so direct care professionals can earn at least a living wage.
- Prepare universal workers who could become direct care professionals in home and community-based settings, nursing homes and assisted living communities, and other settings.

- Reform the LTSS financing system by using insurance-based dollars to provide additional and more consistent funding for LTSS and to help ensure that the LTSS workforce receives adequate compensation.

Conclusion

It can be said that if you have met one family caregiver, you have met one family caregiver. This common adage reflects the fact that caregivers are people first and caregivers second. They must be recognized as such if this strategy is to be successful.

The cross-cutting considerations discussed here should be foundational to the development of all programs and initiatives to support family caregivers. When they are embedded in policy development, they ensure programs deliver services and supports that recognize the individual needs, previous experiences, concerns, and situations of the people receiving support while also seeking to redress the deep inequities that are often present among diverse and marginalized populations, including family caregivers and direct service workers.

The Advisory Councils expect that the ideas and actions presented in this Strategy will serve as the first steps in creating a holistic and systemic approach to family caregiver support. Such an approach will ensure that as change happens, it will occur in an aligned fashion so that all populations of family caregivers receive the recognition and support they need and deserve.



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Appendix A: Acronyms and Abbreviations

- ACL: Administration for Community Living
- ACS: American Community Survey
- ADA: Americans with Disabilities Act
- ADPI: Alzheimer's Disease Programs Initiative (ACL)
- BRFSS: Behavioral Risk Factor Surveillance System
- CBOs: Community-Based Organizations
- CDC: Centers for Disease Control and Prevention
- CFPB: Consumer Finance Protection Bureau
- CMA: Center for Medicare Analysis
- CMS: Centers for Medicare & Medicaid Services
- CSC: Caregiver Support Coordinator (VA)
- CSP: Caregiver Support Program (VA)
- HCBS: Home and Community-Based Services
- HHS: U.S. Department of Health and Human Services
- IDD: Intellectual and Developmental Disabilities
- JAHF: The John A. Hartford Foundation
- LGBTQIA+: Lesbian, Gay, Bisexual, Transgender, Questioning, Intersex, Asexual and Others
- LTSS: Long-Term Services and Supports
- MCOs: Managed Care Organizations
- NAC: National Alliance for Caregivers
- NAPA: National Alzheimer's Project Act
- NASHP: National Academy for State Health Policy
- NFCSP: National Family Caregiver Support Program (ACL)
- NHATS: National Health and Aging Trends Study
- OAA: Older Americans Act
- OAEC: Older Adults Equity Collaborative
- PCPID: President's Committee for People with Intellectual Disabilities (ACL)
- RAISE: Recognize, Assist, Include, Support, & Engage
- RFI: Request for Information
- SGRG: Supporting Grandparents Raising Grandchildren
- VA: U.S. Department of Veterans Affairs