

## INFORMAL CAREGIVING IN THE AGING UNITED STATES: SHIFTING PERSPECTIVES TO MEET SOCIAL NEEDS

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The aging population of the United States continues to spark discussion on the need for increased, adequate care services when looking to the future. Whether home or institution-based, long-term care services are necessary for the wellbeing and daily care of older Americans living longer despite increased chronic medical conditions. Most of these individuals receive care in their homes, often from informal caregivers such as friends, family, and neighbors (Kaye, Harrington & LaPlante, 2010).

Current government policies perpetuate informal caregiving through cutbacks in social service programs, stalls in new legislation to address infrastructure needs, and a lack of universal formal supports, particularly in rural areas. Informal caregivers bear the brunt of these gaps, with government policymakers supporting a service-based system wherein informal caregiving saves healthcare spending.

### Shifting Demographics and Future Need

- In 2011, the oldest of the “baby boomer” generation hit the societally accepted retirement threshold of 65 years old.
- By 2030, 79 million Americans, roughly 18% of the total population, will be at retirement age (Shugarman & Whitenhill, 2012).
- By 2050, 27 million will need support through in-home or institutionalized care, with that number increasing with global aging trends (Plöthner et al., 2019).

This influx in older persons will overburden the already stretched-thin care systems in place, particularly in rural areas where transportation, lower socioeconomic status, and lack of service providers already exist and further complicate the availability of care (Rose, Noelker & Kagan, 2015; Carroll et al., 2018).

In addition to the increasing number of older persons are additional factors including the declining birth rate, internal migration, continued defunding of Medicare/Medicaid and social service programs, and infrastructure needs such as public transportation and universal design, specifically in rural areas, as they exacerbate the barriers to receiving adequate care (Plöthner et al., 2019; Chan, Barnard & Ng, 2020; Minnesota Board on Aging, 2017). Finally, lack of informational resources adds to the burden of care, with internet searches being a significant source of information, despite technology barriers in rural areas (Chan, Barnard & Ng, 2020).

Most older individuals in the United States receive part or all their care from an informal caregiver such as family members, friends, or neighbors (Kaye, Harrington & LaPlante, 2010). The Centers for Disease Control (2019) finds that currently:

- 22% of citizens under the age of 65 are informal caregivers.
- An additional 20% predicts their transition to an informal caregiver in the next several years.

Policymakers view informal caregiving as reducing the burden on the healthcare system (Calvó-Perxas et al., 2018). However, promoting unpaid caregiving to supplement formal services perpetuates the lack of funding and infrastructure for these same formal systems, including those providing support services for informal caregivers (Verbakel, Metzelthin & Kempen, 2016).

### Current Barriers and Policy Perspectives

The United States healthcare system funnels only 22% of its funds to in-home or community-based care despite this being the majority service type (Kaye, Harrington & LaPlante, 2010). Care not covered by insurance, Medicare, or Medicaid fall to the individual consumers themselves or their families through informal caregiving and out-of-pocket expenses (Kaye, Harrington & LaPlante, 2010; Carroll et al., 2019).

Informal caregiver burden due to reliance on unpaid care results in increased medical costs, reduced workforce contributions, and ultimately caregiver burnout for those providing care to others in this capacity—costs that will further burden societal systems as caregivers grow older themselves while choosing between paid work and caregiving (Verbakel, Metzelthin & Kempen, 2016; Calvó-Perxas et al., 2018). These choices have long-reaching consequences, as missed work leads to decreased contributions to Social Security, increased personal costs to provide informal care, and decreased wages due to time off work (Rose, Noelker & Kagan, 2015).

Services available to support informal caregivers are fragmented. Lack of accessibility to respite services due to costs or geographical location strains informal caregiving (Carroll et al., 2018). Defunding respite services and community supports also prevents adequate support for informal caregivers, as governments continue to defund community-based services (Rose,

Noelker & Kagan, 2015). Inconsistent support provided by third-party services increases strain on the relationships between caregivers and care receivers (Carroll et al., 2018).

The Center for Disease Control has publicly recognized informal caregiving as a public health issue due to the number of United States citizens it impacts (Centers for Disease Control, 2019). As of 2017, the CDC recognized that one-third of caregivers provide 20 hours or more per week to informal care. Additionally, half of these informal caregivers have provided care for at least two years (Centers for Disease Control, 2019).

Further, CDC statistics highlight how this devotion places increased health burdens on informal caregivers: According to the CDC, over one-third of informal caregivers get insufficient sleep, and an average of 40% have two or more chronic illnesses themselves. These factors, along with the emotional burden of caregiving and societal barriers to providing adequate care, work against caregivers as they balance their health and other obligations with the care of others (Centers for Disease Control, 2019).

## Research, Policy, and Practice Recommendations

Evidence-based measures to reduce caregiver burden and ultimately improve outcomes for older persons and their families are crucial. These include considerations for progressive policies and infrastructure spending. While increased funding in elder care services would be beneficial across the board, the additional considerations below can build towards needed changes to address an aging society and support caregivers.

### Increase supports for informal caregivers

The internet has become a mainstream source of information in the United States. Utilizing this tool to disseminate information on caregiving, navigating systems such as Medicare and Medicaid, and information regarding online and local community supports can decrease caregiver isolation and increase a sense of wellbeing (Chan, Barnard & Ng, 2020; Minnesota Board on Aging, 2017; Plöthner et al., 2019). Informational resources can benefit caregivers by providing earlier service entry into support groups or more formal community services before informal caregivers reach a crisis point (Rose, Noelker & Kagan, 2015). In areas where the internet is not universal, spending on technology as discussed by Congress while negotiating infrastructure spending provides the opportunity to improve access to these resources.

### Increase incentives for informal caregivers to decrease burnout

Providing benefits to informal caregivers such as tax credits, reimbursement for transportation or care-related costs, flexible work arrangements, and paid leave reduces caregiver burden and can incentivize informal caregiving while reducing the adverse health and workplace outcomes (Calvo-Perxas et al., 2018; Minnesota Board on Aging, 2017). Additionally, shifting the approval of respite and support services based on caregivers' needs rather than care receiver circumstances would reduce caregiver burnout more effectively (Rose, Noelker & Kagan, 2015). These steps recognize the public health issues surrounding informal caregiving and issue acknowledgment to the caregivers for their service, a factor that can benefit informal caregivers and reduce caregiver strain (Rose, Noelker & Kagan, 2015).

### Address infrastructure needs to improve service delivery through universal design and transportation initiatives

Shifting perspectives to view the need for increased eldercare supports as an investment in infrastructure for the future United States and making it a priority in spending now, rather than reactive spending shortages in care worsen, can address multiple societal concerns at once. This debate is happening in real-time as Congress continues to negotiate on multi-trillion-dollar spending to improve infrastructure in the United States.

Implementing universal design strategies that meet ADA requirements into new building projects now is more cost-effective than reactively retrofitting older structures while allowing older persons to age in place (Plöthner et al., 2019). Additionally, increasing transportation options, specifically with public transportation and especially in rural areas, increases accessibility for all while decreasing caregiver burden through missed work for doctor appointments and other errands that older persons may be able to complete on their own but need reliable transportation to achieve (Plöthner et al., 2019). By passing an infrastructure bill that addresses transportation, housing, and building infrastructure nationwide, Congress can make these priorities that improve the lives of United States citizens, including informal caregivers.

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